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Repositioning respite within consumer directed service systems

Carer Respite Alliance, April 2021

ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). Carers NSW is part of the National Carer Network and a member of Carers Australia. 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.

ABOUT CARERS

A carer is any individual who provides unpaid 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. Across NSW, there are approximately 854,300 carers,¹ and to replace the care they provide the NSW Government would have to spend more than \$25 billion each year.² Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

ABOUT THIS PAPER

This paper was developed by Carers NSW Policy and Research team on behalf of, and with extensive input from, members of the Carer Respite Alliance (CRA), a working group formed in 2017 in response to increasing numbers of carers and other stakeholders in NSW expressing concerns about the state of the respite sector in NSW. This paper seeks to reposition the concept of carer respite within increasingly consumer-directed care service systems in NSW and provide an evidence base to support the ongoing provision and funding of supports that enable carers to take breaks from the caring role within these existing models.

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¹ Australian Bureau of Statistics (2019) *Disability, Ageing and Carers, Australia: Summary of findings, 2018*, New South Wales Tables, Canberra.

² Carers NSW estimate based on Deloitte Access Economics (2020) *The economic value of informal care in Australia in 2020*, Carers Australia.

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Glossary

AAT	Administrative Appeals Tribunal
ABS	Australian Bureau of Statistics
ACAR	Aged Care Approvals Round
ADHC	(Former) NSW Department of Ageing, Disability and Home Care
CALD	Culturally and Linguistically Diverse
CCSP	Community Care Supports Program
CDC	Consumer Directed Care
CGSP	Carer Gateway Service Provider
CHSP	Commonwealth Home Support Programme
CLS	Community Living Supports program
COVID-19	Coronavirus
CRA	Carer Respite Alliance
CRCC	Carer Respite and Carelink Centres
DOH	Department of Health
DSS	Department of Social Services
ECEI	Early Childhood Early Intervention
FCMHP	Family and Carer Mental Health Program
HACC	Home and Community Care
HASI	Housing and Accommodation Support Initiative
HCP	Home Care Package
IAC	Independent Advisory Council
ILC	Information, Linkages and Capacity Building
JSC	Joint Standing Committee
LAC	Local Area Coordinator
LGBTQI+	Lesbian, gay, bisexual, transgender, queer, intersex and other sexuality, sex and gender diverse
LLLB	Living Longer Living Better
MHR:CS	Mental Health Respite: Carer Support
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NRCP	National Respite for Carers Program
RACF	Residential Aged Care Facility
RCAC	Royal Commission into Aged Care Quality and Safety
SDA	Specialist Disability Accommodation
SDAC	Survey of Disability, Ageing and Carers
STA	Short Term Accommodation

Executive summary

The Australian disability, aged care and mental health service sectors have undergone major reforms over the past decade. These changes have been characterised by an overarching shift towards Consumer Directed Care (CDC), where care services are allocated in relation to the needs and preferences of people requiring care. While this shift has been important from a human rights perspective, and has often resulted in better support for people requiring care, in many cases it has unintentionally resulted in carers' needs and preferences being relegated to the margins, a phenomenon observed internationally within CDC models of care. This is consistent with international literature that positions CDC as impacting on carer recognition negatively.

While many carers actively choose to provide care for a family member or friend and find caring to be rewarding, without opportunities to take meaningful breaks from their caring responsibilities, evidence shows that carers' physical and mental health can suffer, affecting the sustainability of caring arrangements. Formal care services, such as services called 'respite' and carer-focused wellbeing activities, provide many carers with these much-needed breaks. However, research indicates that many carers are not able to access these opportunities at all or enough to meet their needs. The COVID-19 pandemic has only exacerbated these existing shortages.

Services offering carers a break have been framed and treated differently within the various care services sectors in Australia over time. The disability sector has recently exhibited a shift away from using the term 'respite' because some feel it conflicts with central notions of dignity, self-determination and the worth of people with disability. Concurrently, the National Disability Insurance Scheme (NDIS) has, for the most part, resisted explicit inclusion and support of carers in their own right, especially concerning services traditionally referred to as 'respite'. Recent moves to revisit the term 'respite' in the NDIS landscape and expand carer support have been promising, however the recognition of the need to provide carers with regular breaks from the caring role remains limited.

Within aged care, the concept of respite has remained fairly stable despite ongoing reforms, referring to a specified range of more traditional services providing replacement care while carers attend to other activities. However, significant wait times for services, high co-contributions and limited consideration of carer needs within care planning prohibit many carers from accessing the breaks they need. The Royal Commission into Aged Care Quality and Safety has identified respite as a key area for greater attention in future reform, providing an important opportunity for existing models and frameworks to be revised in the context of the broader service system.

In mental health services, respite often takes a different form than existing services in aged care and disability service systems, in that it tends to focus on providing carer-focused activities outside of the caring role rather than temporarily replacing the carer in supporting the person requiring care. While mental health services do not share the same history as disability and aged care services with regard to formalised respite services, there has still been an apparent shift away from the concept of respite for carers being core business. Furthermore, the expectation that people living with mental illness will be able to access support through the NDIS has meant that disability sector language and practices regarding carer support have been applied in the mental health context.

The care sector most recently undergoing significant reform is the carer support sector, with the launch of a range of nationally available in-person, online and phone-based supports through Carer Gateway in 2019 and 2020. Carer Gateway has continued to fund replacement care services called 'respite' and other support types considered to have a 'respite-effect'. However, these supports are intended to complement rather than replace respite and respite-type supports delivered under other service systems and it is expected that carers will be able to access planned, regular ongoing breaks from caring through these service systems.

The Carer Respite Alliance (CRA) was founded in 2017 out of a shared concern among members that the value and legitimacy of carer respite as a service type was in question. At that time, we sought to establish both the need for and impact of, respite services in a service landscape that was, at times, focusing so much on consumer direction that carers' own needs were forgotten. Since the beginning of this project, much has changed across care sectors, however carer respite remains firmly on the agenda for the CRA. The key challenge in 2021 is applying the existing evidence and learnings emerging from inquiries into the aged care, disability and mental health service systems, and from the significant challenges experienced within these sectors during the COVID-19 pandemic, while also taking the opportunities presented by a newly established, national carer support system, to ensure that as many carers as possible can enjoy the benefits of meaningful breaks from the caring role.

The effectiveness of structured breaks from the caring role is difficult to quantify due to the nature of the caring role and the complexities associated with the conceptualisation of respite. Evidence shows that carers consistently report a number of benefits of accessing respite services, and that taking regular breaks enables them to continue providing care. Respite is most effective in reducing carer stress and increasing the sustainability of caring arrangements when accessed early and regularly. However, research indicates that respite is often not available, not appropriate, difficult to find, or too costly for many carers to use effectively.

This paper demonstrates that services providing breaks from the caring role are needed and valuable, but will remain difficult to access without improved integration between service systems and a reconceptualisation of how carer breaks are provided and funded in NSW. In light of this evidence, it puts forward a range of possible innovations and opportunities to be considered within consumer-directed service systems to secure the ongoing benefits of breaks for carers. The paper's 68 recommendations for a range of audiences are included in full following the conclusion and are summarised below:

Summary of recommendations for the Australian Government

- Develop a whole-of-government approach to carer recognition, inclusion and support (*Recommendations 1-5*)
- Clarify messaging regarding the support offered by Carer Gateway, and ensure that referrals from and to other service sectors are streamlined (*Recommendations 6-15*)
- Improve carer recognition and support within the NDIS (*Recommendations 16-24*)
- Implement the Royal Commission into Aged Care Quality and Safety's recommendations regarding carer identification, assessment and respite (*Recommendations 25-28*)
- Reduce fragmentation in mental health funding and better integrate carer support needs into policy and funding frameworks (*Recommendation 29*)
- Address critical skills shortages and disincentives across the paid care workforce (*Recommendations 30-37*)
- Improve data collection and information sharing (*Recommendations 38-40*)
- Review and improve existing funding models for respite (*Recommendations 41-44*)

Summary of recommendations for the NSW Government

- Strengthen the entitlements of carers under Commonwealth carer recognition legislation (*Recommendations 45-47*)
- Continue to invest in carer-inclusive grant opportunities that provide multiple opportunities to take a break from the caring role (*Recommendations 48-52*)
- Increase funding to education providers to build the skills of paid care workers (*Recommendations 53-54*)

Summary of recommendations for local government

- Provide spaces and venues at no or little cost to host activities that provide carers with a break from their caring role (*Recommendations 55-56*)
- Undertake partnerships with community organisations to deliver carer inclusive recreational activities (*Recommendations 57-58*)

Summary of recommendations for the private sector

- Support local communities by providing volunteers and investing in spaces and venues that can enable carers to take a break from their caring role (*Recommendations 59-61*)
- Partner with other organisations and sectors to develop and deliver innovative solutions to the shortage of respite and respite-like support for carers (*Recommendations 62-63*)

Summary of recommendations for the community sector

- Explore partnership opportunities with a range of sectors to develop innovative, low-cost and inclusive approaches to providing carers with a break from the caring role (*Recommendations 64-66*)
- Support carers to understand and access the existing support options available to them (*Recommendation 67*)
- Advocate for sector reform to improve the range of opportunities available to carers to take a break from the caring role (*Recommendation 86*)

Introduction

This paper is the result of in-depth research, consultation and analysis undertaken by the Carer Respite Alliance (CRA), a working group established by Carers NSW in 2017 in response to increasing reports of concern among carers in NSW regarding the supply and quality of respite services. Throughout the duration of this project, ongoing and significant service system reforms have resulted in constant changes to the respite landscape, and yet access to respite remains a concern for many carers.

This paper aims to examine how carer wellbeing outcomes have been supported in the past through the delivery of services labelled as 'respite', or services considered to have a 'respite effect', and better understand how these outcomes can be achieved in the current context of consumer directed service reform.

Recognising that there remains a significant unmet need for services that provide carers with a break from their caring role within NSW, and drawing on evidence collected by CRA members as to the benefits of, and demand for, supports that provide carers with a break, this paper seeks to reframe the discussion regarding respite services in order to propose solutions for supporting carer wellbeing and resilience within increasingly consumer directed service systems.

This goal has become particularly critical in light of the findings of the Royal Commissions into the aged care and disability sectors, the Productivity Commission's inquiry into Mental Health and the overwhelming challenges experienced by carers and the services that support them during the COVID-19 pandemic.

The target audience of this paper is policy makers, funders, service providers and carer advocates. It aims to highlight the importance of breaks from the caring role to support carer wellbeing and resilience and propose how these may be achieved in a rapidly changing service context. The paper draws on the knowledge base of CRA members as well as input from carers, respite program evaluations and published research on respite and comparable services types.

Carer Respite Alliance (CRA) members

The CRA brings together not-for-profit organisations, academics and carers with a special interest in, and evidence to contribute to, advocacy relating to carer respite. Current membership includes:

Stakeholder representatives:

- Selen Akinci, Partners in Culturally Appropriate Care (PICAC), Multicultural Communities Council of Illawarra (MCCI)
- Debra Dixon, Anglicare
- Jonathan Harms, Mental Health Carers NSW (MHCN)
- Pat Joyce, Seniors Rights Service
- Ann Mehaffey, Aged and Community Services Australia (ACSA)
- Kylie Miskovski, Dementia Australia
- Anna Wilson, HammondCare
- Maureen Flynn, Carer Representative
- Sarah Judd-Lam, Carers NSW
- Melissa Docker, Carers NSW

Contributing researchers:

- Associate Professor Myra Hamilton, Centre of Excellence in Population Ageing Research (CEPAR), University of Sydney
- Associate Professor Lyn Phillipson, University of Wollongong

Carers NSW would also like to acknowledge the contributions of carers and sector experts, including previous members of the CRA and previous Carers NSW staff, who provided feedback and input throughout the development of this paper.

A note on terminology

The term 'respite' holds varying meanings and perceptions across different parts of the Australian community services sector. In some contexts, the word itself has been contentious and can be perceived as pejorative. In others, the word is commonly used with a very specific meaning. While 'respite' is not used universally in Australia to describe formalised breaks from the caring role with a focus on carer wellbeing and resilience, the CRA believes its use continues to be important in describing past and existing service types of this name for clarity. As to emerging service types that may have similar objectives, this paper will not refer to these as respite services unless that term is explicitly used by the providers of that service.

Respite services in NSW: a brief history

Key Points

- The disability, aged care and mental health sectors have been undergoing significant reform within Australia which has seen substantial changes in how respite is delivered in NSW.
- During these reforms, the delivery of respite in NSW has transitioned from being delivered by one government department, the Department of Ageing, Disability and Home Care (ADHC), to national and independent service systems: the National Disability Insurance Scheme (NDIS), My Aged Care and Carer Gateway.
- The shift to Consumer Directed Care (CDC) models during recent reforms has aimed to create more individualised, flexible and holistic care for people requiring support, however this has seen carers needs, including respite, become secondary to those requiring care.
- Despite previous Productivity Commissions inquiries and state and federal carer recognition legislation highlighting the important role of carers and a need to also address carers needs in the planning and provision of care, carers report facing increasing difficulty in accessing supports that meet their own needs, especially respite.

The funding and delivery of aged care, disability, mental health and carer support services within NSW has undergone significant change in the past decade. Formerly delivered by the NSW Government through the one government department, the Department of Ageing, Disability and Home Care (ADHC),³ these services have now completely transitioned to national and independently administered service systems: the National Disability Insurance Scheme (NDIS), My Aged Care and the recently established Carer Gateway. These three service systems have vastly different structures and underlying principles, while the mental health and disability sectors are more interconnected than ever through the eligibility of people with psychosocial disability for the NDIS.

Driving this structural reform has been a significant ideological shift in favour of individualised, Consumer Directed Care (CDC) that focuses on the goals and choices of individuals requiring care. This principle has also led to an increasing emphasis on flexible, holistic service systems supported by evidence of outcomes rather than simply outputs. This transformation has served to improve access to support for many people with disability, older people and people living with mental illness, and by association, their families and carers. However, the current emphasis on consumer direction has also had an unintended adverse effect: the de-prioritisation of carers' own needs.¹ Services in NSW that recognised carers as the primary recipient of support, including but not limited to respite services, have in most cases either lost funding completely or undergone a significant change in scope whereby the carer's own interests become secondary to that of the individual requiring care under the NDIS or through My Aged Care.

The 2011 Productivity Commission inquiries into Aged Care and Disability Care and Support,² which are credited as the catalysts for the present reform trajectory in these sectors, both highlighted the value of carers and the importance of providing them with better support, including individual needs assessments, counselling, training and respite, though sometimes in the context of the care recipient's own needs assessment and support. The more recent Productivity Commission inquiry into mental health has arrived at similar conclusions about the need for more carer inclusion and support, nearly ten years later.³

³ ADHC ceasing as a Department as of 1 July 2021.

The establishment of Carer Gateway (previously referred to as the Integrated Carer Support Service) from 2016, culminating in the commencement of in-person Carer Gateway services from April 2020, represents a timely response to the critical need for carer support identified across these other service systems. However, as the 2020 Productivity Commission report on Mental Health, as well as the recently completed Royal Commission into Aged Care Quality and Safety and the ongoing Royal Commission into Violence, Abuse, Neglect and Exploitation of people with Disability, have indicated, there remain considerable gaps within the care service systems with regard to carer inclusion and support.

As Carer Gateway matures, integration with the disability, aged care and mental health service systems will be critical. The CRA argues that these systems should not relinquish their responsibility for carer inclusion and support to Carer Gateway, but rather continue to reform their approach to carers to ensure that carers' needs are adequately identified and taken into account in support planning and delivery for the person with care needs, while also providing timely referral to external, carer-specific supports where required (provided through Carer Gateway).

These principles are embedded in both NSW and Commonwealth carer recognition legislation, which government funded human services are obligated to uphold. In particular:

“10 Support for carers should be timely, responsive, appropriate and accessible.”⁴

“4(b) Carers should be referred to, and assisted to access, appropriate supports and services.”⁵

But also:

“7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.”⁶

“4(a) The choices, views and needs of carers and the people they care for should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.”⁷

Where a break from caring is the support need identified, this can be achieved by balancing the care recipient's needs and goals with the needs and goals of the carer. In many cases, it is assumed that formal services provided to the care recipient already provide the break required, or could with minor variation. This is also the assumption reflected in the structure of Carer Gateway, which provides limited respite options to complement, rather than replace, these systems.

The CRA believes that a carer-inclusive approach to planning and delivering support to people with disability, older people and people living with mental illness – where carers are present – combined with well-established referral pathways to carer-specific services can assist more carers to voice their need for a break and access the supports and services required to achieve this. As the 2009 report on the House of Representatives inquiry into better support for carers contended: ⁸

“...with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned — carers, care receivers, governments and society — to share the responsibility of providing care more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities.”⁹

Though released more than a decade ago, subsequent reforms have not addressed the issues raised and have not delivered the increased respite recommended. Instead, problems have persisted and the supply of supports providing carers with breaks from the caring role have become even more constrained.

Respite services in the disability sector

Key Points

- Services and supports for people with disability and their carers were previously provided or funded by the NSW Department of Ageing Disability and Home Care (ADHC).
- Following the 2011 Productivity Commission inquiry into Disability Care and Support, the National Disability Insurance Scheme (NDIS) was established with the aim of creating a more person-centred, nationally consistent and more efficient disability service system.
- With the NDIS rolled out in NSW from 2016 to 2018, NSW state disability was funding re-directed to the NDIS. ADHC and any residual state funded services for people with disability and their carers ceased on 1 July 2018.
- The NDIS intentionally moved away from the term “respite” in its initial stages, due to concerns that the term may be pejorative to people with disability, instead opting to use more participant-centred language when referring to service types that may have previously borne this label, like social support and short-term accommodation.
- Despite a recent reintroduction of “respite” to the NDIS Price Guide and NDIS language, carers of NDIS participants, especially those caring for children with disability, continue to experience significant difficulties trying to secure funding or the appropriate services to access respite through the NDIS

The disability sector has undergone significant structural and conceptual reform in recent years, culminating in the implementation of a national person-centred insurance model of disability support, the National Disability Insurance Scheme (NDIS). The NDIS was developed in response to the 2011 *Disability Care and Support* report by the Productivity Commission, which described the existing disability service system as “fragmented, inequitable, underfunded and inefficient.”¹⁰ The NDIS was implemented in stages across NSW, beginning with a trial site established in 2013 in the Hunter region and a gradual roll out from July 2016, ending with a full roll out in all areas of NSW by July 2018.¹¹

Prior to the full roll out of the NDIS in NSW, respite within the disability sector was primarily delivered with funding from the NSW Department of Ageing, Disability and Home Care (ADHC). Much of the respite support was available through State-funded non-government disability support providers, but ADHC also delivered direct services and maintained facilities that were used for respite. In its capacity as a direct service provider, ADHC also acted as a provider of last resort for carers who were unable to find respite elsewhere due to the complexity of their care recipient’s needs and/or the costs associated with that level of care. Since the full roll out of the NDIS in NSW, funding allocated to ADHC and NSW disability support services has been reallocated to fund the NDIS.

ADHC was formally dissolved in 2018 with the expectation that the NDIS would replace the services it had once delivered. In reality, the NDIS has not replaced all the supports that were available through

ADHC, especially where carers are concerned. There is no longer any NSW department dedicated to disability support for those who are not eligible for the NDIS, nor is there a provider of last resort for disability services in NSW. While carer specific programs continue to be delivered by the Australian Government, the capacity for State funded services to provide a respite effect is very limited. With no funding or department dedicated to residual disability services in NSW, the large numbers of people with disability who fall outside of the NDIS eligibility criteria also present a serious challenge to the ongoing need among carers of people with disability for regular, structured breaks.

“Lost a lot of respite care hours/support. Put in a[n NDIS] review - still waiting for a response 7 months later...”

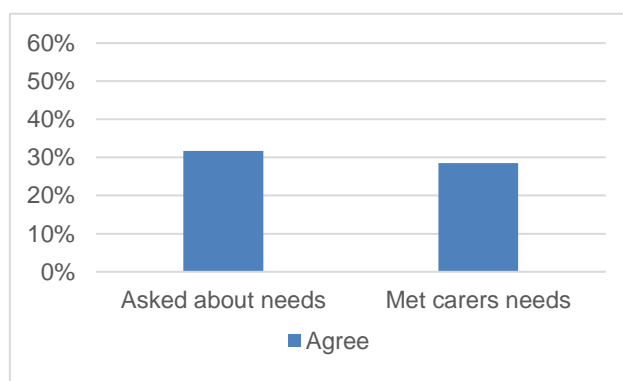
- Carers NSW 2018 Carer Survey respondent

The NDIS reflects a person-centred care philosophy that places the person with disability (participant) at the centre of service delivery. People with disability are offered an individualised ‘package’ of supports developed with the support of a Local Area Coordinator (LAC) and/or NDIS Planner. Planning sessions are focussed primarily on the participant’s goals, their available informal and mainstream supports and the reasonable and necessary additional disability supports required to facilitate these goals, with little systematic consideration of carers’ own needs.

While the policy framework for the NDIS refers explicitly to the importance of carers in the lives of participants,¹² carers are not entitled to an individually funded support package under the NDIS in their own right unless they are living with disability and meet the NDIS eligibility criteria themselves.¹³ There is an opportunity for carers to provide a ‘carer statement’ during the planning process, however this has never been formalised or publicised in any way to ensure that this information is meaningfully incorporated into NDIS plans in a consistent way.

The Australian Government recently noted in a response to the Joint Standing Committee on the NDIS, that the National Disability Insurance Agency (NDIA) in collaboration with Carers Australia, has developed guidance for NDIS staff and representatives on carer identification and inclusion.¹⁴ However, carers continue to report to Carers NSW that their needs are not identified or considered in planning discussions. The Carers NSW 2020 National Carer Survey¹⁵ found that less than one third (31.7%) of respondents caring for an NDIS participant were asked about their needs as a carer when engaging with the NDIS and only 28.5% reported that the services funded under the NDIS meet their needs as a carer.

Figure 1. Carer experiences and perceptions of the NDIS



The service types available to NDIS participants have also been formally defined by reforms in the NDIS price guide which for many years omitted ‘respite’ as a specific service type, instead opting to

use more participant-centred language when referring to service types that may have previously borne this label, like social support and short-term accommodation. The decision not to include the term 'respite' in NDIS terminology and service planning was a deliberate one.¹⁶ By definition, respite represents a break, rest or relief from a task or situation. This definition was initially considered to be offensive, with implications that the term reduces the person with disability to a 'burden'.

"There's nothing useful in NDIS specifically for carer needs... The by-product of those we care for having NDIS packages means we get a brief respite of between 30-100 minutes per activity, excluding transport to and from the activity. Try catching up on missed sleep, run a household or working within that timeframe!"

- 2020 National Carer Survey respondent

While respite for carers was not initially named as a service type in the NDIS price guide, participants could be funded to receive services that had the potential to provide carers with a break, such as support to undertake activities and participate in the community. Supports that could be funded for an NDIS participant that may have provided a respite effect included short term accommodation, assistance in living arrangements (host family/alternative family solutions) or assistance with self-care overnight. However, from July 2018 when the NDIS reached full rollout in NSW and ADHC was subsequently dissolved, very few disability supports providing carers with a break from the caring role were available to people with disability and their carers outside of the NDIS. This has also meant that services performing the function of respite within the NDIS have been further constrained, only accessible to carers of people who are eligible for the NDIS.

This is inconsistent with the recommendation of the 2011 Productivity Commission inquiry that state governments continue block funded community and carer supports, including some existing or modified home and community care services for people living with disability who are ineligible for NDIS and their carers.¹⁷ This is a model that has been implemented in some other jurisdictions, including Victoria.¹⁸

The intentional exclusion of respite from NDIS language during the first few years of the NDIS in NSW made it necessary for carers involved in planning meetings to adjust their vocabulary and frame their needs in terms of the participants' interests. This made support inaccessible for carers less confident and articulate in expressing their needs, including those from culturally and linguistically diverse (CALD) backgrounds and other diverse groups that may have experienced a history of discrimination or mistreatment by Government agencies. More recently, there has been a shift in the NDIA's approach, with Short Term Accommodation renamed to include 'respite' in a December 2019 update of the NDIS price guide, in line with the Productivity Commission's recommendation in 2016 that it be made clear that respite can, and where appropriate, should, be included in an individual's support package.¹⁹

Furthermore, changes to the NDIA's family and carers webpage²⁰ in late 2019 included acknowledgement of the importance of respite for carers and care recipients as well as increased information about facilitating respite through NDIS funding. While this change in language and approach will hopefully enable more carers to assert their need for a break in a straightforward way the Joint Standing Committee (JSC) on the NDIS recently recommended that the NDIA go even further than this, providing carers with information about the supports that the (NDIS) can fund to sustain caring arrangements during the planning process.²¹

As highlighted in the 2019 Tune Review of the NDIS Act,²² JSC report on NDIS Planning²³ and recent consultations for the new National Disability Strategy²⁴, carers of children with disability are continuing

to face significant challenges to accessing adequate support through the NDIS that enables them to take a break from their caring role. The extent to which the NDIS can be expected to provide supports offering a 'respite effect' continues to be tested through the Administrative Appeals Tribunal (AAT), with some NDIA decisions varied by the AAT to increase respite or replacement care to ensure the wellbeing of the family and carers of the NDIS participant (JQJT and NDIA; PNMJ and NDIA; PNFK and NDIA).²⁵

"When I asked for help (respite care) the people I spoke to told me because my son was 6 or 7 at the time I had no chance of getting it. I was in a very bad way mentally at that time and didn't know how I was going to continue caring for my son I actually thought about leaving my family. I called back and was very upset crying and begging for them to give me some kind of respite then they changed their minds and allowed me to have a carer come to my house to care for my son during school holidays."

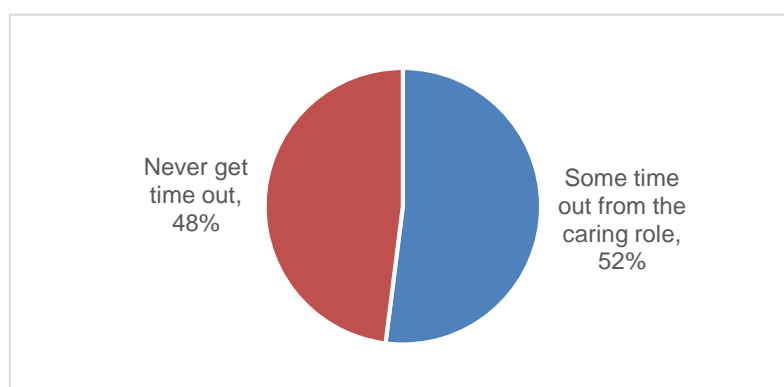
- 2020 National Carer Survey respondent

For carers who are able to access funding for respite or respite-like supports through a participant's NDIS plan, securing services presents a further challenge in utilising these funds. As a market-based system, availability of supports is dependent on the depth and strength of the market and the willingness of the provider to take on the service. This has meant that many participants and their carers have not been able to secure supports where markets are thin, such as in rural and regional areas or in high level or complex supports.

Prior to the NDIS, ADHC acted as the Provider of Last Resort in NSW, with an obligation to provide services regardless of location or complexity, however the closure of ADHC saw the role of Provider of Last Support, in-principle transfer to other non-government organisations. With no provider of last resort provisions within the NDIS market model, some of these organisations have since withdrawn vital services due to concerns about financial viability, leaving many participants and their carers with no or very few local providers available. Although the NDIS has reported that they are currently piloting different models to address thin markets,²⁶ there remains no official provider of last resort in NSW meaning that many carers cannot currently access the respite where they cannot identify a willing provider.

The assumption reflected in the NDIS model is that a well-supported participant will rely less heavily on their carer, creating an indirect 'respite effect' that negates the need for carer-specific services, especially respite. This has certainly been the case for some carers. However, seven years of the NDIS in NSW has demonstrated that for many, a lack of involvement and recognition in the planning process, coupled with frequently inadequate funded support in participants' plans, has further eroded their ability to take a break.²⁷ The 2020 National Carer Survey found that less than half of respondents caring for a person with disability in NSW (47.6%) agreed or strongly agreed that disability services provided a break from caring²⁸ and approximately 48% reported that they never get time out from their caring responsibilities (Figure 2).²⁹

Figure 2. Carer access to breaks from the caring role



Ongoing discussion regarding the inclusion of carer outcomes in NDIS planning is required to avoid the outcome foreshadowed in the Productivity Commission's 2017 report on NDIS costs: *"Without respite services, the sustainability and success of the scheme are imperilled."*³⁰

Respite services in the aged care sector

Key Points

- Following the 2011 Productivity Commission inquiry into *Caring for Older Australians*, a national aged care program, My Aged Care, was established to introduce greater consumer choice, control and competition into the aged services sector.
- Aged care services and services for carers in NSW, jointly funded by state and federal governments delivered by the NSW Department of Ageing Disability and Home Care (ADHC) transitioned to the federally funded My Aged Care between 2012 and 2015.
- The term "respite" has remained largely unchanged within the aged care sector throughout recent reforms, with clearly defined respite services including residential respite, cottage respite and flexible respite available through My Aged Care.
- Despite legislative provisions in the aged care sector that enable access to respite funding, the recent Royal Commission into Aged Care Quality and Safety has highlighted that the growing demand for aged care, capped-funding for home care packages and a lack of available or appropriate services continue to act as barriers to respite for carers in the aged care system.

Aged care is the only community care sector in which an entitlement to respite is embedded in legislation. The *Aged Care Act 1997* and associated *Aged Care (Transitional Provisions) Principles 2014* outline the provision of respite care for carers of older people as a legal obligation.⁴ The Act defines respite care as *"residential care or flexible care (as the case requires) provided as an alternative care arrangement with the primary purpose of giving a carer or care recipient a short-term break from their usual care arrangement"*.³¹ The *Aged Care (Transitional Provisions) Principles 2014* dictate that older people can access up to 63 days of funding for residential respite care per calendar

⁴ *Aged Care Act 1997; Division 2-1: (1)* The objects of this Act are as follows:
(f) to provide respite for families, and others, who care for older people;

(which can be extended by 21 days at a time on further health professional assessment). While this entitles funding for a maximum amount of respite provision for administrative purposes, it does not guarantee this level of support will be available to all carers, a point which often leads to disappointment and confusion among carers attempting to access a very constrained aged care service system.

The ongoing Australian aged care reforms are tied largely to recommendations made by the Productivity Commission in 2011, in the report *Caring for Older Australians*³², which was followed by the introduction of consumer directed care (CDC) to all Home Care Packages in 2013. Between 2012 and 2015, aged care services transitioned from being jointly funded by both the State and Federal governments, to being funded nationally by the Australian Government Department of Health.³³ A centralised service gateway, My Aged Care, was created to manage assessment and referral. The former State and Territory managed Home and Community Care (HACC) program, which had also provided community supports to people with disability, was divided into two programs: the Commonwealth Home Support Programme (CHSP) for people over the age of 65 and the NSW Government funded Community Care Supports Program (CCSP) which provided continuity of support to people with disability in NSW under the age of 65 through HACC-type services. Amongst the individual service types that made the transition to the CHSP were centre-based, cottage and flexible respite, previously funded by the National Respite for Carers Program (NRCP).

In conjunction with changes to the funding structure of aged care services, the Federal Government has acted on recommendations from the *Caring for Older Australians*³⁴ report to introduce greater consumer choice, control and competition into the aged services sector which was implemented through the *Living Longer Living Better (LLLLB)* aged care reform package. This reform saw a shift towards person-centred funding models designed to give aged care service users increased choice and flexibility as 'consumers', in line with the similar shift occurring in disability services. It should be noted however, that the 2011 Productivity Commission report recommended that some services, including emergency respite, carer support centres and social activities, would not benefit from individualised funding models.³⁵

The individualisation of aged care services funding has allowed more providers to enter into an open market contrasting to previous restrictions on who could deliver Home Care Packages (HCPs) linked to regular tendering opportunities called Aged Care Approvals Round (ACAR). Providers must now compete for clients and receive funding based on the number of clients they service and their assessed level of care, rather than through block funding.

The rationale behind increasing competition between service providers supposes that market competition will regulate quality and supply, however this takes for granted that consumers are adequately informed and equipped to exercise choice. It has recently been highlighted by the Royal Commission into Aged Care Quality and Safety that a market-based care system may not be the most effective way of regulating and ensuring high quality, safe aged care services.³⁶ A prior report by the Productivity Commission had also stressed that 'government stewardship' of an open market system was needed to ensure supply in thin markets.³⁷

The CHSP, which includes several forms of respite for people over the age of 65,⁵ continues to be largely block funded, however, service providers are expected to make adjustments for individualised CDC and the department requirement for consumer financial contributions. While consumer contributions are not currently a feature of equivalent services in the disability or mental health sectors they have been factored in, to some extent, in Emergency Respite and Carer Directed Supports under Carer Gateway. Despite early indications that the CHSP would be merged into the HCP program, the

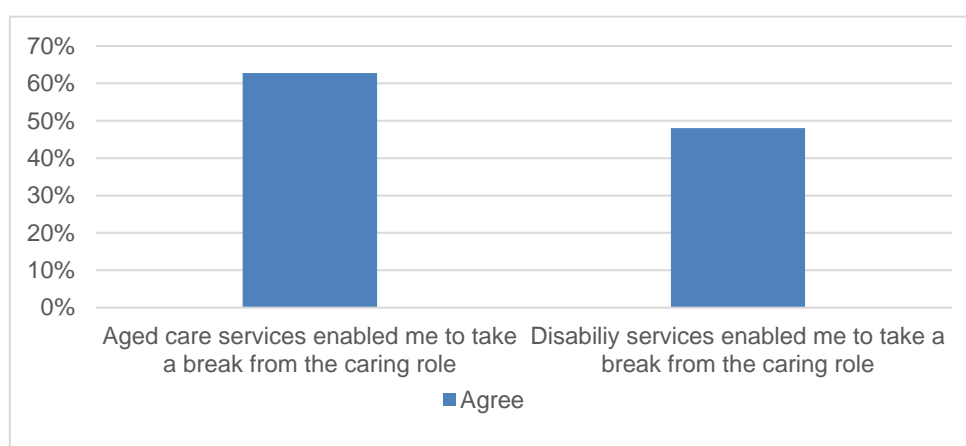
⁵ flexible respite, cottage respite, centre-based respite

subsequent extension of CHSP funding suggested no clear plan for this reform.³⁸ The Government response to the Royal Commission may bring further clarity as to the future of these programs.

Notwithstanding the transition to a national, consumer directed service delivery model, the definition and delivery of respite has remained largely unchanged within the aged care context. Even when the NRCP transitioned into the CHSP the respite service type list remained unchanged in CHSP contracts and the My Aged Care search function.³⁹ As a result, there has been little change to how respite is discussed in the aged care sector, despite the objections raised to the concept and language of respite in the disability sector.

This continued acknowledgment and provision of respite in the aged care sector has seen carers of older people in NSW report higher levels of access to breaks than carers of people accessing disability services in the 2020 National Carer Survey,⁴⁰ with approximately 62.6% agreeing or strongly agreeing that services have enabled them to take a break from the caring role compared to 47.6% of carers of people with disability.

Figure 3. Carers experiences of accessing breaks through formal service systems



In addition to aged care services labelled as 'respite', other CHSP and HCP services such as social support, domestic assistance, personal care and allied health treatments also offer a potential 'respite effect'. Further, formal 'respite' services often include other concurrent assistance such as domestic support. However, despite the relative integration of respite across the aged services sector, the breaks provided to carers in these contexts, with the exception of residential respite, tend to be for short periods only and carers report that respite services generally do not provide the levels of consistency, frequency or flexibility to allow for regular paid work.⁴¹

Furthermore, it has been highlighted that accessing respite can be more challenging and more costly for carers as their care recipient's care needs increase.⁴² Additionally, with over 100,000 people on the HCP National Priority Waitlist⁴³ accessing interim supports at a lower level than they require until a HCP becomes available, many carers are unable to access the level of care or support that would enable them to experience a respite effect. Significant HCP waitlists have also placed additional strain on CHSP services, with many now at capacity or having their own waitlist,⁴⁴ making respite access through the CHSP even more challenging for carers.

“Whilst waiting for a home care package, we were told that we would be able to access some services in the meantime such as respite but it had to be booked in advance and we could only access it for a few hours a week, so it was not enough for me to do anything outside of the house. We were also told that we had to find our own providers and research services ourselves. The person I care for also dislikes external/paid carers and does not like using services.”

- 2020 National Carer Survey respondent

Continuity in the framing of respite in the aged care sector has arguably resulted in greater understanding and awareness of these services among carers, consumers and providers. The downside is that a lack of discussion about how respite is conceived and delivered in the reform environment has led to the continuation of respite language and models which do not reflect the current service delivery landscape. For example, cottage respite is a popular form of respite among consumers and carers that is widely promoted within the aged care sector, but significant funding constraints mean that supply is, in fact, very limited.⁴⁵ Further, host family respite continues to be listed as a form of flexible respite on the My Aged Care service finder, but in reality, barely exists in NSW.

Further, maintaining and prioritising residential respite beds is simply not attractive to many residential aged care facilities given the additional costs and reduced longer term pay-off.⁴⁶ Many carers report that they are unable to access short periods of residential respite, only being able to secure at least two-weeks booked well in advance. In many cases, this respite is also often disrupted as the facility is not equipped or able to provide the level of care needed by the care recipient, frequently contacting the carer to attend to provide support or seek advice.

To compound the issues of thin markets, availability and flexibility of current models of respite, the Royal Commission highlighted that there is limited data collected by the Department of Health to assist governments and the sector to understand and improve how these services operate, what level of demand and usage there is, and whether they are the most effective solutions.⁴⁷

The Royal Commission into Aged Care Quality and Safety has emphasised the inability for carers to access adequate and appropriate respite within the aged care system.⁴⁸ It has also been noted that while current carer support system reforms will aim to address some carer needs, there is an expectation that the aged care system will continue to provide some carer-directed supports, including planned respite for carers.⁴⁹ However, throughout proceedings, it has been identified that the current aged care framework does not enable or promote this. The opportunity for carers, consumers and the sector to voice their concerns and make recommendations regarding system reform promises to provide the evidence base the aged care system needs to overhaul its treatment of respite and ensure it is better able to meet current needs.

Respite services in the mental health sector

Key Points

- Respite in the mental health context can be broader than other sectors and often represents a break or 'getaway' for the carer, with no direct care provided to the carer recipient in the carers absence.
- Little is known about historic respite spending and use within the mental health sector, making it difficult to understand and meet the respite needs of mental health carers.
- The Mental Health Respite: Carer Support Program (MHR:CS), which previously provided specialised respite supports for mental health carers, has been transitioned to the NDIS, however, it is estimated that less than 10% of people living with psychosocial disability or mental illness will be eligible for support through the NDIS.
- While there are some support programs for people with severe mental illness funded by NSW Health and the Commonwealth Government, funding under these programs is limited and supports focus on the support needs of the person directly accessing support, with limited capacity to provide carer focused supports.
- While Carer Gateway and the NDIS may be able to provide some opportunities for respite for mental health carers, due to the unique nature of their caring role, ongoing engagement and consultation with mental health carers will be necessary to ensure that respite options meet their needs.

Compared to the aged care and disability sectors, carers navigating mental health services with or on behalf of the person they care for tend to have even fewer opportunities to access respite in their own right. In addition, it was highlighted in the recent Productivity Commission Inquiry into Mental Health Draft Report⁵⁰ that respite spending for mental health carers is not well known and as such it is difficult to understand and meet mental health carer respite needs.

Respite in the mental health context can be broad and can often represent a break or 'getaway' for the carers with no direct care component for the person with mental illness. While not unique to the mental health sector, an example of this would be a carer retreat with an overnight stay where the carer has access to carer training, counselling, information provision and relaxation sessions. This form of respite is designed to build carer resilience and sustain the caring role by giving the carer access to an environment away from their daily activities. Although services for care recipients may be facilitated, many mental health carers will take advantage of these retreats only when they can make other arrangements for care, or in the case of episodic mental illness, when the care recipient is well.

Psychosocial disability is recognised by the NDIS, meaning that some people living with mental illness, if deemed eligible, may have access to NDIS supports that may facilitate a respite effect for the carer, as discussed previously in the 'respite services in the disability sector' section of this paper. However, of the estimated 700,000 Australians who experience a severe mental illness in any one year, only 64,000 people with psychosocial disability are expected to be eligible for individual packages through the NDIS.⁵¹

People living with severe mental illness in NSW who are not accessing NDIS may receive supports in the home and community through the Housing and Accommodation Support Initiative (HASI) or the Community Living Supports (CLS) program,⁶ which are funded by NSW Health. Similar to the present forms of NDIS and aged care services, these supports are focused on the consumer's support needs, yet may provide a respite effect for carers or family. However, funding available through these programs is prioritised for people at risk of losing their social housing or are unable to be discharged from hospital due to insufficient informal supports in the community, therefore is not likely to be available to those who receive support from an informal carer who may also need respite themselves.

Limited supports exist for people experiencing mental ill-health who do not have a confirmed diagnosis or whose condition is not considered permanent, as well as people whose symptoms cause them to lack insight into the nature of their condition, or have episodic, mild to moderate psychosocial disability that does not meet the NDIS eligibility threshold. The cessation of outreach services during the NDIS transition has also raised further concerns in regards to those who are homeless or transient and those living in regional or remote communities.⁵²

Several mental health specific respite service types are no longer available directly to carers as a result of the transition from the Mental Health Respite: Carer Support (MHR:CS) Program to the NDIS.⁵³ Other respite services have shifted towards consumer-focused models which are funded through the NDIS or federal health department. Examples include day activities for consumers and step up, step down accommodation. While these services may enable carers to take a break from their caring role, specific activities and supports for carers are not funded and are delivered at the discretion of service provider. These consumer-focused models do not take into account the additional challenges faced by mental health carers, such as when the person they care for has limited insight into their condition or is unwilling to participate in services. In such cases, without participant consent, services that provide a respite effect may not be accessible to carers.

Luke* has severe depression and lives with his mother Jo*. Jo was previously able to access support through the Mental Health Respite: Carer Support program. However, when it came time for that program to transition to the NDIS in their area, Luke was reluctant to access the NDIS. He refused to seek formal assistance or acknowledge that there was an issue. As a result, neither Jo nor Luke have access to support.

* Names changed

Young carers of family members or parents with mental illness have also benefited from carer respite retreats that allow them to meet and socialise with other young carers, gain greater understanding of mental illness and engage in specialised activities to support them with work and study. However, much of the funding delivering these supports has been withdrawn and/or redirected with transitions to the NDIS and Carer Gateway.

There has been considerable reluctance for the mental health sector to embrace Carer Gateway because it does not provide specialised support. The stigma experienced by people living with a mental illness and their carers in relation to the presence of mental illness can be a significant barrier when seeking to access carer services.⁵⁴ It is common for mental health carers to report that they are uncomfortable seeking support from generalist carer services.

Mental health carers often also require specialised carer supports as the caring role differs substantially from other types of caring. Mental health caring involves higher level of emotional support and psychosocial care, with lower levels of support around activities of daily living, and the

⁶ <https://www.health.nsw.gov.au/mentalhealth/services/Pages/hasi.aspx>

nature of mental illness also means that carers manage significant uncertainty in their day to day lives. This can impact the support needs of carers or lead them to feel left out of programs that focus on caring situations that are more predictable and physical in nature.⁵⁵ It will therefore be important Carer Gateway services and the NDIS engage with mental health carers to ensure that services address their needs and that they do not lose support that was previously available.

Respite services in the carer support sector

Key Points

- The Department of Social Services (DSS) has recently introduced a new, national carer support system – Carer Gateway. In-person Carer Gateway services, including planned and emergency respite, were rolled out nationally in April 2020.
- Carer Gateway respite services aimed to replace and build on existing respite services such as those available through the NRCP and Commonwealth Respite and Carelink Centres (CRCCs).
- Complementing existing Consumer Directed Care models in the aged care, disability and mental health sectors, Carer Gateway aims to focus on, and respond holistically to, the individual needs of carers.
- Carer Gateway also provides the potential for carers to access respite and services that provide a respite like effect, while measuring the effectiveness of these services, something that is still not well understood.

The Department of Social Services (DSS) has recently introduced a new, national carer support system – Carer Gateway⁷ – to replace and build on the NRCP service offerings. Online services commenced in June 2019, with in-person supports rolling out nationally from April 2020. Recognising that there was a need for a dedicated funding stream and access point for carer supports, Carer Gateway was initially launched in December 2013 as an online gateway and directory of carer supports.

Despite early indications that respite would not be included in this service, the in-person services delivered under Carer Gateway now include Emergency Respite as well as the capacity for limited planned respite to be funded under Carer Directed Packages within a 12 month period. In replacing the more than 50 Commonwealth Respite and Carelink Centres (CRCCs) across Australia with a network of 10 Carer Gateway Service Providers (CGSPs) across 16 service areas, the Carer Gateway reform provides some continuity with respite service models, but represents a new, more holistic approach to supporting carers.

With the ageing, disability and mental health sectors undergoing a significant shift towards person-centred service delivery models, carer supports have struggled to find compatibility with a system guided by the choices and preferences of the person receiving care. As a result, many services within these systems that have targeted the carer as the recipient of support have not transitioned well to a care recipient centred model. Funding for services that were considered in scope for the NDIS such as the Older Parent Carer Program and Mental Health Respite: Carer Support did not have their funding renewed and could not be replicated under the NDIS funding model. Carer Gateway has the potential to provide the missing link between service provision that provides respite or a respite effect

⁷ Previously referred to as the Integrated Carer Support Service (ICSS)

and measuring the carer outcomes associated with these supports, as it works directly with carers in response to their individual needs.

Respite services for people with chronic or life limiting conditions

Key Points

- There are limited opportunities for carers of people with chronic or life limiting illness to access respite services or services that may provide a respite like effect, as the person they care for is often not eligible for support through existing service systems.
- Carers of people with chronic or life limiting illness may be able to access short-planned or emergency respite through Carer Gateway, however they have limited access to regular planned respite.
- Recent funding of a respite facility by the NSW Government has highlighted the need for improved integration between service systems, as funding for infrastructure, direct care and ongoing maintenance, are required to effectively operationalise respite options for carers of people with life limiting or chronic illness.

Carers of people living with chronic or life limiting illness often have limited options to access respite. Previously some people living with chronic illness could access support in NSW through HACC programs. However the separation of aged care and disability sectors, resulting in strict eligibility requirements in relation to age and condition, has created significant challenges for people under 65 with chronic or life limiting illness (e.g. dementia, cancer, Parkinson's disease, Multiple Sclerosis) who require support.

While there have been negotiations between the NDIS and state health departments, chronic illness remains contentious in regards to NDIS eligibility. Currently, a person requiring support must be able to prove that they require support due to a disability, not their health condition, in order to access support through the NDIS.⁵⁶ Additionally, while some exceptions have been made to enable people under 65 to access aged care supports where no other services have been available, this is also not common.

Furthermore, palliative or end of life care programs which may be able to provide in-home support such as assistance with personal care, domestic tasks and community nursing are often limited to those in the final stages of life. This means that many with serious or life limiting illness have limited access to formal supports during treatment or early in their palliative care journey, despite having increasing care needs and requiring increasing support from informal carers. Carers of these individuals as a result have limited access to services or supports that may be able to provide them with respite or a respite effect, with Carer Gateway able to provide short-term planned or emergency respite in some instances.

There are limited funding options both for infrastructure to develop respite facilities and ongoing care costs with those requiring respite not eligible for funding through the aged care or disability systems. The 2019-20 NSW Budget saw the announcement of a one-off capital investment in a respite facility in Queanbeyan for people with chronic or life limiting conditions.⁵⁷ However, limited streams of funding to pay for the direct care required by those intending to use the respite facility has seen significant delays in the facility's development and use.

While Carer Gateway may play a role in providing short term respite support to fill this funding gap, respite provided through the Gateway is not intended to be regular or ongoing. Investment in alternative funding options or programs will be required by Government to enable carers of people with chronic illness or life limiting conditions to access regular planned breaks from the caring role.

Are respite services effective?

Key Points

- The effectiveness of respite is difficult to measure due to the complexities of respite as a concept and the stressful and ongoing nature of the caring role.
- Evaluating the effectiveness of respite requires a review of both quantitative and qualitative data as quantitative measures may not be sensitive to illustrate the positive effects of respite.
- While national data suggests that demand for respite is low, it is not clear if this is a result of a lack of need, or a lack of awareness or appropriate respite options.
- Based on evidence collected and published by CRA members, and member's experiences in supporting carers, the CRA provides an alternative viewpoint that stresses the value of respite services to carers and the importance of maintaining these outcomes amidst significant sector change.

The previous section established the diversity of services which may be referred to, or which are considered as providing, respite to carers in the NSW context. The varying definitions, objectives, eligibility criteria and delivery models described above,⁵⁸ in combination with the varied approaches to program and reporting due to several different sources of funding, has made it difficult to consistently and holistically measure the effectiveness of respite services. Furthermore, the emphasis by governments on outcomes-based reporting and in-depth evaluation has, until recently, been very limited in relation to respite programs.⁵⁹

Another difficulty in measuring the effectiveness of respite services, as well as other carer support types, is the limited potential for health and wellbeing measures to improve while the key 'stressor' – the caring role – remains. While formal services, informal support networks and other interventions may reduce the amount or intensity of care required to some extent, substantial reduction in, or stabilisation of, the caring role is uncommon due to constraints in service availability and adequacy. Indeed, the timing and type of respite have been identified as potentially critical in determining its effectiveness.⁶⁰

Due to the chronic stress often associated with caring, carers are likely to continue to score highly for psychological distress following breaks from caring, but this does not necessarily mean the breaks themselves have not been beneficial.⁶¹ Understanding the perceived value of respite through qualitative methods must be part of evaluating its effectiveness as a service type, as standard outcome measures identified by funders and providers do not always capture the information of the most value to carers and care recipients.⁶²

The CRA was established largely because of a shared concern among members that influential statistical data and policy papers were conveying a message about respite that both did not capture the full extent of its value to carers and did not reflect the many and complex factors affecting awareness and uptake of respite services among carers. Firstly, reflecting an ideological position strongly reflected in the development of the NDIS, a paper by the Independent Advisory Council (IAC) to the NDIS in 2014⁶³ clearly framed respite as a problematic concept, and questioned the assumption that a break operationalised through a formal service was in fact the right strategy for supporting carers' wellbeing.

In 2015, a survey conducted by AMR on behalf of Healthdirect Australia⁶⁴ in preparation for the development of Carer Gateway found that while more than half of respondents were aware of respite services, usage was low, and carers' perceptions of the value of respite services were mixed, depending on the type and appropriateness of respite service options available. The draft service concept for Carer Gateway released in 2016 by the Department of Social Services⁶⁵ added that while research indicated carer satisfaction with respite services was generally high, there was an overall lack of reliable evidence that respite was in fact effective.

The Survey of Disability, Ageing and Carers (SDAC) has also consistently reported low uptake of respite, as well as low need. In 2018, only 11.4% of primary carers in NSW reported using respite in the prior 3 months, with 11.9% of all primary carers indicating that they needed respite. The majority who had not used respite indicated that it was because they did not need it,⁶⁶ however it is not clear if this is a reflection of the true need for respite, or a reflection of a limited awareness of respite in the community, a narrow understanding of what services or supports might constitute respite or a lack of suitable, available respite options.

Based on evidence CRA members had collected and published, in combination with their experience supporting carers, the CRA was committed to providing an alternative viewpoint that stressed the value of respite services to carers and the importance of maintaining these outcomes amidst significant sector change.

Reflecting an understanding that respite's effectiveness may be difficult to measure and therefore to establish, this section focuses on evidence of the benefits of respite, evidence of demand for respite, and analysis of key barriers to accessing respite. Its aim is to demonstrate respite's value as a service type and highlight the influence of barriers in determining low uptake that might otherwise be interpreted as a lack of need, interest or value.

Benefits of respite services

Key Points

- Despite the difficulties associated with identifying and measuring the benefits of respite, evidence suggests respite supports improved health and wellbeing and increased social and economic participation.
- Carers often report worse health, wellbeing, social and financial outcomes than non-carers, with carers often neglecting their own health and wellbeing, social interaction, education or employment to focus on their caring role.
- In order for carers to sustainably maintain their caring role, carers' health and wellbeing must be supported through the ability to take a break from their caring responsibilities, both planned breaks and in emergencies.
- Evidence suggests that respite can have a positive effect on perceived level of burden, motivation, fatigue, sleep and mental health and increase life satisfaction and self-efficacy.
- Research has also found that respite may provide carers with opportunities to build, maintain and strengthen personal relationships or participate in education or employment opportunities where they choose to.

In spite of the difficulty of identifying and measuring outcomes for respite services, the Social Policy Research Centre's 2016 report, *Transitioning Australian Respite*, identified common outcomes of respite reported in the literature, including: improved health and wellbeing, increased social and economic participation and strengthened personal and community relationships.⁶⁷ Across a range of studies, respite has been found to improve emotional wellbeing and physical health, provide time for carers to look after themselves and enhance autonomy and independence.⁶⁸

For many carers, especially those living with the person they care for, their caring role is a 24 hours, 7 day per week, year round commitment that is relieved only occasionally by alternative care arrangements.⁶⁹ In NSW, nearly two thirds of carers have been caring for over five years.⁷⁰ When carers have no alternative to continue providing high intensity care day-in, day-out, this can have a significant impact on relationship stress, wellbeing and social and economic participation.⁷¹ If a carer or family is not supported with providing ongoing unpaid care, there is the risk that they will become 'burnt out' or overburdened, which can lead to a breakdown in care arrangements or disengagement from the caring role, resulting in premature residential placements or substantial community care costs.⁷²

"My Dad would have been able to stay in the home longer if day centre respite was available however because he was high level care including incontinence, in pads, and in a wheel chair we were told there was no service for him."

- National respite needs survey respondent

Many carers have long term, intensive caring roles yet access few or no formal services and have few if any family members or friends with whom to share their caring responsibilities.⁷³ In NSW, nearly one in three primary carers cares for more than 60 hours per week, and more than one in three has been caring for 10 years or more. Most (62.4%) are not accessing any formal services.⁷⁴ Further, the 2020 National Carer Survey found that one in four people being cared for by respondents (24%) could not be left alone at all, such were the extent of their support needs; and one in two carers responding to the Survey (50.1%) reported that they were the only one providing care to that person, with no other family member or friend available to share their caring responsibilities.⁷⁵

Carers with especially time-consuming caring roles, those lacking informal support networks and those who are financially disadvantaged are more likely to have worse wellbeing.⁷⁶ This may be exacerbated by the fact that carers commonly neglect their own health, putting the needs of the person they care for ahead of their own.⁷⁷

Evidence indicates that carers have poorer physical and mental health than non-carers and a higher rate of disability than the broader population.⁷⁸ While the vast majority of Australians report experiencing low levels of psychological distress, one quarter of Australian carers experience high or very high levels of distress.⁷⁹ The Carers NSW 2018 Carer Survey found that more than three quarters of carers with a long-term illness or disability said their caring role had contributed to their condition.⁸⁰

Carers also commonly experience financial hardship as a result of the additional costs associated with caring and the long term impacts of caring on accruing income and assets.⁸¹ The 2020 National Carer Survey found that approximately half of respondents were living on a household income of less than \$50,000 per year, and 53% reported experiences of financial stress in the last 12 months.⁸²

While carers generally report lower than expected unmet needs, financial support, health support and access to respite ranked in the top unmet needs of carers in NSW in the 2018 SDAC.⁸³

In order for carers to sustainably maintain their caring role, carers' health and wellbeing must be supported. The ability to take a break from caring responsibilities, both planned and in emergencies, is a crucial mechanism by which carers' ongoing wellbeing can be sustained. This section focuses on evidence that respite services can improve carer health and wellbeing and carers' social and economic participation.

Improved health and wellbeing

A national survey of carers' respite needs conducted by Carers NSW on behalf of the National Carer Network in 2016⁸⁴ found that carers most commonly saw the purpose of respite as giving carers a break from their caring responsibilities (84%). The majority also saw respite as an opportunity for carers to look after their own health and wellbeing (76%) and to help carers sustain their caring role (68%). When asked how important respite had been for them with regard to a range of personal outcomes, respondents indicated that respite was highly important for sustaining their caring role, the quality of care they provide, and maintaining their health and wellbeing.

A 2017 meta-analysis of 75 research studies on carer supports found that respite had positive effects on carer health and perceived level of burden, motivation, fatigue and psychological adjustment.⁸⁵ Studies conducted in Australia and England have reported that carers' wellbeing has been positively impacted when they have been able to access supports to take a break from caring⁸⁶ and studies conducted in the United States and European Union have demonstrated improved life satisfaction and increased self-efficacy⁸⁷. Another meta-study of caregiver support interventions for informal caregivers or community-dwelling frail elderly found evidence that respite services can be helpful in reducing caregiver depression, burden, and anger.⁸⁸

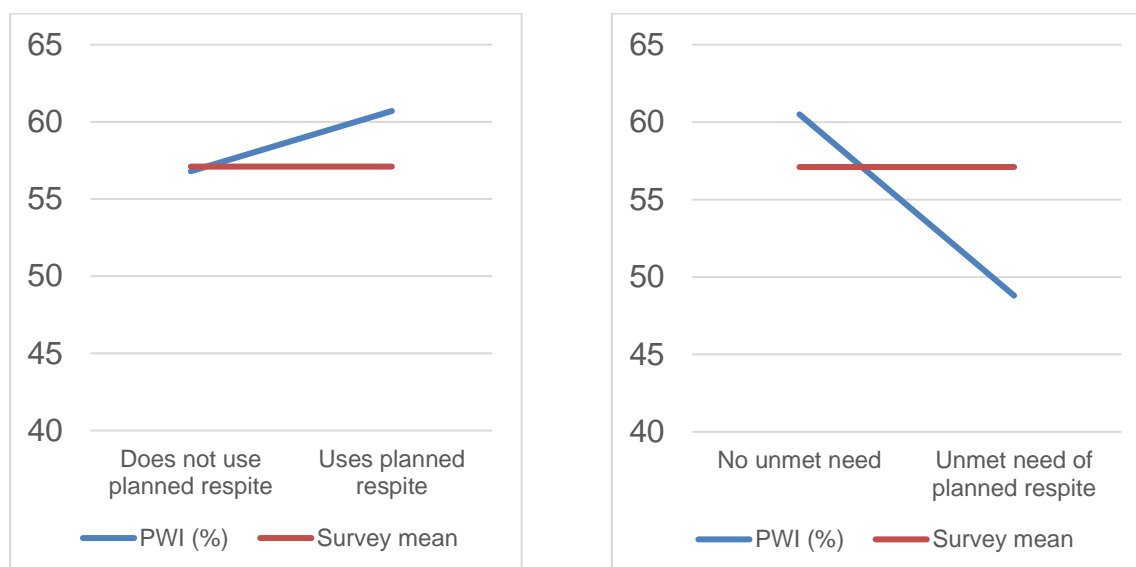
Additionally, a study which measured physiological responses to stress found that the provision of respite services correlated with elevated levels of a biological indicator of positive mood, suggesting that respite services resulted in better psychological and physiological wellbeing amongst the participant cohort.⁸⁹ A further study found that sixty-four percent of caregivers of the elderly receiving 4 hours of respite per week after one year reported improved physical health, 78% improved their emotional health.⁹⁰

Other studies have highlighted that respite had a positive effect on sleep and fatigue levels and psychological adjustment levels.⁹¹ The restorative effect from the ability to rest has been noted,⁹² with carers able to return to caring after a period of respite, and some carers have been reported to return to caring with an improved ability to care.⁹³

The 2020 National Carer Survey⁹⁴ found that there was a positive relationship between use of planned respite and wellbeing (Figure 4), with carers who reported using planned respite reporting higher wellbeing on the Personal Wellbeing Index (PWI)⁸ than those who did not use planned respite. The Survey also found that carers who identified an unmet need for respite experienced significantly lower wellbeing than the average wellbeing of respondents. These findings suggest that access to adequate, ongoing respite improves carer wellbeing.

⁸ The PWI scale is percentage of scale maximum with 100% being perfect wellbeing. The reference PWI score for the Australian population is 75%, the mean score in the 2020 Carer Survey is 57%.

Figure 4. Respite use and carer wellbeing



Benefits of flexible respite support for carers include improvements in mental health, reduction in caring responsibilities and prevention of unplanned or premature transition to alternative accommodation, more evidently when carers are provided with long term planned respite periods.⁹⁵

Social and economic participation

In response to the national survey of carers' respite needs,⁹⁶ carers indicated that respite was highly important for maintaining the quality of their relationships with other family members and connecting with friends and community. Respite has also been reported to have a benefit on building and maintaining personal relationships for carers, participants and families.⁹⁷ Respite services can provide an opportunity for marriages and partnerships to be strengthened as it gives partners an opportunity to focus time on each other.⁹⁸

Additionally, short breaks that allowed parents of children with a disability to engage in activities with their other children, giving undivided attention, were shown to be of great benefit to both parents and children.⁹⁹ A UK survey of siblings of children with a disability indicated that 93% of respondents stated that even a short break, such as respite services, enabled them to have more, and better quality, time to spend with their parents and other children.¹⁰⁰

Studies have indicated that respite offers carers the opportunity to engage in social and recreational activities, reducing feelings of isolation, building social and life skills and increasing connectedness to community.¹⁰¹ Respite has also been acknowledged as important for enabling carers to feel recognised and validated in the community, as formal support is provided that acknowledges the emotional and physical stress associated with caring.¹⁰²

While using respite services to participate in, or build skills to support paid employment is not always a key aim, employment is sometimes considered a type of respite. In particular, participation in paid employment (and activities to improve job readiness, such as education) is associated with improved health, wellbeing and social connectedness for carers.¹⁰³ The Carers NSW 2020 National Carer Survey asked carers of NDIS participants whether the supports in that person's plan had provided them with time to take a break, attend to their own health and wellbeing and/or participate in paid employment. Interestingly, less than half (47.6%) agreed they had been able to take a break from the caring role as a result of NDIS supports. However, just under one in three had been enabled to take

care of their health and wellbeing, and only approximately one in three had been enabled to stay in or go back to paid work.¹⁰⁴

Demand for respite services

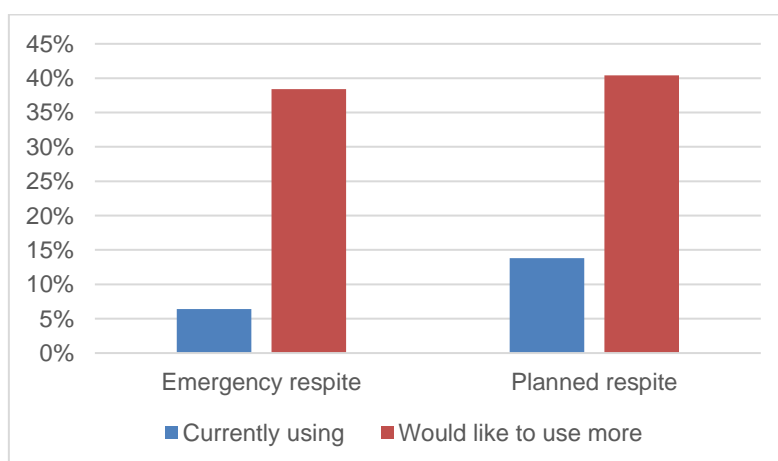
Key Points

- The Survey of Disability, Ageing and Carers (SDAC) has tended to reflect relatively low demand for respite, with only 11.9% of primary carers in NSW reported as needing respite, and the majority of those who had *not* used respite stating that their lack of need was the main reason.
- Research conducted by Carers NSW and Carers Australia suggest that carers have a much stronger interest in accessing respite than expressed in the SDAC.
- Many carers *not* accessing respite services report that a lack of awareness or respite options and limited appropriate or affordable respite options, as opposed to a lack of need, are the main reasons for not accessing respite.

As noted earlier, the SDAC has tended to reflect relatively low demand for respite. The 2018 SDAC found that only 11.9% of primary carers in NSW reported needing respite, and the majority of those who had *not* used respite stating that their lack of need was the main reason.¹⁰⁵ Both of these findings were counterintuitive to members of the CRA, as anecdotally and in our own consultation and research, high demand for respite, outstripping supply, was known to be chronic and widespread. Subsequent surveys and focus groups conducted by Carers NSW and Carers Australia sought to gain a more comprehensive understanding of how and why carers were – and were not – engaging with respite and found that the reasons for lack of engagement were indeed more complex than just lack of demand.

The national respite survey conducted by Carers NSW on behalf of the National Carer Network found that more than one in three respondents had never used respite.¹⁰⁶ The 2020 National Carer Survey also registered relatively low use of services identified as emergency respite (6.4% of respondents had used this) and planned respite (used by 13.8%) (Figure 5). However, respondents expressed strong interest in accessing these services more, with more than one in three carers identified a need for respite services (38.4% for emergency respite and 40.4% for planned respite).¹⁰⁷

Figure 5. Carer use of and interest in respite services



Among these respondents to the national respite survey who had *not* used respite services, the most commonly cited reason was lack of knowledge about where or how to access it (30% of respondents). Given the general lack of service awareness among many carers, especially mental health carers¹⁰⁸ and culturally and linguistically diverse (CALD) carers,¹⁰⁹ this is not a surprising finding. The next most common reasons related in lack of appropriate and affordable respite service options. Only 11% of respondents identified that they did not want to use respite. These findings suggest that access to respite may be mediated more by knowledge and access to choice of respite service than by need.¹¹⁰

"I really do not know a lot about the services available or how to use them and not really clear on when we should utilise respite."

- Carers NSW 2018 Carer Survey respondent

This is also supported by the findings of six focus groups conducted with culturally and linguistically diverse (CALD) carers in 2018, in which respite by four focus groups in the context of maintaining carers' physical and emotional health and wellbeing. In these groups usage of respite was low and interest for accessing these services was high.¹¹¹

A further survey conducted by Carers Australia with respite brokerage services on behalf of the National Carer Network in 2017 found that demand for both planned and emergency respite in their area of operation was high, and that certain types of respite could be difficult to access. NSW/ACT registered the highest level of difficulty regarding service access.¹¹²

It should also be noted that while SDAC data apparently reflects relatively low need for respite in NSW, after financial assistance, health improvement and emotional support, respite was the highest unmet need identified for carers in NSW.¹¹³ In 2018, approximately 38,600 primary carers reported this unmet need.¹¹⁴

Barriers to access and effectiveness

Key Points

- There are a number of key barriers to accessing respite that carers face: availability, awareness, accessibility, appropriateness and affordability.
- There is a limited availability of residential and in-home respite due to funding models which incentivise permanent residential placements over respite placements, the increasing demand for care services, growing workforce shortages, especially in rural and regional areas, and an over reliance on market-based systems to mature and meet needs.
- Many carers are not aware of the existence of respite or services that may provide a respite effect, or how to access these types of support through existing service systems.
- The increased digitisation of services and limited integration between service systems created additional barriers for many carers who have limited digital literacy or who may find it difficult navigating multiple service systems to access respite.
- While a move towards Consumer Directed Care across sectors has seen the increased flexibility and appropriateness of services, many carers continue to report that respite options are not appropriate and do not meet the expectations or needs of the carer or their care recipient, especially for carers of people with high or complex needs.
- Cost is often cited as a barrier to respite by carers, with a lack of cost transparency across the ageing, disability and mental health sectors, making it difficult for carers to make informed decisions when planning or choosing a service.

As identified above, the key barriers to carers accessing respite services include unawareness of the options available and lack of appropriate options to choose from with regard to the needs of the carer or care recipient. Appropriateness can relate to cost, location, timing and level of care or other factors. This has been identified as a particular barrier for carers of people with dementia, carers of people with complex needs, carers from CALD backgrounds and carers living in regional and rural areas.¹¹⁵

Availability

Residential respite

Availability of residential respite is of particular concern across all service systems. High costs associated with providing residential respite, limited financial support to meet overheads and reduced financial security in market-based systems have created financial disincentives for providers to offer residential respite options. The survey conducted by Carers Australia of respite brokerage services reported that 80% of respondents agreed low availability made it difficult to access residential respite.¹¹⁶

“The one time we did use respite (local aged care facility) it felt like the facility had to move heaven and earth enable Mum to stay. And then she had to stay for two weeks when she only wanted one week.”

- Carers NSW 2018 Carer Survey respondent

In the present aged care system, residential respite tends only to be available when a facility has an unoccupied bed that has not yet been filled by a permanent resident. These vacancies are unpredictable, as they often become available only as the result of the death of an existing resident. Additionally, service providers are often unwilling to provide residential respite for less than two weeks due to the administrative costs associated with short-term respite placements.¹¹⁷ During COVID-19, respite placements have become even more challenging, especially where facilities have been particularly concerned about admitting short term residents due to transmission risks and already stretched resources.

“Respite and emergency respite, especially short term, are impossible to obtain. Even the best (frantic) efforts by my wife’s...case worker came to nothing, resulting in my being discharged from hospital emergency (my wife had to be with me all during this time) to care for my wife.”

- Carers NSW 2018 Carer Survey respondent

Research indicates that the funding structure of residential respite within the aged care sector may also be a contributing factor. Facilities have little financial incentive to accept respite clients, who attract little to no additional subsidy, are generally short term and often require additional support (and therefore resources) to settle at the facility.¹¹⁸

Supply is further restricted by a practice of using respite beds for ‘try before you buy’, whereby a potential resident may be encouraged to accept a respite place as a “trial” before moving permanently into residential aged care. This measure is often used where a potential permanent resident is waiting for a long-term bed to become available or while their approval for permanent residency is being processed.¹¹⁹ The availability of residential respite is therefore largely determined by the practices of individual service providers, rather than systematically managed to meet demand.

While it is often in the interest of older people, residential facilities *and* carers to trial residential care before permanent admission, in order to ensure that the facility meets the person’s needs and to facilitate a smooth transition in what can be a challenging shift, the CRA believes that this practice should not be made to compete with the availability of respite beds. Additionally, it should not be assumed by providers or the Government that this is the only progression of older persons through the aged care system, and that in many cases, older people and their carers have every intention of returning to previous caring arrangements following a period of residential respite.

“Hurt my shoulder...moving my husband in lifter. To have an operation done. I found it hard to get respite. I found respite 25th of June to 2nd July now I need to find a doctor who will operate with this date - still trying.”

- Carers NSW 2018 Carer Survey respondent

Within the disability sector, accessing Short Term Accommodation (STA), comparable to residential respite, has been reported to be equally as difficult, with few options available, especially for children with complex behavioural needs. Specialist accommodation providers are unable to hold places due to a lack of certainty that they will be filled, leading them to prefer long term Specialist Disability Accommodation (SDA) participants, as these residents provide a level of secured income. Providers have reported difficulty maintaining respite facilities that cater to under 65’s due to narrow profit margins associated with prices for NDIS supports. Additionally, similar to residential respite in aged

care, administrative costs to facilitate short term accommodation can be extensive and may exceed the NDIS pricing benchmarks.

Feedback from programs supporting ageing parent carers of adult children with disability funded by the NSW Government prior to its withdrawal from disability support indicated a simultaneous high demand for long-term respite and chronic shortage of respite beds for both planned and emergency respite. The NDIA has looked to overcome ongoing access issues for short term accommodation with increased STA pricing, however carers continue to report an inability to locate or utilise available services due to high demands.¹²⁰

“Now that her respite house has been handed over to a private group, we will end up losing it, as it is now not operating at capacity due to clients receiving little to no funding, therefore making the respite house unviable to continue operating into the future.”

- Carers NSW 2018 Carer Survey respondent

In home and community respite

Carers and care recipients often report a preference for home and community-based respite options to enable carers to take a break that they care for with a meaningful, positive experience, however, these options are often not available.

In line with the ongoing aged care reforms, planned respite in aged care was transitioned from the previous National Respite for Carers Program (NRCP) to the CHSP program to provide a number of possible respite options, including flexible respite, cottage respite, and centre-based respite. However, ongoing reports indicate that this has not improved the availability or accessibility of respite services in the community. A small study of carers of people living with dementia found that, in 2016, following national aged care reforms, 73% of respondents reported an unmet need for respite, suggesting that ongoing barriers to accessing services continued to persist.¹²¹

Capped funding within the aged care sector has also created a significant barrier to accessing in-home or community-based respite options. To access a Commonwealth Home Care Package (HCP), a person must be assessed, approved and then allocated a package. Carers have reported that this process can be lengthy with potential delays at every stage. Nearly one in three (30.4%) respondents to the 2020 National Carer Survey who accessed aged care services with or on behalf of the person they care for indicated that waiting to access services was a key challenge, with one in five (21.1%) reporting the same in relation to assessment waiting times.¹²²

Furthermore, unlike NDIS plans, HCP numbers are capped and continue to be funded at numbers well below demand, especially for higher level packages. At 30 September 2020, there were 62,395 Australians who were waiting for a HCP at their approved level and had not yet been offered one. A further 36,873 people had been offered an interim HCP while waiting for a HCP at their approved level. The estimated wait time for an approved Level 1 package was 3-6 months, or more than 12 months for Level 2, 3 and 4 packages.¹²³ In practical terms, this means that towards the end of 2020, nearly 100,000 older Australians were waiting for months, or even years, for the level of support for which they had been formally assessed as eligible.

While 97.7% of those awaiting access to a package were approved to access support through the CHSP, many CHSP services are now at capacity and any additional care needs those people had would either need to be purchased privately, provided by family members and friends, or remain unmet, placing the older person at risk. In many cases, this shortfall is met practically, emotionally and financially by carers, often balancing other family responsibilities and paid work with the direct and administrative tasks required to keep their family member or friend safe and well. As the final Royal Commission report noted, ongoing, unacceptably long waiting periods present risks such as inappropriate hospitalisation, premature admission to a residential facility, carer burnout and even death.¹²⁴

“Although Mum was assessed for a 3/4 package a couple of years ago we are still on a 1/2. There is no communication with us about this... The whole process of accessing services is mysterious, e.g. Mum is now receiving some respite care which would have been great to know about earlier if it existed...”

- Carers NSW 2018 Carer Survey respondent

Additionally, for those who are allocated packages, there is little remaining budget for respite services with the carer’s wellbeing in mind, once the care recipient’s basic needs are met. Carers may be able to access further funding for respite in four situations through the CHSP or in cases of emergency, through Carer Gateway however the multiple steps and pathways required to access alternative options places further barriers in the way. Even when carers do identify alternative sources of respite, there is no guarantee that these will meet their needs.

“I am using In-Home Respite via DVA and CHCP (level 4) to full capacity which totals 15hrs in business hrs. This is inadequate to be able to maintain employment skills at my level.”

- Carers NSW 2018 Carer Survey respondent

Similar to accessing aged care services, accessing the NDIS requires an assessment of eligibility, followed by an assessment of support needs, the development of a plan or package of funding, implementation of the plan and ongoing plan reviews, both scheduled and unscheduled in relation to changes of circumstances or disagreements regarding decisions.

The Joint Standing Committee on the NDIS¹²⁵ has raised concerns in regards to the ongoing delays faced by participants in getting their NDIS plans approved, activated and reviewed. For example, an NDIA submission to the Joint Standing Committee in 2019 reported that the average period of time from determination of eligibility to NDIS plan approval for those accessing Early Childhood Early Intervention (ECEI) was approximately 90 days.¹²⁶ Although the NDIA has taken measures to reduce wait times, Carers NSW continues to hear from carers that they have experienced significant delays in accessing support for, or on behalf of the person that they care for. An inability to access services in a timely manner again results in carers providing increased care, facing higher levels of psychological stress and unable to take a break due to inability to fund respite services or services that provide a respite effect.

“7 months to get a NDIS plan. Then they tell me I won’t get any home supports as it is my parental responsibility. I explained I would have to quit my job if I didn’t get in home supports.”

- Carers NSW 2018 Carer Survey respondent

Low pricing benchmarks, a lack of capital funding to sustain transport and building maintenance and increased flexibility for individuals have also rendered some types of group activities financially unviable for providers. In some cases, especially in regional and rural areas, funding may be allocated for a certain type of activity but there may not be adequate venues, workers or other participants for it to occur. Furthermore, ongoing market challenges resulting from the individualisation of funding in the disability and aged care sectors have also resulted in the cessation of a number of long running day programs or community activities, including some volunteer led, flexible respite programs, which are no longer financially viable. For many carers these programs provided a respite effect and were beneficial for care recipients who had developed long running relationships and social networks.

Location of services

There is an over representation of carers outside of metropolitan areas,¹²⁷ which often makes accessing services challenging with many carers reporting needing to travel vast distances to access the appropriate services for the people for whom they provide care.

“There are no cottage respite or residential respite in our area, have to go to Sydney...that’s over 100 miles travel. I’ve only done this once. What I do now when I can is take my son to a hotel somewhere and stay there.”

- Carers NSW 2018 Carer Survey respondent

Additionally, funding is often not allocated to cover the entirety of costs, for example, some people have been funded for community activities such as day programs or centre-based activities, however have not been funded adequately for transport to attend these activities, particularly in the case of NDIS. This has seen a reduction in the respite-effect of these activities for carers who are required to provide transport for care recipients. This exacerbates the difficulties faced by carers, especially those in regional and remote areas who report having to drive significant distances to access activities.¹²⁸ Respite activities that previously gave carers a break of 3 hours may now only give carers a break of 2 hours due to travel time, it also limits the activities the carer can do during these periods if they are far from home.

Awareness

Carers’ understanding of what respite involves and their entitlement to it can vary. This is a common issue for all carers but is likely to be more prominent for special needs groups including CALD and older carers. Many carers do not identify themselves as carers, perceiving their caring role as an extension of a family/friend obligation or duty. As such, many do not seek supports or assistance to maintain their caring role. For those who do identify as carers, many are not aware of the services and supports available and often report that they do not have the time to go looking for services.

Similarly, carers consistently report that on requesting services and supports, they are given inconsistent information or service providers are unable to give them an answer in regards to respite supports. Carers report having little time to search for and source services, especially within the context of the current, complex services and support systems. A recent study found that carers were required to contact four or more information sources to gain sufficient knowledge to access respite

“When you are a carer running on low batteries you don’t have the energy to source support for yourself. All your energy goes into caring.”

- Carers NSW 2018 Carer Survey respondent

services.¹²⁹ Due to a long history of under-funded and under-resourced services, many carers are hesitant to reach out for support, often assuming that it will not be available or suitable based on past experience.¹³⁰

Accessibility

A further limitation to accessing supports has been the ongoing digitisation of services with My Aged Care, the NDIS myplace portal and Carer Gateway now serving as the digital hubs for carers to gather information, initiate assessments and source service providers. The digitisation of services relies on the assumption that carers are digitally literate and have access to the internet and appropriate devices. However, contrary to those assumptions, the 2020 National Carer Survey found that more than one in ten respondents lacked confidence accessing information and services online.¹³¹ Another recent study found that only 25% of carers had utilised My Aged Care website to gather information, and those who had did not rate it as a useful source of information.¹³²

“... have no idea on how to use some parts of the package, the website [NDIS] is impossible to navigate you go round in circles and still can't get answers.”

- Carers NSW 2018 Carer Survey respondent

Inaccuracy of digital service finders due to incorrectly entered or reported information or irregular updates has increased the challenges for carers in finding and utilising services. Currently, there is no service finder on Carer Gateway, and it is not clear if this feature will be incorporated. Additionally, with increased onus put on carers to support participants to source and coordinate their own services within the NDIS, carers have reported increased time needed for administrative tasks.

Aged care and disability reforms have explicitly been aimed to overcome the fragmentation of support systems in the community, enabling easier, more consistent access to services and supports. However, the separation of carer supports from the supports received by the person they care for has resulted in increased service gaps and complex systems, which many carers require assistance navigating. The proposed introduction of Care Finders and Carer Hubs in the final report of the Royal Commission into Aged Care Quality and Safety¹³³ recognises this need; however, service navigation should be available not only to carers of older people, but across service systems, such as through Carer Gateway, if carers are to be able to access the full range of opportunities available to take a meaningful break.

“I never get respite. I have always been rejected for this through NDIS even though I am the sole Carer of 3 disabled children.”

- 2020 National Carer Survey respondent

Service systems are often independent of each other. If a carer of a person who is ageing or frail would like to access specialised carer supports (e.g. counselling), they may need to contact My Aged Care, their service providers or Carer Gateway to coordinate alternate caring arrangements in order to attend services and supports for themselves. Not only is this confusing and complex for carers, but also requires them to provide their carer story multiple times in order to access the appropriate supports. It has been suggested that although Carer Gateway is intended to reduce the number of touchpoints for carers, as Carer Gateway will not provide extensive planned respite, carers looking to access regular planned respite will continue to be redirected to the appropriate funding body (i.e. My

Aged Care or NDIS) and will therefore need to contact multiple service systems depending on the supports required.

Access to services has been further hampered by the COVID-19 pandemic, where many in-home care services were cancelled and many external social support and peer support activities were suspended or driven online, rendering them inaccessible or less effective for many.¹³⁴

“COVID isolation has worsened the situation for us as my carer respite activities like aqua aerobics has cancelled. This has left me more isolated.”

- 2020 National Carer Survey respondent

Appropriateness

Flexible and responsive services

Commonly, supports that provide a respite effect are dictated by the service provider. In both the aged care sectors, planned respite has - prior to the proliferation of the ‘gig’ care economy represented by services like HireUp and Mable – predominantly been provided in two to four hour blocks during business hours on weekdays. Services provided outside of these times either attract an additional cost or are unavailable due to limited staff capacity or inadequate financial incentives to provide shorter periods of support. A two to four hour block of care is also inadequate for most people to engage in paid work or an activity outside of the home. Restricting supports to business hours and weekdays may also further isolate carers from friends and family who work full time and engage in social activities on the evenings or on the weekend.

“While my wife enjoys the Day Care facility that we use, I find it unreliable as respite for myself. While it is meant to finish at 3:00pm, she can be delivered home anytime between 2:05pm and 3:00pm which prevents me from using that day as a suitable one for arranging lunches with friends.”

- Carers NSW 2018 Carer Survey respondent

Supports appropriate for the care recipient

In cases where the care recipient may be eligible and willing to participate in community or in-home services, it is often the case that the activities are unsuitable for the person they care for and therefore, they are hesitant or resistant to engage the service. Residential respite in a residential aged care facility (RACF) is also often unsuitable for younger people, however there are very limited alternate options due to a lack of more appropriate Short Term Accommodation options. Similarly, carers themselves often report hesitation around utilising services that are not appropriate for the person they care for.

In many cases, an inability to utilise available services highlights the need for more flexible, holistic services that meet both carer and care recipients’ needs, which falls in alignment with ongoing sector reforms towards Consumer Directed Care.

High/complex needs

Carers supporting people with high or complex care needs are more likely to need and benefit from respite, however limited appropriate activities or adequately trained staff make it difficult for these carers to experience a true respite effect. These carers report that they are just simply unable to access services that are able to cater to the needs of the person for whom they provide care due to potential risk to staff, lack of adequately trained staff or unwillingness of providers to provide services. In some cases, allocated funding is not adequate to meet the high needs of the care recipients and therefore providers are unable to provide the services due to concerns regarding ongoing financial viability of the service or potential risks to staff.

“The short term respite care in nursing homes has not been successful as they say that they don’t have enough staff to care for her as she is high needs.”

- 2020 National Carer Survey respondent

Carers that have been able to access respite or respite-like services have often reported a high level of ongoing vigilance that prevents them from totally ‘switching off’ and thus from fully benefiting from a break; 81.5% of respondents to the 2020 National Carer Survey reported that even when not directly engaged in their caring responsibilities, they were still thinking about the needs of the person they care for.¹³⁵ Many carers report that they may be interrupted at any time by a call or email they need to attend to, or be required to return home to deal with an arising issue. Additionally, some available services are not fit for purpose, such as programs that run for a number of consecutive hours when some participants are unable to engage for prolonged periods due to their complex or behaviours of concern.

“It is difficult to access respite services as our disabled son has high anxiety and problem behaviours. Respite services for clients with high needs such as his, are, from personal experience, impossible to find.”

- Carers NSW 2018 Carer Survey respondent

Often people living with disability may also have a number of comorbid complex health issues. With the transition to NDIS, there has been a lack of clarity around boundaries between funding bodies, for example, there has been ongoing disagreement between departments about how complex and mainstream health supports are funded. A number of carers have reported that where community nursing is required to support in-home respite, often in the case of diabetes, there has been a lack of clarity around which system is appropriate for funding this service and as such, participants have been unable to access respite as the appropriate level of care cannot be accessed. Recently the NDIS has been required to clarify arrangements around the funding of mainstream healthcare services, however there appears to be ongoing lack of clarity around service barriers between mainstream and disability supports.

Reluctance to engage

Often overlooked and arguably the key to most access barriers is an unwillingness of the service user to engage in activities and supports that provide a carer with a break. The SDAC 2018 indicated that the second most common reason for not accessing respite services was service-user unwillingness.¹³⁶ This creates a large challenge for carers accessing services and supports in CDC models. The exclusion of carers in the assessment and planning process for the person requiring care can also be detrimental to a carer's ability to access supports. Care recipients may report higher levels of ability or lower levels of support required, especially those who are ageing or frail or those who have limited insight or difficulty articulating their support needs due to the nature of their condition resulting in inadequate funding for formal supports that aim to sustain informal caring arrangements.

"My respite is limited as [the person I care for] refuses to accept support from others."

- 2020 National Carer Survey respondent

For mental health carers, lack of insight from the care recipient into their condition can be particularly challenging. In some cases, people requiring care may refuse to apply for or engage with formalised services, creating additional challenges for carers to accessing support that may provide respite or a respite like effect.

Quality of services

For carers to utilise respite or respite-like services, they must place the person they care for in an alternative caring arrangement, either with formal or informal supports. For carers, this can be highly distressing due to concerns regarding the quality of care that their friend or loved one will be receiving whilst they are utilising the time to take a break from caring. Many carers refer to concerns regarding quality when it comes to utilising formal services in general, noting that due to experience or expectations, the quality of care will be lower than that which they can provide, to such an extent that it may put their loved one at risk.

Affordability

Cost is cited as a common barrier for carers to access support and can contribute to a reluctance to use a service or, for some, make the service unattainable. This issue is aggravated by a lack of cost transparency across the ageing, disability and mental health sectors, making it difficult for carers to make informed decisions when planning or choosing a service. Cost is also related to the cost of providing respite and subsidies associated with respite supports which can impact on supply and demand if service providers are not financially incentivised to provide respite services, or the service is not adequately subsidised to be cost effective for the carer.

Cost transparency is particularly prominent in the aged care sector. Despite significant moves to improve transparency of service cost it is still difficult to find information relating to cost on the My Aged Care website or on the websites of service providers and there is no standard pricing or cost guidelines for such services.

Similarly, for those accessing HCPs, there may be substantial overhead costs for accessing services with reports of a 1000% increase in service charges, from \$8 to \$80 dollars for the same service, when people who are ageing or frail transfer from a CHSP (a low-level support package) to a HCP (a higher level support package), making services financially unavailable.¹³⁷

Similarly, although prices in the disability sector are set by the NDIA in the NDIS Price Guide, which is reviewed and released periodically, participants and their carers are still required to be informed about standard pricing and budgeting, and actively review and negotiate service arrangements to ensure optimal plan utilisation.

“Whilst our funding has not been approved for in home care and respite, we have had to cut into his funding for therapy to fund in home care and do not have enough to cover both therapy and care/respite.”

- Carers NSW 2018 Carer Survey respondent

Although the NDIA publishes standardised pricing, carers continue to report that services are not transparent in their quoting, particularly in relation to transport costs, where services initially report that transport would not be charged, but later invoicing the participant for transport costs, making it difficult to budget available NDIS funds. Furthermore, carers of people with disability who are not accessing the NDIS have reported that providers are quoting them significantly more than NDIS prices, which are often well beyond their means if they are not receiving any services or supports. Carers, often already facing financial disadvantage may be limited in their ability to cover the additional costs of services.

While the NDIA is committed to ensuring no participant is ‘worse off’ many carers have reported that due to a reduction in respite provisions, they are indeed in a worse position compared to previous service arrangements. Some carers have reported that in order to access respite/in-home care that has not been allocated in the NDIS plan of the people they care for, they have had to or would have to re-allocate funds that have been provided for other services such as therapy to enable them to manage their ongoing care arrangements.

“Under NDIS I have to rearrange his core funds to pay for it [respite], which I can only do as I self manage, and it is very expensive. A month off would cost over \$20,000, a quarter of his funding.”

- Carers NSW 2018 Carer Survey respondent

Parents have also reported to Carers NSW increased difficulty accessing services and supports for their children as they have been advised that mainstream services are more appropriate to provide some supports, such as childcare. Carers NSW has heard anecdotally that children under the age of 12 are not considered to need specialised care supports funded through an NDIS plan due to the assumptions that this care falls within the scope of ‘parental responsibility’ and that mainstream care services already exist for that age group. However mainstream supports are not always equipped to provide support to children with disability.¹³⁸

Special needs groups

Key Points

- Many carers experience barriers to accessing respite, however some diverse carer groups face additional barriers due to stigma, discrimination, a lack of appropriate options or geographic location.
- Many diverse carer groups experience stigma or discrimination which may make them hesitant to seek support for themselves through formal service systems
- Carers of people living with dementia may have higher intensity caring roles than other carers, however may have greater difficulty accessing respite due to an ongoing overreliance on carers to provide support during periods of respite and an inability to access preferred respite options such as cottage respite due to a lack of availability.
- Despite the higher prevalence of caring in Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) communities, carers from these communities experience greater difficulty accessing respite through formal service systems, often finding limited availability of services that are culturally appropriate and culturally sensitive.
- Carers living in regional and rural areas may experience greater difficulty accessing services and supports due to geographic isolation, lower digital access and workforce shortages.

Many carers have difficulties accessing respite that meets their needs and the needs of their care recipient, however, for diverse carer groups these challenges can be exacerbated due to stigma, discrimination, a lack of culturally appropriate options, geographic location or distrust due to historic mistreatment by government and formal services. Those in diverse carer groups are often in higher intensity caring roles, caring for more than one person or report higher levels of psychological distress, and are therefore likely to benefit from opportunities to take breaks from their caring role.

Carers of people living with dementia

In 2021, it was estimated that almost 1.6 million people in Australia are involved in the care of someone living with dementia.¹³⁹ Dementia describes a collection of symptoms that are caused by disorders affecting the brain and is not one specific disease. While dementia is more common after the age of 65 years, people can also receive a diagnosis in their 40s and 50s, referred to as younger onset dementia. Consequently, the carers of people living with dementia may be engaged with either or both the aged care and disability services sectors.

In a survey Australian carers, 31% of respondents reported that caring for the person with dementia had a negative impact on their physical health,¹⁴⁰ and 34% reported feeling weary or lacking in energy. The care needs of people living with dementia relative to other cohorts within either the aged care or disability sectors are generally more intensive as a consequence of the complexity of their condition. This often makes it more imperative, yet more challenging for carers of people living with dementia to access respite.

“After trying 3 Aged Care facilities for my husband with Alzheimer's Dementia to have respite, there was only one facility at which the staff were appropriately trained to care for him.”

- 2020 National Carer Survey respondent

The Royal Commission into Aged Care highlighted the overuse of psychotropic medications on people with dementia in residential respite and the inability of some residential facilities to meet the high care needs of the care recipient, with providers often relying heavily on carers to support with the residential respite placement, limiting their ability to take a break from the caring role.¹⁴¹ For people living with dementia, it can often take additional time and support to settle into a new environment, such as a residential facility, however this is not adequately reflected in respite funding models. While many carers would prefer to access cottage respite as it is less institutional and can be utilised for shorter periods, limited availability and high costs often mean that residential respite is the only option.

Furthermore, accessing in-home respite can also be challenging for carers of people living with dementia. Due to the casualisation of care, there is often limited continuity in paid care workers, making it difficult for the care recipient to develop relationships and routines with care workers. Many carers report that much of the time that could be used for respite is instead dedicated to arranging quality care from paid care workers.

Culturally and linguistically diverse (CALD) carers

In 2018, one in five carers in NSW (20.1%) reported being born in a non-English speaking country, with more than one in ten carers (11.2%) speaking a language other than English at home. Of this group, just under one in ten do not speak English at all, while nearly one quarter do speak English, but not well.¹⁴² Culturally and linguistically diverse (CALD) family and friend carers are often 'hidden', as they do not identify as a carer due to limited awareness or cultural expectations and therefore do not access the same level of support and information as other carers. The 2020 National Carer Survey found that CALD carers experienced significantly higher levels of psychological distress, higher levels of social isolation and lower levels of wellbeing than other carers.¹⁴³

In 2018, Carers NSW, in partnership with CALD sector representatives, conducted six focus groups with 83 CALD carers from a variety of different cultural and language groups to supplement the Carer Survey.¹⁴⁴ Although the focus groups identified limited engagement with services and a number of barriers to access, the carer service in highest demand was respite. This was mentioned by four of the six groups, predominately in the context of maintaining carer health and wellbeing, both physical and emotional. CALD carers reported that they often rely on their children to help them to understand and navigate systems to access services, and rely heavily on word of mouth and community knowledge due to low digital literacy and conceptual differences between cultural values and beliefs. They also indicate that services are often not culturally appropriate and as such do not meet their expectations or needs.

A further study found that CALD carers are less likely to access respite services due to perceived community expectations that caring for a loved one is a responsibility, accessing services may be frowned upon, services such as recreational/community based respite are considered more appropriate, and there is no translatable word for respite in some languages, making it difficult for some carers to conceptualise respite and accept services.¹⁴⁵

The Federation of Ethnic Communities' Councils of Australia (FECCA) submission to the Aged Care Financing Authority on respite care¹⁴⁶ indicated, based on consultation with CALD carers, that the process to obtain respite is not accessible or user-friendly for anyone trying to access support, but even more so for CALD carers. FECCA further highlighted that there are a number of barriers to accessing respite services for CALD carers including, but not limited to, a lack of translated information to advise of services, a lack of flexibility in services, substantial administrative requirements (ie. paperwork) and there was a lack of knowledge or awareness of respite processes, especially for those who have not accessed services in the past.

The Consumer Directed Care (CDC) Initiative program evaluation¹⁴⁷ highlighted the importance of culturally appropriate respite services for CALD carers. The evaluation found there was underrepresentation of CALD carers in the uptake of Consumer Directed Respite Packages, however CALD carers who did access the program placed greater emphasis on services and supports provided by someone of the same or similar cultural or language background, suggesting the importance of culturally appropriate and inclusive services.

"... it's hard to get support for respite for consumer with language barrier and have the familiar to persons whilst I'm attending a close relations or a function."

- 2020 National Carer Survey respondent

Aboriginal and Torres Strait Islander carers

According to the National Aboriginal and Torres Strait Islander Social Survey 2014-15, approximately one in four (24%) Aboriginal and Torres Strait Islander people living in New South Wales (NSW) had provided unpaid care to a person with disability, a long-term health condition or person who was ageing in the four weeks prior to being interviewed.¹⁴⁸ While the methods for identifying carers in this survey differs from the SDAC, these findings suggest that caring is nearly twice as prevalent in Aboriginal and Torres Strait Islander communities.

Aboriginal and Torres Strait Islander women were more likely than men to care for someone (30%), as were Aboriginal and Torres Strait Islander people living in remote areas (34%).¹⁴⁹ The 2020 National Carer Survey also indicates that Aboriginal and Torres Strait Islander carers may be more likely than other carers to support multiple people in need of care.¹⁵⁰ This is particularly true of older Aboriginal and Torres Strait Islander people, who often have multi-generational caring roles.

The higher incidence of caring in Aboriginal and Torres Strait Islander communities is linked, in part, to the greater prevalence of disability and chronic health conditions in these communities.¹⁵¹ Other contributing factors include limited appropriate service options and reluctance to engage in formal services for historical and cultural reasons. At the same time, Aboriginal and Torres Strait Islander carers often have strong connections with their families and communities through kinship systems and view care as a shared family and community responsibility.

Service providers working with Aboriginal and Torres Strait Islander communities report very high levels of caring, suggesting that the true number of carers in these communities is much greater than formally reported. It has been suggested that Aboriginal and Torres Strait Islander carers often don't identify themselves as carers as the term 'disability' is not used by many Aboriginal communities within NSW,¹⁵² and may be rejected to avoid labelling, stigmatisation or exclusion. Similarly, because caring is so common, it is often seen as a natural extension of family roles and ultimately a community responsibility, reducing the likelihood that carers will seek assistance from formal carer support services. Despite the higher prevalence of disability and caring in Aboriginal and Torres Strait Islander communities, Aboriginal and Torres Strait Islander carers are less likely to use support services.¹⁵³

Respite has been highlighted as one of the primary needs of Aboriginal and Torres Strait Islander carers.¹⁵⁴ Aboriginal and Torres Strait Islander carers who participated in a teleconference by the Centre for Rural and Remote Mental Health, Queensland, identified that respite was necessary for taking time out and that there was an ongoing unmet need for respite.¹⁵⁵

A number of studies, that have aimed to understand why Aboriginal and Torres Strait Islander people have had lower level of formal services usage than others, suggest that barriers to support services include lack of awareness or self-identification as a carer, limited or culturally inappropriate information about services, lack of culturally appropriate services, poverty and low levels of household resources, and lack of transport.¹⁵⁶

The Aboriginal Disability Network found on consultation with Aboriginal people with disabilities and their carers in NSW, that there was a lack of respite and in-home support, with very few Aboriginal-operated services, and insufficient mainstream services to meet the need.¹⁵⁷ The evaluation of the CDC program found that there was an underrepresentation of Aboriginal and Torres Strait Islander carers in the uptake of consumer directed respite packages.¹⁵⁸ One Aboriginal carer who did utilise a carer directed respite package used the funds to purchase petrol to visit family with the person he cares for, as this enabled him to access a respite-effect while family members assisted with caring tasks, as opposed to the purchase of formal services to support with caring. It was suggested from the evaluation that approaching respite with a focus on the carer as an individual is not culturally appropriate for Aboriginal and Torres Strait Islander carers, and therefore, carers may be more willing to engage in services that focus on the community and family opposed to the individual.

LGBTQI+ carers

Many individuals who identify as lesbian, gay, bisexual, trans/gender diverse, intersex or queer (LGBTQI+) care for a partner, friend or family member. There is limited data available on LGBTQI+ carers, largely because the Australian Bureau of Statistics has not consistently collected information on diverse gender identities and sexual orientation. However, research suggests that people within the LGBTQI+ community are more likely to be carers and more likely to be cared for by family and friends.¹⁵⁹ The Stonewall report found that older members of the LGBT community had a significantly higher rate of providing care than the broader population,¹⁶⁰ and in a survey of 3,800 LGBT Australians, more than one quarter of respondents identified as carers.¹⁶¹

LGBTQI+ carers can experience stigma and discrimination in service settings as well as their workplaces, families and communities. As a result, many LGBTQI+ people are reluctant to access services.¹⁶² One study found that a significant proportion of young LGBTQ carers felt that their sexuality and/or gender identity impacted how they ask for help in their caring role, and who they seek this help from.¹⁶³

Historical discrimination, particularly for older LGBTQI+ Australians, has necessitated specific service reform to ensure that aged care service providers adequately meet the needs of service recipients and/or their carers who identify as LGBTQI+. The Aged Care Diversity Framework and action plan for older lesbian, gay, bisexual, trans and gender diverse, and intersex elders developed by the Department of Health aim to enable inclusive and appropriate service provision. However, LGBTQI+ carers continue to experience barriers to accessing formal services. The 2020 National Carer Survey found that LGBTQI+ respondents had significantly higher levels of psychological distress, higher levels of social isolation, lower levels of wellbeing, higher rates of long term illness or disability, and higher rates of financial distress than other carers.¹⁶⁴

One survey that looked to understand the experience of LGBTI carers and the carers of older LGBTI people¹⁶⁵ found that 43% of respondents reported discrimination as an LGBTI carer or carer of an

ageing LGBTI family member, 28% of carers delayed accessing services due to fear of stigma and discrimination, and 18% reported feeling uncomfortable or very uncomfortable with accessing carer services. Many reported not being recognised or acknowledged by a service provider or the care recipient's family of origin and expressed fear that faith based services would discriminate against them. Some reported that they had experienced refusal of services by providers supposedly 'exempt' from providing LGBTQI+ services due to their CALD cohort or as a faith based service.¹⁶⁶ A further study found that 33.6% of LGBT carers surveyed reported occasionally or usually hiding their sexuality or gender orientation when accessing services.¹⁶⁷

Research suggests, services should acknowledge the population specific legal, social and emotional challenges faced by LGBTQI+ carers and care recipients, acknowledge diversity within the LGBTQI+ community and ensure that services are appropriate for or cater to the needs of all groups and be inclusive and non-discriminatory, including supporting an inclusive workforce.¹⁶⁸

Young carers

Young carers are children and young people aged 25 years and under who provide unpaid 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. Young carers can be, but are not always, the main provider of support (the primary carer).

Young carers provide a range of practical, specialist and emotional assistance which often exceeds community expectations of what a child or young person can and should be responsible for. The tasks undertaken by young carers can range from domestic duties such as meal preparation and cleaning, to personal care such as showering, supervising siblings and providing emotional support.¹⁶⁹

According to the 2018 Survey of Ageing, Disability and Carers, there are 83,700 young carers in NSW, of whom 11,600 (13.9%) are primary carers. Around one in ten carers in NSW (9.7%) are young carers. However, many young carers are not included in these statistics as they are likely not to identify. Fifty percent of young carers are female.¹⁷⁰ Research has also shown that young primary carers are more likely to be Aboriginal or Torres Strait Islander, or be of a culturally or linguistically diverse background than non-carers of the same age.¹⁷¹ In terms of geographical location, 21.5% of young carers live outside of a major city.¹⁷²

The 2020 National Carer Survey found that 40.8% of young carers had been caring for 10 years or more, indicating that many started caring as young children. More than one in four young carers (28.2%) who responded reported their own long-term illness or disability, and young carers reported significantly higher levels of psychological distress than older carers, and higher overall levels of social isolation. Only one in three young carers (36.4%) felt their caring role was recognised by service providers, much lower than older carers.¹⁷³

Caring at a younger age has 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.¹⁷⁴ Consequently, many young carers live in low resource households and are less likely to have access to a motor vehicle or an internet subscription, which may contribute to difficulties in work and studies.¹⁷⁵ Limited finances can impact on a young carer's ability to participate in employment, education and social activities, which often also double as opportunities to access a respite effect for young carers.

While young carers report many positive aspects associated with their caring role, they are more likely to have poorer mental health than their peers.¹⁷⁶ Young carers commonly report worrying about the person they care for even when they are not with them, impacting on their mental health. Many young carers find that they have limited time or financial means to socialise due to their caring role and other commitments,¹⁷⁷ while others may avoid inviting friends over which can lead to social isolation.¹⁷⁸ A

young carer's physical health may also be impacted by inappropriate manual handling procedures or interrupted sleep.

The ongoing transition of young carer supports into the NDIS and Carer Gateway has seen the cessation of a number of service types that previously enabled young carers to take a break from caring or provided a respite-like effect, such as siblings camps and tutoring.¹⁷⁹ While Carer Gateway has allocated funding for young carers, it is not clear if Carer Gateway will be able to recreate the services that were previously available and valued by young carers.

Regional and remote carers

Carers living in regional, rural and remote NSW are individuals who provide unpaid 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, and who live outside of the major city of Sydney. Of the estimated 854,300 carers living in NSW, nearly one in three (29.7%) live in rural or regional areas.¹⁸⁰ Around three quarters (72%) of primary carers living outside of major cities are female, and at least 33% of young carers (aged 25 years and below) live outside of a major city.¹⁸¹

Rates of disability and chronic health conditions are higher in rural and remote areas, increasing the need for informal carers.¹⁸² However, carers themselves living in these areas also experience disability and chronic health conditions at higher rates compared to carers living in metropolitan areas.¹⁸³ Respondents to the 2020 National Carer Survey who lived in regional and remote areas were better off than metropolitan respondents in terms of psychological distress and social connectedness, but had higher rates of financial hardship and less access to support services.¹⁸⁴

However, another study found that 29% of carers living in regional areas felt isolated due to their caring role and only 42% were able to take a regular break from caring.¹⁸⁵ The poorer health and wellbeing of non-metropolitan carers is often attributed to a lack of services such as respite, increased isolation, and the tendency for such carers to have fewer informal networks to provide additional support.¹⁸⁶

Despite disproportionate rates of disability and chronic health conditions in rural and remote areas, health care is not distributed accordingly. Many services are centralised in regional centres and major cities and inadequate or inaccessible public transport infrastructure often requires carers to drive vast distances to access the services they and the person they care for require.¹⁸⁷ Not only is this time-consuming, but carers in non-metropolitan areas are more likely than those in metropolitan areas to find transport costs to be an added financial burden.¹⁸⁸ While there are schemes available to cover travel costs for specialist appointments, anecdotal evidence indicates that such programs are not being adequately promoted to carers. Furthermore, such schemes have strict eligibility criteria and often do not adequately cover the out-of-pocket costs associated with such travel.

Carers in non-metropolitan areas may also be disadvantaged by the digital divide. As government services such as My Aged Care and the NDIS are increasingly being accessed through online platforms, carers who lack access to appropriate and affordable broadband technology may miss out on key services that provide them with opportunities to take breaks from caring.¹⁸⁹ It is important that services continue to be available face-to-face or via the telephone to ensure equitable access for all carers regardless of their place of residence. This is particularly pertinent given that many carers do not use the internet due to lack of access, affordability or digital literacy. Of the carers surveyed in the SDAC, almost one in five (18.03%) indicated that they had not used the internet in the last three months.¹⁹⁰ The most common reasons for not using the internet was no need, lack of confidence/knowledge or no access to a device.

Where to next for respite in NSW?

Key Points

- The way respite is viewed and delivered in NSW continues to change, however there remains an ongoing need for carers to have opportunities to take breaks from the caring role.
- Recent reviews of the aged care, disability and mental health sectors have identified that many carers experience an unmet need for respite across all service systems.
- Ongoing constraints on government expenditure in established service systems may necessitate greater exploration of hybrid modes of funding, such as philanthropic or community contribution to supplement government investment.
- As awareness and usage of Carer Gateway continues to grow, Royal Commissions and inquiries are finalised, and the Australian economy and care sectors begin to recover from the pandemic, we are faced with an unprecedented opportunity to design a comprehensive, integrated and innovative respite system that avoids duplication and better meets needs.

While the way in which respite is conceptualised, perceived and delivered in NSW continue to change, there remains an undeniable need for carers to have opportunities to take breaks from their everyday caring commitments. Breaks can benefit the health and wellbeing of both carers and the people they care for and can make time for both parties to build their skills, knowledge and resilience, while also pursuing other personal goals and interests. Breaks can also increase social and economic participation and improve the sustainability of care arrangements in the longer term.

The importance of regular, planned breaks from caring arrangements has been highlighted repeatedly in recent reviews and inquiries into the disability, aged care, mental health and carer support sectors. Supporting the earlier emphasis in the 2011 Productivity Commission reports¹⁹¹ on respite and other carer supports as critical to the ongoing viability of community care services in Australia, the final report of the Productivity Commission inquiry into mental health¹⁹², the final report of the Royal Commission into Aged Care Quality and Safety¹⁹³ and the 2020 Tune Review of the NDIS Act¹⁹⁴ have identified breaks from the caring role as an ongoing unmet need for many carers.¹⁹⁵ These points are also continually reiterated by carers and service providers across NSW.

As discussed in earlier sections of this paper, opportunities to take a break from the caring role can take many forms, and diverse options are important in order to enable choice and flexibility to accommodate the needs and preferences of carers and the people they care for. Some of these options are currently within the scope of the established disability, aged care, mental health and carer support systems. However, the CRA is of the opinion that significant additional investment – either within or outside of these service systems and funding arrangements – is required in order to address the present extent of unmet need.

This final section of the paper aims to examine opportunities in the current and emerging service landscape, and outside established care service systems, for breaks from caring arrangements to be sustainably resourced. It aims to identify where existing offerings can be expanded and improved, and how apparent gaps may be innovatively addressed, with reference to models developed overseas. Investment in respite-type services is conceptualised throughout this section in terms of the three key components of respite identified by the CRA: people, places and activities. It is proposed that all forms of respite – whether more traditional service types or more innovative, flexible approaches –

require people to facilitate the offering, a place in which to conduct it, and a task or experience to participate in.

Ongoing constraints on government expenditure in relation to one or more components may necessitate greater exploration of hybrid modes of funding, such as philanthropic or community contribution to supplement government investment. Alternatively, some components may be able to be offered in-kind by one or more parties, such as a community centre or volunteer program, to a greater extent than exists currently. While diverse funding models will allow for greater choice and flexibility to reflect the diversity of carers and the people they care for, it is the position of the CRA that governments should not consider alternative funding sources a reason to divest or reduce their contribution to these important services. Rather, additional and innovative resourcing can and should complement government investment where appropriate and sustainable.

In this time of transformation, all levels of government have an opportunity to respond to the needs of carers, ensuring adequate provisions are in place.

Emerging opportunities within established service systems

Key Points

- Carer Gateway, NDIS and aged care services enable many carers to take breaks from their caring responsibilities, however there are a number of opportunities emerging to improve access to breaks for carers within these established service systems.
- Carer Gateway provides an opportunity to provide flexible, carer-focused services, including respite where gaps between other formal care systems exist, and to better understand carer respite need and use through improved data collection and ongoing monitoring of outcomes.
- While the NDIS is not a carer-focused support system, improved education regarding accessing respite through NDIS funding and the changing ILC service landscape present valuable opportunities to access breaks for carers of NDIS participants *and* carers of people with disability who are not eligible for supports through the NDIS.
- The recent recommendations of the Royal Commission into Aged Care Quality and Safety, including the increase in carer services and supports available through the aged care system, ongoing review of funding models, and potential streamlining of aged care services, are likely to create a vital opportunity to increase access to respite.
- The Productivity Commission inquiry into Mental Health has highlighted the need to ensure the continuity of supports for carers of people living with mental illness who may no longer be eligible for mental health carer services that have transitioned to the NDIS, and/or cannot access equivalent, specialist supports through Carer Gateway.

While Carer Gateway, NDIS and aged care systems present valuable opportunities for many carers to take breaks from their caring responsibilities – either through more traditionally structured respite services or other activities providing a respite effect – many other carers report that these opportunities are either inadequate or out of reach. Clearly, the ability for these systems to meet the needs of carers in their current forms is inherently limited.

Furthermore, not all carers can benefit from these limited systems, as many of the people they care for simply do not meet the eligibility threshold for this kind of support. Recent consumer-directed

reforms to these systems have also resulted in some formerly funded supports with 'respite effect' (such as educational and recreational opportunities) to be effectively discontinued, with no clear 'home' in the current funding environment, despite ongoing demand from carers.

In spite of these acknowledged limitations, this section explores opportunities for improved access to breaks for carers within these established service systems, before identifying additional opportunities outside of their scope.

Opportunities within Carer Gateway

The Emergency Respite and Carer Directed Support streams of Carer Gateway both represent opportunities for carers to access a break from the caring role. This, coupled with the increase in respite funding under Carer Gateway announced in the 2019-20 Federal Budget,¹⁹⁶ reflects the Australian Government's acknowledgement that respite remains an in-demand support type for carers. The other in-person supports available from Carer Gateway – In-Person Peer Support, In-Person Carer Counselling and In-Person Carer Coaching – can also act as opportunities for carers to step away from direct caring responsibilities temporarily and shift their focus from the caring role to their own needs, thereby holding the potential for a degree of 'respite effect.'

Carer Gateway's prevention focus, emphasis on carer health and wellbeing outcomes, and commitment to centralised, carer-centred support planning represent significant innovation in the carer support sector. Its holistic approach to addressing carer needs – while still somewhat unknown and/or misunderstood in some parts of the care sector – promises to provide ongoing, responsive support for carers and add to the evidence base regarding 'what works' through comprehensive monitoring of service data.

The requirements for Carer Gateway Service Providers (CGSPs) to map, complement and connect carers with other local carer-specific, care recipient-focused and mainstream services also allow for responsive, localised approaches to providing diverse opportunities for direct and indirect respite, including community and volunteer-led responses.

This service model will test the inherent assumption that a holistic, early intervention approach will reduce the need for crisis based services – such as Emergency Respite – over time. It will also allow for a more transparent, responsive approach to identifying and forecasting nationwide demand for the respite-focused supports.

Carer Gateway has capacity to provide 'people' who can facilitate respite through direct service provision to carers and delivery of replacement care to the people they care for. It also has capacity to, where appropriate, provide 'places' for this to occur, such as through referrals to residential respite facilities in the aged care sector, in keeping with the previous practice of CRCCs.

In delivering carer-focused peer support, counselling and coaching, 'activities' are also in scope to some degree. Carer Directed Support packages that are used for purposes other than direct respite also promise to enable carers to increase their social and economic participation, which broadly could be described as 'activities'.

The first twelve months of in-person service delivery under Carer Gateway indicates that barriers preventing some carers from benefiting from respite-type supports include: a lack of awareness or understanding about the supports that are available through Carer Gateway, and difficulty accessing services either digitally (due to limited digital literacy and financial resources) or physically (due to geographical distance from face-to-face service locations). Ongoing workforce challenges in the aged care and disability sectors have also been compounded by a new stream of demand for respite services.

However, initial service delivery has also indicated that there is enough flexibility within the model to allow for coverage of transport costs, replacement care costs and digital support to mitigate these barriers. For example, between January and June 2021, Carers NSW is delivering a digital literacy pilot project that connects eligible carers in the Hunter New England, Central Coast and North Coast Carer Gateway region (known as NSW 4) with an iPad, data and group training sessions to enhance confidence, connection and wellbeing outcomes among Carer Gateway clients.

Ongoing monitoring and evaluation at national and local level will assist Carer Gateway services to be innovative and responsive to local need and continually improve their alignment with carers' identified support needs.

Opportunities within the NDIS

While the NDIS has been fully rolled out in NSW for nearly three years at the time of writing, significant change continues with regard to NDIS policy and implementation and the structuring of residual disability support within NSW. The retendering of LAC provision, defunding of Ability Links NSW with funding transitioned to the LAC program, ongoing Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, legislated review of the NDIS Act, development of the Participant Service Guarantee, ongoing review of disability advocacy in NSW and proposed introduction of Independent Assessments present continuous opportunities to identify and address gaps for carers in NSW.

In its current form, the NDIS presents a range of opportunities to people with disability that may benefit their carers directly with a break from the caring role or indirectly with a respite effect. The reintroduction of the term 'respite' to NDIS policies and processes in 2019, subsequent AAT decisions regarding the accommodation of carers' needs in NDIS supports, and recommendations in regards to increasing respite for parents of children with disability stemming from the review of the NDIS Act and Joint Standing Committee inquiry into NDIS planning,¹⁹⁷ may provide an opportunity for carers' needs to be better reflected in NDIS plans and supports.

The proposed introduction of Independent Assessments, along with the NDIA consultation and Joint Standing Committee inquiry on the subject, has provoked many concerns among disability and carer advocates. However, it does provide the opportunity to reinvigorate the conversation about explicitly addressing carers' roles and support needs early on in NDIS processes.

The ongoing and broadening nature of Information, Linkages and Capacity Building (ILC) grant funding is also providing more and more capacity building, peer support and educational opportunities that are inclusive of carers and may have a respite effect. Successive ILC funding rounds and collaboration opportunities with LAC providers have demonstrated increasing openness to a focus on these outcomes.

In these ways, the NDIS offers 'people,' 'places' and 'activities' to enable carer breaks, in the explicit context of direct services to eligible people with disability that have a secondary respite effect for carers. Well prepared, confident people with disability and carers may be able to achieve a package of support that meets both of their needs in this area. Further, some 'activities' may be within scope of ILC grants, on a case by case basis. For example, Mental Health Carers NSW (MHCN) recently received an ILC grant under the Individual Capacity Building Program to deliver peer-led psychoeducation and training for mental health carers, framed as having direct benefits for the people with psychosocial disability who they care for.

While the NDIS will never be a carer-focused support system, improved education for LACs and planners as well as participants and carers about direct and indirect respite supports available within NDIS plans and the ILC service landscape present valuable opportunities for carers of NDIS participants *and* people with disability not eligible for the NDIS to access breaks from caring arrangements.

Opportunities within the aged care sector

The national aged care reforms continue, following the final report of the Royal Commission into Aged Care Quality and Safety, review of the CHSP, and changes to residential aged care funding models. The transition to the Aged Care Quality and Safety Commission, implementation of the Aged Care Quality Standards, introduction of the NSW Ageing and Disability Commission and increasing focus on 'wellness and reablement' outcomes within the CHSP are also likely to present new opportunities to understand and address the importance of a break for carers and the older people for whom they care.

Existing aged care services provide ongoing opportunities for carers to access breaks from the caring role when the person they care for accesses respite through the CHSP or a HCP. These services offer 'people', 'places' and 'activities' to support the older person requiring care, with indirect benefits for carers. Unfortunately, however, evidence indicates that the supply of these opportunities is severely constrained, limiting access and benefit for many carers. These constraints have been exacerbated during the COVID-19 pandemic, heightening carer stress.

While the Government response to the Royal Commission's final recommendations is still forthcoming at the time of writing, the CRA feels the recommendations regarding, and relating to, respite are promising. Most notably, the Commissioners' emphasis on better integrating carer assessment and referral into aged care service planning and delivery and strong support for a revised approach to linking carers with respite services.

In these ways, the Commissioners' vision for an improved aged care system certainly involves the funding of 'people' (such as Care Finders) and 'places' (such as residential aged care and cottage respite facilities, as well as the proposed Carer Hubs) to support breaks for carers, as well as an enhanced paid workforce to deliver replacement care to the older people they care for.¹⁹⁸ While carer-focused 'activities' do not feature as strongly in their recommendations, the Commissioners' commitment to streamlining carer referral to Carer Gateway may compensate for this.

Furthermore, ahead of the end of its current funding period, the CHSP will continue to provide 'activities' like social support groups that enable some carers, especially those over the age of 65 years who are eligible for the CHSP in their own right, to step away from their caring responsibilities and focus on their own wellbeing. Increasing focus on wellness and reablement also offer the dual benefits of providing carers with a break while increasing the capacity for the older person participating, potentially increasing the sustainability of caring arrangements.

The current review of residential aged care assessment and funding tools also provides an opportunity for the role of residential respite in the carer support landscape to be considered and refocused. For example, specific provisions within funding allocations that require minimum availability of respite beds within residential aged care facilities ('places' to accommodate breaks from carers) and changes to funding models that capture the need for ongoing capital investment in residential facilities, may result in more carers accessing a break in these contexts. Increased market data will also strengthen provider confidence and encourage them to invest in areas of need.

An adequate supply of skilled, quality workers, including coverage in thin markets, are also current major priorities in the aged care and disability sectors. Greater skill levels and geographic coverage in the direct care workforce (the 'people' essential to the provision of more traditional types of respite), especially where options are currently limited such as in areas of regional NSW, will likely improve the range and quality of respite opportunities available to carers. This scrutiny on the care workforce and marketplaces also presents opportunities to embed carer identification and support in staff training and practice standards, thereby improving understanding of and responsiveness to respite needs across the sector.

Opportunities within the mental health sector

The Productivity Commission inquiry into mental health provided an in-depth analysis of key issues and gaps, including the need for a stronger carer focus, and findings and recommendations have presented the opportunity to better understand and address the respite needs of mental health carers.¹⁹⁹ In particular, the Productivity Commission has noted the transition of Mental Health Respite: Carer Support to the NDIS and Carer Gateway, highlighting the need to ensure continuity of support for carers of people living with mental illness who may not be eligible for the NDIS, and/or cannot access equivalent, specialist supports from Carer Gateway.

These lost supports include specialist ‘people’ with a background in mental health who are focused on working with carers themselves regardless of the engagement of the person they care for, and ‘activities’ such as educational, social and recreational events, including retreats. The inquiry presented an opportunity to identify where these lost supports can and should be funded; either specifically tailored to the needs of mental health carers or in general.

Continuing work regarding the mental health and NDIS interface, including but not limited to the National Community Connectors Program, also promises to improve outreach and support to people with psychosocial disability, ultimately benefiting their carers. Capacity building funding opportunities through ILC grants are also inclusive of people with psychosocial disability and their carers, as noted earlier. And in the NSW context, block-funded support for mental health carer education, information and advocacy continues through NSW Health funded services such as the Family and Carer Mental Health Program (FCMHP). These kinds of supports provide ‘people’ with an understanding of mental health and the caring role, as well as ‘activities’ that specifically address the needs of mental health carers and the people they care for.

The challenges of the COVID-19 pandemic have also created concurrent opportunities for resourcing and raising the profile of mental health support. In response to an anticipated spike in mental ill-health and suicide resulting from the social isolation and economic uncertainty experienced during the pandemic, governments have boosted mental health funding through a range of grant increases and new grants, including mental health specific grants for CGSPs which have allowed for a range of new ‘people’ and ‘activities’ to be funded. What does appear to remain limited within the established service system is investment in ‘places’ to support time out for mental health carers.

Improved implementation of instruments to measure demand for mental health and carer support services, such as the National Mental Health Service Planning Framework, which provides a benchmark of community need for mental health services, and the Carer Experience Survey, will also provide additional insight into the experiences of mental health carers and identify potential areas for improvement.

Potential opportunities outside established service systems

Key Points

- A number of opportunities exist outside of established care service systems to improve access to meaningful breaks from the caring role.
- In addition to traditional models of funding for respite or respite like services, investment by private or philanthropic organisations, volunteer investment, or a combination, may provide opportunities to expand or create models that better meet carers needs.
- Non-traditional investment in, and of, 'people', 'places' and 'activities', as opposed to 'respite' as a distinct service type, may result in increased opportunities for carers to access a respite effect.
- Investment in 'people' to support the development and growth of the paid and volunteer workforce is likely to increase availability of respite options, with more people available to provide replacement care.
- Investment in 'places' through government grants and philanthropic donations, as well as improved coordination and use of existing public spaces will create more places in which respite options can be delivered.
- Investment in 'activities' will see the development of more recreational or carer-focused activities that encourage carers to take time out from the caring role to focus on their own health and wellbeing.

Outside the specialist service systems there are many other opportunities for meaningful carer breaks to be resourced in less traditional ways. Some of these are currently in use, however the CRA believes that many opportunities to expand, tailor and invent models resourced by private, philanthropic and volunteer investment – or a combination – remain. Further, underutilised public and community infrastructure, as well as mainstream government funding sources, could be used creatively to address gaps identified within the established service systems without substantial new funding required.

Rather than addressing 'respite' as a distinct support type, this section aims to identify possible sources of resourcing for carer breaks through non-traditional investment in, and of, 'people', 'places' and 'activities' that could result in a respite effect for carers. The CRA believes that all levels of government, as well as the community and private sectors, have resources that can be mobilised in these three areas to offer more carers a break.

Investment in people

A range of different people may assist with the provision of direct respite or activities that provide a respite effect. From paid workers or volunteers assisting with personal care or community access for the person requiring care, to paid workers or volunteers facilitating peer support groups and recreational activities, to members of the community, not-for-profit organisations or for-profit companies organising free or subsidised events, there are many opportunities for funders of all kinds to provide and/or support 'people' to enable carers to take a break.

Funding for volunteer in-home and flexible respite programs has been explored by some governments in Australia at a small scale. With adequate block funding to cover training and volunteer management costs, volunteer respite programs can provide a cost-effective complementary form of respite that can be offered alongside more formalised services. Host family respite is a model available through CHSP funding, however it is not well known and it is not clear who provides this type of care as an option. Additionally, the NDIS also funds host family arrangements under the line item “Individual Living Option – Host Arrangement”, however it is not clear what the uptake of these services is under the NDIS or whether funding is adequate to enable effective service provision.

Interchange, a traditional volunteer respite model facilitator under HACC, highlighted in their 2014 report on volunteer respite models in the NDIS, that due to the high administrative costs associated with sourcing and successfully matching volunteers with care recipients, the individualisation of funding does not provide enough certainty to providers to hire volunteer coordinators.²⁰⁰ Volunteer providers require initial investment to enable the effective development of their organisation to provide cost saving measures in the long term.

Adequate resourcing of volunteers is also important in the context of carer support groups, many of which are run by volunteers who are carers themselves. With recent funding changes in NSW, many carer support groups have indicated that covering their operating, facilitation and/or activity costs can make it less viable to start or continue a group. A small amount of recurring funding to these groups, such as was previously available through the NSW Government funded *together* Program, can enable the ‘people’ that support groups hinge on to continue in their role, as well as supporting groups to address the cost of ‘places’ and ‘activities’ that offer a respite effect.

Local councils, charities and condition-specific peak bodies all offer this support to some extent, however it is rarely coordinated and even more rarely recurrent. Small, local grants that allow more than a small number of carer support groups to access ongoing support are a cost-effective investment into local community wellbeing. While peer support groups are not a formal respite service, with adequate resourcing they can offer the ‘people’, ‘places’ and ‘activities’ required for some carers to experience a meaningful break from their day to day caring role.

An additional way in which people can be mobilised to assist carers achieve a respite effect is to help with service navigation. Ongoing case management and support coordination are currently very limited within the NDIS, aged care, mental health sector and Carer Gateway, and advocacy organisations in NSW are experiencing greater and greater funding restraints, limiting their capacity to assist individuals in this way.

The My Aged Care Navigator trial has aimed to leverage volunteers to assist their neighbours and peers to navigate the aged care system. In addition to ‘people’, this trial has provided limited ‘places’ in the form of physical ‘hubs’ where older people can access face to face assistance. While this is a government funded program and part of the established aged care services sector, it is a model that could be replicated on a local scale to assist carers to access a range of service systems.

Community organisations, local councils and for-profit organisations may be able to provide and/or resource networks of volunteers to deliver service navigation support, which, while not necessarily providing a break directly, may assist carers to better access opportunities for a break. Carers also report that organising services and addressing problems takes up a lot of their time and can cause a lot of stress, reducing the time they have available for other pursuits; therefore simplifying these processes may also free up additional time.

Investment in places

Many carers and service providers report that the individualised funding models adopted within the disability and aged care sectors have presented challenges to financial viability for some organisations and facilities offering overnight and longer term accommodation and day centre type supports, leading to a reduction in overall supply. Sometimes this has meant people who have funding for these support types are, in the end, unable to use it. Buildings and equipment are expensive and require ongoing maintenance, and yet little government funding is consistently available to address this shortfall of 'places' to provide respite opportunities for carers.

One-off grants from councils, charitable organisations, companies or infrastructure-focused government departments and grants programs could go a long way to improving, renovating or building facilities and infrastructure to better accommodate activities that provide carers with a break. My Community Project and other electorate-focused community grants are one way of addressing this, as are grants from local councils, Rotary, and other community, charitable and philanthropic organisations.

The CRA is aware of some cases where local funding partnerships have facilitated the building of high quality respite facilities, solving a local shortfall of 'places'; and yet, accessing 'people', which requires high ongoing expenditure and coordination, has been difficult to source, even through government service systems. Opportunity exists for government departments providing 'people' to deliver care and activities but lacking 'places' to partner with these local networks to provide a holistic solution to respite shortages.

Existing infrastructure available within these jurisdictions that is being underutilised also presents an important opportunity. For example, community and neighbourhood centres with spaces that are not used at certain times of the day or week and which could be provided for free or a small fee, could be better utilised than they are currently. Programs such as the Empty Space Project,²⁰¹ where available community facilities can be utilised for creative projects, provide an opportunity for innovative respite options. With small amounts of government block funding, organisations may be able to operationalise volunteer-run creative initiatives for carers and the people they care for.²⁰² Bequeathed property and underutilised local club infrastructure may also be 'places' that could be converted with a small grant to be used for 'activities' that provide carers with a break.

Supported Disability Accommodation (SDA) providers within the disability sector experiencing vacancy challenges could also consider temporary placements to assist with respite needs, similar to how aged care facilities have typically allocated respite beds. However, like residential aged care facilities, funding models mean that staffing is stretched, and the complexities and additional administration of introducing temporary residents to an established residential environment offer little incentive to these providers to lend out their space for this purpose.

Importantly, all of the 'places' mentioned above require ongoing resourcing of 'people' to maintain them, whether that be direct care workers, project managers / concierge personnel, or booking agents to manage vacancies. Parties looking to finance the establishment or upgrading of 'places' to facilitate respite should therefore ensure that plans are in place to engage volunteers, care sector workforce or newly funded positions, taking into account the salaries and on-costs associated with making such arrangements sustainable.

Investment in activities

Resourcing for 'people' and 'places' is not always sufficient to allow for opportunities for a break from the caring role. Recreational activities, such as attending entertainment events, eating out, participating in formal training, or staying in accommodation for a few days, are highly valued by many

carers and seen as having a respite effect, but costs can be prohibitive for those on lower incomes. Many of these activities were previously fully funded or subsidised under block funded programs supporting carers directly and/or the people they care for. However, increasingly carers are being required to pay for them out of their own pocket as they are out of scope in individualised funding models. The NSW Companion Card and NSW Seniors Card provide many carers with some degree of subsidy for certain kinds of events, however these are not specifically targeted to carers and may not cater to forward-planned group activities such as carer support group outings.

Sponsorship to cover or reduce activity costs for carers – whether participating individually, with the person they care for, or as part of a group – may be relatively low cost but enhance community engagement and support local economies. Given that one of the criticisms of more traditionally structured respite services has been that activities are not always appropriate or enjoyable for the person being cared for, they also provide more flexible opportunities for carers to enjoy unstructured leisure time with the person they care for, which many carers cite as a form of respite. Improving the accessibility and inclusion of recreational activities at a local level may also enhance these opportunities.

Local councils, community and charity organisations, philanthropists and other potential funders may be able to fund more of these kinds of opportunities ongoing. National Carers Week grants, funded by the NSW Department of Communities and Justice, are currently the only targeted source in NSW of activity funding that is flexible to a range of applications and inclusive of all carers. Carer retreats and young carer camps, while also requiring resourcing for people and places, are also rapidly losing their funding base although demand from carers remains high.

Examples from overseas

Key Points

- Exploring overseas examples and considering their application within NSW may present additional opportunities for respite in Consumer Directed Care models.
- Volunteer respite models utilised in the UK and USA have provided low-cost respite options which increase the availability of preferred respite options for carers.
- Cash-for-care models, utilised in some European countries, and associated carer-focused services have aimed to recognise the economic impact of caring and ensure that carers needs are also met to increase the sustainability of these caring arrangements.
- The development of a Respite Strategy in New Zealand has seen greater focus on ensuring that carer's respite needs are met effectively by all levels of government through increased investment in carer-focused, early intervention supports.

In identifying opportunities to enhance the respite effect for carers in NSW, is it important to look to overseas examples. Other countries that have also made the shift toward consumer directed care have faced similar challenges in addressing carers' needs for a break. Below are some international examples which could be examined for application in the Australian context. While there is some overlap with prior and current federal, state and territory initiatives, none currently exist in Australia at scale.

United Kingdom

Volunteer respite models

The UK has implemented a number of approaches to carer breaks, ranging from educational resources for carers around taking breaks in their day to day life, to a range of programs that offer opportunities for respite. For example, the Shared Lives model is a volunteer respite model with approximately 152 local schemes operating in the UK, which traditionally cater to people with intellectual disability.

Whilst volunteer respite models are often cost effective, with lower overall costs, these models carry high administrative costs. The primary role of service providers facilitating volunteer respite is to establish and implement a comprehensive process for recruiting, screening and assessing volunteers, a thorough assessment of carer and care recipient needs, individual matching between volunteers and care recipients, support for volunteers, care recipients and carers, training, monitoring and the reviewing of care arrangements.

Funders must be willing to make long-term, upfront investments in these organisations to enable them to develop thorough policies and procedures, recruit and train a volunteer workforce, attract carers and care recipients, develop effective matches between volunteers and care recipients, and foster those relationships to enable long term arrangements.

Carer breaks awareness campaign

Carers UK released a series of videos and online resources to increase carer awareness of taking breaks and to encourage carers to take proactive steps to improve their health and wellbeing. The resources were developed following the findings from Carers UK Carer Breaks 2017 survey which found that 40% of carers surveyed had not taken a day off in a year, and almost a quarter had not had a day off from caring for over five years.²⁰³ The resources address the emotional barriers to accessing carer supports including guilt and anxiety, and deal with the practical aspects of initiating and undergoing an assessment.

Carer retreats

Philanthropic investment or fundraising for 'carer retreats' in the UK enable families to take time out, with the support of volunteer or paid carer workers. Some options for investment by private organisations include adopting a caravan²⁰⁴ or funding a holiday for carers and care recipients.²⁰⁵ However, whilst cost effective to the government, they require initial investment in the organisations that source funding, manage vacancies, organise retreats, match families with retreats, and ensure staff are screened and appropriate.

Europe

Cash-for-care

Cash-for-care programs have been implemented in many countries throughout Europe including Austria, France, Germany, Italy, Netherlands and Sweden, with different models including home care grants, service vouchers, direct payments and personal budgets. Several of these countries have accompanying carer focused support models which enable carers' needs to be assessed and met. Sweden provides carer assessments with subsequent referrals for respite or counselling as needed. Netherlands provides 'care brokers' targeted at carers engaged in the workforce to assist carers with navigating health and care systems and coordinating services to reduce the time spent on administrative tasks, enabling carers to increase their participation in employment.

United States of America

Volunteer respite models

In the United States, a number of organisations have started initiatives where volunteers support the facilitation of day programs for people requiring care in community spaces. One example of this is The Gathering, a faith-based volunteer outreach program for people with early memory loss. The program is delivered in partnership with churches whose role is to provide facilities and host The Gathering.²⁰⁶ Currently, volunteers plan and run five hour respite days for eight to ten participants under the supervision of a Registered Nurse (RN). While the RN is not always present during the respite sessions, they oversee the training of volunteers and are on-call for telephone support for the duration of the respite sessions.

Community volunteer hubs again require initial investment in organisations to source, assess, match and support volunteers, care recipients and their carers. Volunteer hubs require accessible community facilities where volunteers can provide support.

Canada

Video Respite

Canada has also seen the innovative use of technology to broaden the range of respite options. One example of this is video respite as a service type, whereby a carer is able to view the person they care for via video link while they are not in the home.²⁰⁷ The use of technology requires the funding or subsidising of devices and applications that carers, who often face economic disadvantage, may not be able to afford. Additionally, training to use digital devices may also be required for those with lower digital literacy.

New Zealand

Respite Strategy

New Zealand (NZ) has seen a shift in strategic direction towards choice and control of disability services, however simultaneously, it has been identified that current respite models are not meeting the needs of carers. As such, the NZ government has developed a respite strategy which aims to reframe respite as a stress-free break for carers that also provides a positive, empowering experience for the person with disability.²⁰⁸

The respite strategy outlines the movement from a focus on hours or type of respite towards what it takes to enable carers to get the breaks that they need. The strategy aims to shift the focus from inputs to outcomes including resilience, inclusion, engagement and the ability to continue providing care. It places greater emphasis on carers defining what a break looks like to them. This investment approach recognises the importance of early intervention to provide stress relief and assist families to stay together, continue caring, reducing possible associated future costs. A similar model has been implemented in Scotland.

Increased data provision to support a market system

To support the adequate provision of respite, the NZ government has provided a market guide which outlines what respite services are available in each region and highlights the gaps/market opportunities for providers/potential providers.²⁰⁹ The provision of the market guide aims to enable providers to identify areas of need and develop services that meet market gaps. The long term goal within the strategy is to transition to flexible carer respite packages.

Conclusion

The Carer Respite Alliance (CRA) was founded in 2017 in response to shared concern that the value and legitimacy of carer respite as a service type was in question among policy makers. At that time, we sought to establish both the need for, and impact of, respite services in a service landscape that was, at times, focusing so much on consumer direction that carers' own needs were forgotten.

Since the beginning of this project, much has changed, and carer respite has, fortunately, moved from the margins back to the centre of the policy agenda. The individual and collective research and advocacy work of CRA member organisations in relation to ongoing disability, aged care, mental health and carer support sector reform throughout the period has likely contributed to this shift.

The key challenge facing Australian policy makers now is how to ensure that the various service systems that carers access work together effectively in order to make meaningful breaks available to as many carers as possible in forms that meet their individual needs and preferences. Concurrent national inquiries into aged care, disability and mental health services, alongside the launch of a new national system of carer supports, provide an unprecedented opportunity to develop a holistic, integrated and flexible approach to providing carers with meaningful breaks regardless of the service eligibility of the person they care for. While not fully 'consumer directed' in the same way as the NDIS and Home Care Packages, the carer's own needs and outcomes are at the centre, and some support is funded through an individualised 'package' of sorts.

Carers have a diverse range of situations and needs, and as such, there is no 'one size fits all' solution to the ongoing unmet need for respite in the community. Carer Gateway is already addressing short term unmet need for emergency and planned respite for a range of carers, supplementing what is available within other service systems, and the Australian Government's response to the final report of the Royal Commission into Aged Care Quality and Safety may result in considerable changes for the funding and oversight of aged care respite services. However, at the time of writing, many questions still remain as to whether, how and when these two systems will integrate, and the extent to which the services provided align with carers' needs and preferences.

Furthermore, at the time of writing the Australian Government is still considering its response to the recommendations resulting from the Productivity Commission's final inquiry report on mental health. As this report's recommendations regarding carer support did not focus on respite-type services, it is unclear to what extent additional services offering mental health carers a 'respite effect' will be established, or whether this will continue to be positioned as the joint responsibility of Carer Gateway and the NDIS.

For carers of people with disability, including psychosocial disability, the ultimate findings and recommendations of the still ongoing Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, as well as the three recently closed consultation opportunities provided by the NDIA in relation to major proposed changes to individual service access and planning, will be critical in elucidating whether opportunities for carers to take meaningful breaks will be expanded or further contracted within the disability sector.

As wide-ranging recommendations continue to emerge from the current reform landscape, the centrality of breaks from the caring role that enhance carers' wellbeing outcomes will continue to be an important consideration across all of these sectors. Great opportunities exist at national, state and local levels to research, evaluate, pilot and innovate to improve our understanding of carers' respite needs and ensure that our service systems are fit for purpose.

Ultimately, the CRA believes that caring is a responsibility that should be shared by governments and communities and not only taken on by carers themselves. Evidence shows that without support, the

health and wellbeing of carers, and the people they care for, is at risk. It is also clear that 'getting respite right' will require coordination and collaboration between the different levels of government and between the different departments and agencies that engage with carers and the people they care for so that policy, practice and data collection is streamlined, complementary and subject to rigorous oversight.

An innovative and responsive approach may also require increased engagement with community and for-profit organisations; however, the CRA wishes to emphasise that these partnerships should always be adequately resourced and not seen to devolve government of its ultimate responsibility to address current respite shortfalls.

It is therefore imperative that meaningful breaks for carers be prioritised not only as part of Carer Gateway, but also as central to the design of the aged care, disability and mental health sectors, so that carers of all circumstances and backgrounds are able to access a range of support options that meet their needs. Furthermore, additional sources of funding, assets and other resources at all levels of government should be seriously considered as potential avenues for improving outcomes for carers.

Summary of recommendations

A list of specific recommendations for a range of audiences based on the findings presented in this paper is included below.

Recommendations for the Australian Government

Whole-of-government carer focus

1. Introduce new whole-of-government national carer strategy that supports better coordination of respite-type supports across care service sectors.
2. Establish regular, high level communication and coordination between policy makers across care service sectors to improve consistency and equity, and reduce duplication.
3. Review the Commonwealth Carer (Recognition) Act 2010 and include:
 - Reference to the importance of breaks from the caring role in the Statement for Australia's Carers
 - Stronger enforcement of the obligations of public sector agencies to consult with carers and make carer-inclusive policies
 - A redress pathway and independent advocacy support for carers whose experiences are not consistent with the Statement for Australia's Carers
4. Ensure that the ongoing review of Commonwealth NDIS legislation and the review of aged care legislation recommended by the Royal Commission refer to and uphold the principles of the Commonwealth Carer Recognition Act 2010.
5. Review policy making principles regarding Consumer Directed Care (CDC) to ensure that people requiring care are viewed within the context of their families and communities.

Carer Gateway

6. Develop clear national messaging and marketing collateral regarding what forms of respite are available under Carer Gateway, including:

- Clear and nationally consistent promotion of the (limited) after-hours capacity for emergency respite referrals
 - Plain language explanation of the scope and purpose of Carer Directed Support packages in regards to planned respite, and promotion of these packages to carers
 - Consistent messaging regarding whether and how carer breaks/activities can be funded
7. Increase the funding amounts available within Carer Directed Support packages to allow for regular, planned breaks from the caring role as a preventative intervention to support carer wellbeing.
 8. Enable carers to access both a Carer Directed Support package and a One-off Support within a 12 month period so that planned respite is available to more carers.
 9. Preserve the independence of Carer Gateway from the Disability Gateway and My Aged Care and the eligibility of carers in their own right, regardless of the condition(s) of the person they care for.
 10. Better integrate NDIS and My Aged Care planning and assessment processes with Carer Gateway to streamline carer referrals and reduce the time spent by carers telling their story.
 11. Expand information sharing arrangements between service systems to streamline referral to and from Carer Gateway.
 12. Develop a clear policy regarding how ACAT approval for residential respite should interact with Carer Gateway respite referrals, and communicate this clearly to aged care providers.
 13. Should 'care finders' and 'carer hubs' be established in the aged care sector, ensure that these integrate well with Carer Gateway Service Providers, e.g. through co-location.
 14. Continue to fund targeted, one-on-one assistance for older carers accessing the NDIS through the National Community Connector Program ageing carers stream.
 15. Work in partnership with key mental health organisations and network to address concerns within the mental health sector regarding the ability of Carer Gateway to meet the needs of mental health carers.

NDIS

16. Improve recognition of carers in NDIS assessment and planning processes to ensure carers' needs for a break from the caring role are captured and addressed.
17. Strengthen access to breaks from the caring role within NDIS legislation and policy frameworks, especially for carers of children with disability receiving NDIS funding.
18. Provide clear, publicly available information to LACs, participants and carers on opportunities for respite-type supports and supports with a respite effect within NDIS guidelines so that these are consistently made available.
19. Increase the capacity for participants and carers to trigger a rapid review of funded support when in crisis or when a plan budget is expended, and make this process known to NDIS and Carer Gateway service providers.
20. Identify one or more responsible providers that is/are required to accommodate people with complex needs or behaviours of concern who are turned away elsewhere due to the high costs or high skill level required to meet their care needs.

21. Provide publicly available guidelines that specify the scope of Coordination of Supports and Local Area Coordinators in relation to assisting with system navigation assistance, service booking and referral to supports outside of the NDIS.
22. Increase the funding allocated towards Coordination of Supports and/or Local Area Coordination to allow for these services to perform the functions of system navigation assistance, service booking and referral to supports outside the NDIS.
23. Create one or more line items in the NDIS Price Guide to accommodate service booking and coordination tasks so that time spent on these tasks can be adequately funded in plans and claimed by Support Coordinators.
24. Broaden participant eligibility for funded Coordination of Supports to reduce the reliance on carers for system navigation, service booking and other administration tasks previously undertaken by case managers.

My Aged Care

25. Review the aged care legislation as recommended by the Royal Commission into Aged Care Quality and Safety, reframing the entitlement to access respite services as a carer right rather than only as a funding limit for service providers.
26. Implement the Royal Commission's recommendations regarding identification and inclusion of carers at all stages of assessment, referral and support delivery.
27. As recommended by the Royal Commission, explore additional block funded respite options alongside the CHSP and Home Care Packages to prevent discontinuity and inequity in moving between the two programs.
28. Build greater incentives into the ACAR for residential aged care facilities to maintain respite beds.

Mental health sector

29. Reduce fragmentation in mental health funding and better integrate carer support needs into policy and funding frameworks.

Paid care workforce

30. Address shortages of skilled direct care staff in the aged care, disability and carer support sectors with one coordinated strategy to streamline workforce development initiatives.
31. Invest in block funding to providers of residential and in-home respite across sectors to support job security, staff training and coverage of travel and incidentals for direct care workers.
32. Improve remuneration and conditions for the direct care workforce to attract and retain more skilled workers to deliver residential and in-home respite across sectors.
33. Attract more workers from CALD and Aboriginal backgrounds, and workers for regional, rural and remote positions, through incentives such as training scholarships and relocation bonuses.
34. Fund training and job readiness initiatives to upskill family and friend carers looking for paid employment as direct care workers, especially in regional, rural and remote areas and within diverse communities.
35. Ensure that staff providing respite services receive mandatory training in carer awareness and support, and in upholding the principles of the Statement for Australia's Carers.

36. Ensure that staff providing respite services receive mandatory dementia education to improve outcomes for people living with dementia and their carers.
37. Mandate and resource compulsory cultural competency training for all staff delivering respite and respite-type services, and all students undertaking relevant formal qualifications.

Data collection and information sharing

38. Monitor, compare and report on data regarding demand for, use of, and satisfaction with respite and respite-type services delivered under Carer Gateway, NDIS, CHSP and the Home Care Packages program so that gaps can be identified and continuous improvement applied across sectors.
39. Pilot, evaluate and adapt innovative respite models across service sectors.
40. Improve mechanisms that record service provider respite offerings across service systems and ensure that these mechanisms are publicly available, searchable and accurate.

Funding models

41. Review funding levels and models to incorporate investment in the development and maintenance of physical respite infrastructure, including purpose-built overnight respite facilities available to users of Carer Gateway, NDIS, CHSP and Home Care Packages, as well as fee-paying and sponsored clients outside of these service systems.
42. Review evidence of demand for, satisfaction with and quality of day programs across sectors and address remaining demand with sustainable funding models or alternatives.
43. Ensure that funding models for respite and respite-like supports consider and accommodate incidental costs such as transport and administration, so that they remain viable.
44. Review the use and levels of co-contributions for respite and respite-like supports across sectors to ensure equity.

Recommendations for the NSW Government

Legislation

45. Specify the importance of breaks from the caring role in materials support public sector agencies to implement the NSW Carers Charter.
46. Strengthen redress for carers where public sector agencies do not fulfil their obligations under the NSW Carers (Recognition) Act 2010.
47. Strengthen the recognition and inclusion of carers in the assessment and planning of supports under the mental health legislation.

Investment in activities that provide a respite effect

48. Include carers in mainstream subsidies and rebates that reduce the costs of community participation and activities with a respite effect (e.g. Regional Seniors Travel Card) and promote other mainstream subsidies and rebates directly to carers (e.g. ActiveKids, Dine and Discover) and consider new, targeted initiatives to expand what is available to carers (e.g. carer-specific discount cards).

49. Invest more in regularly occurring competitive community grant opportunities that can fund small-scale, local respite infrastructure development and/or associated staffing.
50. Invest in training and development for community organisations and associations to improve the inclusiveness of available mainstream activities and services that may provide a respite or respite like supports.
51. Fund project grants linked to the NSW Carers Strategy: Caring in 2020 – 2030 that enhance carer health and wellbeing through addressing identified gaps regarding respite.
52. Establish and resource an ongoing oversight function within the NSW Government or non-government sector to monitor demand for, and use of, supports with a respite effect, identify policy gaps and explore opportunities for innovation.

Direct care workforce

53. Expand financial incentives and subsidies for people (including carers) to pursue training in direct care work to meet growing workforce demand (e.g. Summer Skills program, JobTrainer fee free courses).
54. Increase investment in the development and regulation of Registered Training Organisations (RTOs) to enable the ongoing training and development of the care workforce to ensure adequate workforce to meet respite demand.

Recommendations for local government

55. Catalogue accessible spaces and venues that can be used for no or little cost to carers and community organisations to host activities, and ensure this catalogue is publicly accessible and promoted within the local community.
56. Identify under-utilised local government land and assets which may be repurposed as residential accommodation for respite purposes.
57. Expand investment in community grants and joint grant bids that support respite-type activities and/or spaces.
58. Develop and invest in inclusive, affordable local community programs that provide respite or respite like support in line with Disability Inclusion Plans.

Recommendations for the private sector

59. Partner with community organisations to provide volunteers to assist with upgrading spaces and venues to host activities for a respite effect, and with organising those activities.
60. Invest in community grants to assist local development of facilities and activities that can provide carers with a respite effect.
61. Invest in the conversion or development of assets that can host activities or residential accommodation to provide a respite effect.
62. Develop Social Impact partnerships with evidence-based programs or pilots run by community organisations which aim to provide respite or respite like supports.
63. Engage in business partnerships to support the development of innovative IT solutions which improve information sharing for governments.

Recommendations for the community sector

64. Explore and develop partnerships with private sector, government and other community organisations to support the development of innovative, collaborative programs offering a respite effect.
65. Explore, deliver and evaluate innovative, low-cost respite models (e.g. voluntary respite models) that increase respite or respite like options for carers and their care recipients and share findings and successes with the sector and with government.
66. Invest in cultural training and diversity action plans to ensure respite and respite like supports are appropriate and culturally safe.
67. Provide information and navigation assistance to carers to raise awareness of respite or respite-type support options.
68. Continue to advocate for greater access to respite and respite-like supports across all levels of government

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