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Transitioning Australian Respite

Prepared for:
National Respite

February 2016

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SPRC
Social Policy Research Centre

Acknowledgements

Thank you to the Service Leadership Group and other stakeholders at the National Respite Conference 2014 for their input. Thank you to the Disability Team from AIHW for discussions about the data presented in the service mapping.

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© UNSW Australia 2016
ISBN: 978-1-925218-56-5

The Social Policy Research Centre is based in Arts & Social Sciences at UNSW Australia. This report is an output of the costs, benefits and impacts for care recipients, carers, communities and government of transitioning respite outputs and outcomes into consumer directed care markets research project, funded by National Respite Association.

Suggested citation:

Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016). Transitioning Australian Respite (SPRC Report 04/16). Sydney: Social Policy Research Centre, UNSW Australia.

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Abbreviations and Glossary

ABS	Australian Bureau of Statistics
ACFI	Aged Care Funding Instrument
Carer	Family, friends and significant other people who support the participant
CDC	Consumer directed care
CHSP	Commonwealth Home Support Program
HACC	Commonwealth Home and Community Care Program
DS NMDS	Disability Services National Minimum Data Set
HACC MDS	Home and Community Care Minimum Data Set
Individual budget	Individual funding package allocated to a person, such as an NDIS package
IPCSS	Integrated Plan for Carer Support Services
NDA	National Disability Agreement
NDIS	National Disability Insurance Scheme, including NDIS packages (10 per cent of people with disability) and information linkages and capacity support
NRCP	National Respite for Carers Program
Participant	Person with disability or older person receiving support
RCS	Resident Classification Scale
SDAC	Survey of Disability, Ageing and Carers

Executive Summary

The Social Policy Research Centre, at UNSW Australia, has conducted a research project with the aim of examining the impacts for participants, carers, communities and government of transitioning respite services into consumer directed care (CDC) markets. The focus was on the major reform processes of the National Disability Insurance Scheme (NDIS) and the Commonwealth Home Support Program (CHSP), which involve a focus on personalised services and a shift to CDC in the disability and aged care sectors. Consumer directed care (CDC) can take many forms, including personalisation, self-directed care, direct payments, personal budgets (introduced into English social care policy in 2007), and 'cash-for-care'. CDC typically involves the provision of cash or vouchers to consumers so that they can select and purchase services directly and receive them where they prefer in their homes and communities.

Respite care consists of short intervals of rest from the routine of a caregiving relationship to support the health and wellbeing of both the carer and the service participants, i.e. people with disability, long-term illness or frailty due to old age. However, the term respite is contested by some disability advocacy groups and scholars in the field, who suggest that it can emphasise service participants' 'dependency' and their representation as a carer 'burden'. In recognition of these views, in the United Kingdom, the term respite has been replaced with 'short breaks'.

The research was commissioned by National Respite, which is a small peak organisation that evolved from Interchange NSW. National Respite has 80 members in NSW and a small number in the ACT, QLD and SA, and collaborates with Interchange peaks in Victoria, South Australia and Tasmania.

The research project used three methods:

- a review of the national and international literature from January 2004 to September 2014 on the implications of CDC markets on respite services, including policy documents, position papers and submissions by relevant stakeholders
- roundtable discussions – two with the project's Service Leadership Group, which is a group of representatives from respite services in Australia; and one with a Consumer Reference Group, which included service providers, carers and users of respite services
- a synthesis of the main outputs and trends in the use of respite services in disability support services, aged care services and among informal carers using national datasets.

The policy and stakeholder analysis showed that the NDIS is a shift from block to individual funding, focusing on the needs of the person with disability and making provision for the carer only insofar as it improves the care and support of the person with disability. Although carers' goals and aspirations are recognised in the guidelines for carer support under the NDIS, there is no formal assessment process for their needs. In the UK, carers' needs are assessed independently of the needs of service users. In the US, needs of all members of the family are assessed at once.
The CHSP is characterised by a mix between block funding and person-centred support. It focuses on the participant and the care relationship, not on the carer, although it continues to fund some respite for carers of frail older people.

The literature review shows that direct payments and personal budgets can have a positive impact on the life of both personal budget holders and carers. For personal budget holders, the positive impact consists of being in control of their support, improved mental wellbeing, physical health, and relationships with family members. For carers, the positive impact consists of improved finance, quality of life, physical and mental wellbeing, and support to continue caring. In England, carers of older people were more likely to report an improvement in their ability to do paid work, although this was not the case for most personal budgets holders and carers of people with disability. The introduction of a CDC can sometimes limit the choice of services available to some participants if the services are not block funded. Examples include resource-intensive services such as day centres, advocacy or services with a niche demand. The availability of services shape the choices people can make. For example, in the UK, direct budget holders were more likely to spend their budgets on personal care than social or leisure activities; whereas, in the Netherlands, a third of budget holders have outsourced personal assistant-management services such as recruitment and payroll, which has become an important source of income for service providers. Research findings also show that high levels of support at set-up and planning stages and resources to purchase more than basic personal care are needed for older people to benefit fully from individual budgets.

The service mapping found that there were an estimated 312,539 people with disability who accessed disability support services in 2012/13 in Australia, of whom about 12 per cent (38,072) received respite services. Between 2011-12 and 2012/13, expenditure for respite services increased (8 per cent) at about double the rate of other disability support services (4 per cent). People with intellectual and learning disabilities were more likely to use respite services compared to people with other types of disability.

In 2012/13, 93 per cent of service users of respite services report having an informal carer compared to other service users. Users of respite services and community support were more likely to have a co-resident carer than were users of other service groups. Most primary carers (the person who provides the most ongoing care for the person with disability) had never used respite care (89.1 per cent). Most primary carers (54.8 per cent) reported that they did not use respite because they did not need it. However, 10.5 per cent of primary carers who did not use respite reported that they needed it, highlighting a significant area of potential unmet need. The Consumer Reference Group highlighted that carers are often reluctant to look for help. Overall, although the combined level of fully unmet and partly met need is similar across all states, some states and territories have a higher number of service users per outlets than others, e.g. Victoria, suggesting a risk for a potential shortage of services, particularly in light of the constant increase in the number of users of respite services in Australia.

The evidence suggests that CDC markets, and the focus on person-centred care that underpins them, potentially changes the way we conceptualise and describe what has traditionally been called respite care. In a CDC context, the focus is more directly on the needs and activities of participants, shifting from ‘respite’ to a ‘respite effect’, which does not necessarily meet the needs and preferences of the carer. Policy changes in other countries that recognise the needs of carers in their own right are not currently evident in the Australian Government policy frameworks of the NDIS or CHSP. Without such recognition, the benefits from support which aims to achieve respite effects for both participants and carers may be lost.

1. Introduction

Traditionally, respite care in Australia has sought to deliver outcomes for both carers and participants (defined in this report as people with disability and older people). Initially, the focus was on outcomes for carers but over recent decades, the focus extended to participants. Most recently, policy frameworks governing disability and aged care services have shifted again, as enshrined in the National Disability Insurance Scheme (NDIS) and the Commonwealth Home Support Program (CHSP) in aged care. The new frameworks have a greater emphasis on a consumer directed model (CDC) of service provision. In this model, the twin outcomes for participants (or 'consumers') and carers are more difficult to accommodate if they are not explicitly incorporated into the CDC design.

This report examines the impacts for participants, carers, communities and government of transitioning respite into CDC markets with the focus on the major reform processes of the NDIS and CHSP. The report has been prepared for National Respite and conducted by the Social Policy Research Centre at UNSW Australia.

National Respite is a small peak organisation that evolved from Interchange NSW. National Respite has 80 members in NSW and a small number in the ACT, QLD and SA and collaborates with Interchange peaks in Victoria, South Australia and Tasmania. National Respite is strong in strategic advocacy, member services and research. In late 2013, it shifted its strategic focus to the structural adjustment process in the disability and aged care sectors with the transition to CDC. As a result, National Respite commissioned the Social Policy Research Centre to conduct a research project with the aims of: improving understanding of the impact of the structural adjustment on stakeholders; and contributing an evidence base to guide government agencies, participants, carers, and communities on action they may take during the transition that could maximise stakeholder benefit and minimise avoidable negative impact.

The research set out to understand the current policy changes and their possible implications for respite in Australia to develop a framework for understanding and evaluating change in respite outputs and outcomes. The aim is also to map current respite outputs in Australia in order to provide a service baseline for understanding the potential impacts of changes to respite provision. This report examines the Australian and international literature on the costs, benefits and outcomes of respite and what the transition to CDC markets could mean for these costs, benefits and outcomes. Drawing on this Australian and international evidence, the research team developed a service framework for understanding and responding to change in the way that respite outputs and outcomes are organised and delivered.

1.1 Method

In undertaking the research project, a number of different approaches were taken in order to draw out the possible implications of the recent policy changes for respite in Australia.

Review of international literature

The review objectives were addressed using a purposive review methodology, covering January 2004 to September 2014. Electronic searches were performed using combinations of keywords

related to respite, carers, consumer directed markets, disability support and older people. We adopted four main techniques to identify relevant literature:

- electronic searching on key databases such as PsycINFO, MEDLINE, Social Sciences Citation Index, and CINAHL Plus
- use of websites of relevant research organisations, for example the Australian Government
- tracking references and authors' names from the retrieved papers. The titles and abstracts of the studies identified in the searches were screened based on their relevance in relation to the review objectives and the full text of the chosen papers was retrieved and analysed.

Policy and stakeholder analysis

The purpose of the policy and stakeholder analysis was to analyse the possible implications that the policy changes in the NDIS and CHSP may have for respite in Australia. The approach included:

- consultations with the project's Service Leadership Group and a Consumer Reference Group. The Service Leadership Group was a group of representatives from respite services in Australia, made up of representatives from services of different sizes located in metropolitan and regional areas. The Consumer Reference Group consisted of service providers, carers and users of respite services. Consultations involved three Roundtables, two with the Service Leadership Group and one with the Consumer Reference group, and ongoing consultation by email and phone.
- a review of legislation and policy documents associated with the policy changes and position papers by relevant stakeholders.

The analysis focused on expected changes, based on the current legislative stipulations, and possible changes, based on what is implied but not yet clear from the policy documents.

Service mapping of current respite outputs in disability, aged care and carer services

The service mapping of current respite outputs presents a synthesis of the main outputs and trends in the use of respite services in disability support services, aged care services and among informal carers. Its purpose is to provide a service baseline for understanding the potential impacts of changes to respite provision. It draws on six sources:

- Disability Services National Minimum Data Set (DS NMDS), which collected data on disability support services provided under the National Disability Agreement (NDA) in 2012–13.
- Survey of Disability, Ageing and Carers (SDAC) 2012, which is the seventh comprehensive national survey conducted by the Australian Bureau of Statistics (ABS, 2013) to measure disability.
- Home and Community Care Minimum Data Set (HACC MDS), which collects data on clients that received HACC services.

- Australian Government *Report on Government Services* (2014) (Aged Care Services)
- Australian Institute of Health and Welfare Residential aged care in Australia 2010–11: A statistical overview (2012)
- Carers NSW '2012 Carer Survey'.

Drawing on the above data sources, the service mapping provides details of respite outputs across Australia by the type and number of service users, the number of service hours, the service type, the geographical location, and government expenditure.

2. The Australian policy context: The shift to a consumer directed care model

Main points

- The National Disability Insurance Scheme (NDIS) and the Commonwealth Home Support Program (CHSP) reforms focus on personalised services and a shift to consumer directed care in the disability and aged care sectors.
- The NDIS shifts from block to individual funding. It focuses on the needs of the person with disability and makes provision for the carer only insofar as it improves the support of the person with disability.
- The CHSP is characterised by a mix between block funding and a person-centred model. It focuses on the participant and the care relationship, not on the carer, although it continues to fund some respite for carers of frail older people.
- Prior to the NDIS reform, respite was funded by the state and Commonwealth Governments and was provided by private for-profit and not-for-profit organisations.

Prior to recent reform processes, which have involved a shift to CDC, respite services to people with disability, older people and carers were provided through a number of state and Commonwealth programs. State Governments funded respite services for people with disability and their carers as part of a suite of disability services. The joint funded state- and Commonwealth Home and Community Care Program provided respite services for older people and their carers. The Commonwealth-funded National Respite for Carers Program (NRCP) provided respite to carers both of people with disability and older people. A range of other smaller programs at the state and Commonwealth levels provided respite to specific groups of consumers and carers. While funded by the state and Commonwealth Governments, most respite was provided by private for-profit and not-for-profit organisations and local governments.

Two large reform processes with a focus on personalised services and CDC in the disability and aged care sectors are likely to change the way that respite is organised and provided. The NDIS and the CHSP both focus on the needs of the consumer, which raises challenges for a traditional model of respite as a method of meeting the *dual needs* of the participant (or 'consumer') and the carer.

The NDIS means a shift from block to individual funding to meet the needs of the person with disability. It addresses the needs of the carer only in that it improves the care and support of the person with disability. It does not make provision for the carer's needs in their own right. In contrast, the CHSP aged care reform has a mix of block funding and person-centred support. It continues to emphasise and fund some respite for carers of frail older people, but the outcomes framework is focused on the participant and the care relationship, not on the carer. At the same time, in Australia, other policy processes are moving to recognise the needs of carers and their right to have their needs met, such as the emergence of the Commonwealth *Carer Recognition Act 2010* and the growing momentum behind calls for a carer assessment process in Australia similar to those existing internationally (AHRC, 2013; Anglicare 2014; Carers NSW, 2014).

2.1 National Disability Insurance Scheme (NDIS)

The NDIS is a new scheme that aims to support people with a *permanent and significant disability* and their families and carers. It takes a lifelong approach, aiming to provide ongoing individualised support packages to people with disability (Arunachalam, 2013). The aim of the NDIS is to provide participants with the opportunity to play an active role in selecting the support that they need to achieve goals across different areas of their lives, including independence, community engagement, participation in education and work, and health and wellbeing. It aims to place people with disability at 'the centre of decision-making about their lives' (NDIS Booklet, An introduction to Disability Care Australia). Those people assessed as being eligible to receive services through the NDIS (approximately 10 per cent of people with disability) work with an NDIS planner to develop a support package that meets their needs, funded by an NDIS package (NDIS Factsheet, What is the NDIS). Other people with disability (90 per cent) are expected to organise their support through mainstream services. They can seek help to do so through the NDIS Information, Linkages and Capacity program.

The NDIS is not designed to replace existing mainstream systems. Whether or not particular support or a service can be funded with an NDIS package is subject to the 'reasonable and necessary' principle, whereby the NDIS does not fund a support service if it can be appropriately funded through another system (NDIS Factsheet, The NDIS and mainstream interfaces). The focus of the NDIS is on the person with disability, and where specific provision is made for the carer, the emphasis is on the extent to which it supports the care arrangement of the person with disability such as training for the carer about the person's disability (Carers NSW, 2014).

State and territory governments are currently negotiating with the Commonwealth Government about transitioning their disability services into the NDIS. In order to deliver services under the NDIS, service providers must register with the National Disability Insurance Agency (the body set up to administer the scheme) (NDIS Factsheet, Transition to the NDIS). The NDIS therefore changes the way that services for people with disability and their carers operate. Rather than receiving block funding through various state and Commonwealth government programs, people with NDIS packages can choose to purchase their support from service providers registered with the NDIS.

From July 2013, the NDIS began rolling out in trial sites across Australia. The roll-out of the NDIS across all states and territories is planned to take place between 2016 and 2018. It is anticipated that, once it is fully operational, 460,000 Australians with disability will have individual care plans with the NDIS (10 per cent; Joint Standing Committee on the National Disability Insurance Scheme, 2014).

2.2 Commonwealth Home Support Program (CHSP)

The Commonwealth Home Support Program (CHSP) is part of the major reforms of aged care. It aims to provide *basic* support services for older people and their carers so that they can continue living in the community and enhance their independence (DSS, 2014). The focus is on providing services, such as maintenance, care, support, and respite services that are centred on the older person's 'individual goals, preferences and choices' (DSS, 2014).

To be eligible for support under the CHSP, people must be 65 years or over (or 50 years or over for Aboriginal and Torres Strait Islander peoples), live in the community, and have difficulty 'performing the activities of daily living without help or due to functional limitations', or be a carer of a person who fulfills the above criteria (DSS, 2014, p 27). The older person or carer access services under the CHSP through My Aged Care, a streamlined national assessment process that assesses eligibility and need and refers clients to the appropriate services (DSS, 2014).

The CHSP, from July 2015, provides these services by consolidating a range of existing programs including the Commonwealth Home and Community Care (HACC) Program, the National Respite for Carers Program, the Day Therapy Centres' Program, and potentially the Assistance with Care and Housing for the Aged Program (DSS, CHSP information sheet/info sheet). The HACC program, previously a jointly Commonwealth and State funded program for a large proportion of aged care services in the community, is subsumed into the CHSP and funded at the Commonwealth level. Unlike the NDIS, the CHSP stipulations make possible the provision of services to carers, including respite. This will be discussed in more detail in Section 4.4.

2.3 Reforms to Carer Recognition and Support

Over the last few decades, there has been increasing emphasis on developing policy frameworks that explicitly recognise the role of carers, the fact that they have needs that are independent from the needs of the person they provide care for, and that they have a right for those needs to be met. In 2010, the first national legislation was introduced in Australia – the *Carer Recognition Act* and its accompanying *National Carer Strategy and Implementation Plan* – forming part of the *National Carer Recognition Framework* (AHRC, 2012). The Framework has a focus on recognising the contribution that carers make and supporting them to maintain and enhance their health and wellbeing, their social and economic participation, and on recognising them as 'partners in support' of the person receiving care (Carer Recognition Act 2010). The *Carer Recognition Act*, however, does not set out any legally enforceable entitlements for carers to have these needs assessed and met. This is unlike several other countries, such as the UK and Sweden, where carers have a legal right to have their needs assessed and addressed (AHRC, 2012). There is growing momentum in Australia to introduce a carer assessment or some other mechanism for more comprehensively addressing carers' needs. In 2009, the report of the *Inquiry into Better Support for Carers* recommended that the Government consider introducing a national carer card for use with government agencies and service providers (AHRC, 2012). Since then, some organisations, such as Carers Australia, Carers NSW and Anglicare have recommended the introduction of a carer assessment, or a formal right of carers to have their needs assessed and addressed, and several organisations have suggested that this assessment should be built into the policy frameworks of the NDIS and CHSP (AHRC, 2012; Carers Australia, 2013; Carers NSW, 2014; Anglicare, 2014).

Over the past several months, the Federal Government and the Department of Social Security have set out plans to engage in a consultation process to design and develop an Integrated Plan for Carer Support Services (IPCSS) (DSS, 2015b; Fifield; 2015; Wilson, 2015). In the 2015-16 Federal Budget, the Australian Government committed $33.7 million over four years to establish a National Carer Gateway, which will provide support and linking services to carers both online and through a national 1800 telephone contact centre (DSS, 2015b). The Carer Gateway, which became operative in December 2015, provides a carer specific entry point for all carers, regardless of the need or the age of the person they care for, to go to for information, support and referral to

services. Its aim is to simplify access to information and support to help carers maintain their caring role (DSS, 2015b).

At the same time, there have been efforts in Australia to introduce services that more comprehensively address the needs of carers. In particular, the National Respite for Carers Program (NRCP) and the National Carer Counselling Program were introduced with the aim of addressing two of the areas in which carers report the greatest need for support. They are accessible through Commonwealth Respite and Carelink Centres that were designed to offer a 'one-stop shop for carers'. The role of Commonwealth Respite and Carelink Centres is currently undergoing review by the Federal Government as part of the consultation on an Integrated Plan for Carer Support Services (Wilson, 2015). Under the aged care reform changes, the National Respite for Carers Program will be rolled into the CHSP, so that only carers of people aged 65 years and over will be entitled to access the program. At present, it is unclear what will happen to the National Carer Counselling Program.

At this stage, these reform processes are in their early stages. The NDIS is in its trial phase, the CHSP is in a consultation stage and has not yet been implemented, and the carer recognition processes are in a state of ongoing change and improvement. There is therefore a great deal of uncertainty about precisely what each of these reform processes will entail for disability, aged care, and carer support services in Australia, and even more so when it comes to understanding how these processes will interact to produce outcomes for participants, carers, service providers and communities. However, it is likely that these reforms will change the way that respite is conceived, organised and delivered in Australia.

3. How can we best understand and evaluate change?

Main points

- Respite consists of short intervals of rest from the routine of a caregiving relationship to support the health and wellbeing of both the carer and the service participants (people with disability, long-term illness, or frailty due to old age).
- The term respite is contested by some disability advocacy groups and scholars in the field, who suggest that it can emphasise service participants' 'dependency' and their representation as a carer 'burden'. In recognition of these views, in the United Kingdom, the term respite has been replaced with 'short breaks'.
- The costs and outcomes of respite are difficult to identify, measure and evaluate because they are diffuse, subjective, changing and differentiated across different beneficiaries, including service participants, carers and their families.
- The type and nature of respite services varies accordingly to the *setting* or *location* of the respite (e.g. in-home or out-of-home), its duration and timing (e.g. flexible and emergency respite), and the *activities or type of care* involved.
- Five main categories of respite outcomes are identified in the literature: *individual health and wellbeing*, including physical health and emotional wellbeing; *social and economic participation*, including engagement with institutions and community activities; *personal relationships*, including the care relationship, family and friends; *community capacity and support*, including fostering community activities or a volunteer workforce; and *respite itself,* i.e. the nature and quality of the respite breaks, including the conditions under which they are made available, their length, accessibility and convenience.

This section develops a conceptual framework to understand and evaluate possible changes to respite in Australia resulting from the current reform process. As the current service context is undergoing significant change, the framework focuses on understanding the possible implications for respite *outputs* and *outcomes*, rather than the changes to respite services per se. The framework can be used to understand changes to outputs and outcomes even if the system of respite services looks very different.

3.1 What are respite care and respite services?

This section begins with a discussion of what respite care is, who benefits and how they benefit, before discussing who provides respite and in what form. The first part builds a picture of the costs, benefits and *outcomes of respite*. The second part is an account of *respite outputs*. These accounts of respite outcomes and outputs, drawn from the Australian and international literature, inform the development of the service framework. The service framework is a conceptual tool for understanding continuity and change in respite outcomes and outputs in the new Australian policy context.

What is respite care?

This section set outs what respite care is, what its history and purposes are, and what its costs, benefits and outcomes are. It is the foundation of the outcomes section of the service framework. Research suggests that the costs, benefits and in particular the outcomes of respite, research suggests that these are difficult to identify, measure and evaluate. This is because the potential outcomes are diffuse; differentiated across beneficiaries, such as participants and carers; subjective and changing; and are sometimes shared within families. Consequently, it is extremely difficult to evaluate the extent to which these kind of outcomes are a result of respite or a result of a wide array of other factors, including other services that also provide a 'respite effect' (Cotterill et al., 1995). This means researchers have found it difficult to define outcomes that can be quantified and effectively measured. In addition, outcome measures developed through these methods are not necessarily consistent with the outcomes that are valued by those whom respite is meant to support: participants and their carers and families (Bamford et al., 2009, 16). This is problematic as the accounts of service users and what they value should be central to the evaluation of respite service effectiveness (Cotterill et al., 1995). As a result, in understanding the costs, benefits and outcomes of respite, this report draws on the perspectives of those who use respite, focusing on what participants and carers report about why they value respite, how they benefit from it, and where the challenges lie.

Background

In the first instance, respite care emerged in response to a reported need by families and carers of a person with disability, long-term illness, or frailty due to old age for a break or 'relief', i.e. 'time and space' (Ashworth and Baker, 2000) from their caring responsibilities (Robinson, 1994; Bamford et al., 2009). The time and space would provide them with the opportunity to rest or to undertake activities that would contribute to their emotional, social, physical and material health and wellbeing. It would also, it was hoped, ultimately contribute to the ongoing health and wellbeing of the care relationship.

More recently, there has been much greater emphasis on the importance of respite in providing a break and a 'positive and enriching experience' for the service participants, (Robinson, 1994; Bamford et al., 2009; Kirkley et al., 2011). The important role of respite in supporting independence, social participation and a range of other outcomes for the participant has become increasingly central, so that the service objectives, equally contribute to the emotional, social, physical and material health and wellbeing of both the carer and the participant. Research with participants, however, suggests that the term respite can be viewed in a pejorative way, suggesting that they are a carer 'burden' and emphasizing participant 'dependency' (Arksey et al., 2004). In recognition of this change in the function of what was traditionally respite, and in response to concerns among participant groups about the language of 'respite', some countries have replaced the term with other terms such as 'short breaks', as in the United Kingdom (Bamford et al., 2009).

The *dual objectives* of respite in meeting important outcomes for the health and wellbeing of both the carer and the participant have become central. At the same time, the broader outcomes for the care relationship and for all family members have now become a focus of policy and service provision, such that in some countries, respite has now become a service that is provided to *families* (Canadian Healthcare Association, 2012).

As such, the costs, benefits and outcomes of respite are experienced by participants, carers, and other family members and the outcomes are not just for individuals but for relationships between participants and carers and other family members. From this point, the report replaces the phrase 'costs, benefits and outcomes' with the term 'outcomes', and discusses positive and negative outcomes.

Outcomes of respite

The review of the literature identified a wide range of outcomes of respite for different individuals, relationships, groups and the community. The literature is concentrated on the outcomes for *individual* participants and carers and on improving emotional, relational, social, physical and material wellbeing. It is also more heavily focused on the perspectives and experiences of carers rather than those of participants, and more research needs to be done that draws on the perspectives of participants. However, this report includes literature on the views of participants wherever possible. From the broad range identified in the literature, the outcomes for all parties can be loosely grouped into five outcome categories:

- *individual health and wellbeing*, including outcomes with a focus on the physical health and emotional wellbeing of the individual
- *social and economic participation*, including outcomes with a focus on improving the opportunities for engagement of the individual participant or carer with institutions and community activities
- *personal relationships*, including outcomes with a focus on providing opportunities to cultivate or strengthen personal relationships with family or friends
- *community capacity and support*, including the outcomes of respite for the communities in which participants, carers and their families live.

It is important to note the considerable overlap between the outcome categories. Creating opportunities for social and economic participation, for example, by providing opportunities for participation in work, may also improve individual wellbeing. In addition, within each category, the outcomes that are valued may be different for different groups. For example, participants may value different outcomes for social and economic participation to carers. However, we suggest that they are useful analytical categories for organising respite outcomes. These categories are elaborated in more detail in the following sections.

<u>Individual health and wellbeing</u>

The focus of the literature on respite is on outcomes pertaining to the individual health and wellbeing of participants and carers. Research with service users, including both participants and carers, suggests that the outcomes of respite for individual health and wellbeing include improving emotional wellbeing, improving physical health, providing time for self-care, enhancing autonomy and independence, and offering a period of enhanced 'freedom' or 'choice' or diversity in activity.

Research with carers suggests that they value respite because it can relieve emotional stress associated with their caring responsibilities (Arksey et al., 2004; VON Canada, 2002), and can reduce their experience of depression and anxiety by giving them opportunities to address their own mental health, to rest, and to provide 'worry-free time' with 'peace of mind' (Arksey et al., 2004; VON Canada, 2002). Research also suggests that respite can be beneficial for participants'

mental health. For example, studies of people with dementia found that they valued respite because it helped them to feel less isolated, they had 'less time on their own to become low in mood or bored', and they were able to relax during periods of respite care. In some instances, respite improved the cognitive abilities of the participant and improved behavioural challenges (Arksey et al., 2004).

Research also suggests that respite can create positive outcomes for the physical health of both carers and participants (Arksey et al., 2004). For example, carers report being able to overcome tiredness or 'recharge' their batteries during periods of respite (Laragy and Naughtin, 2009). Respite can also be beneficial for the participant's physical health, particularly where it is designed to meet their therapeutic needs (Canadian Healthcare Association, 2012), and where it provides opportunities for diagnosis of medical conditions or needs (Arksey et al., 2004). Respite can also provide participants and carers with time for 'health-promoting self-care' (VON Canada, 2002). For example, carers report getting rest, catching up on sleep (Cramer and Carline, 2008; Laragy and Naughtin, 2009), taking a walk or doing other exercise or just having some time for themselves (Arksey et al., 2004; VON Canada, 2002).

Respite can also have positive outcomes for individual wellbeing by increasing autonomy for both participant and carer, creating enhanced freedom, choice, and diversity in tasks and activities or a break to the routine. For example, carers report experiencing 'a sense of peace and freedom' without worrying about the wellbeing of the person they care for (Laragy and Naughtin, 2009), a sense of freedom and choice about the activities they can undertake during periods of respite, and more control over their use of time (VON Canada, 2002; Arksey et al., 2004). Participants report increased independence, a break to the routine, a 'widened range of activities' (Cotterill et al., 1995) and 'broadened experiences' (Cramer and Carline, 2008), alongside having more control over 'when and where they go, who they are with, what they do, what they eat, what they spend their money on and when they go out' (Cotterill et al., 1995).

Social and economic participation

Respite can also generate positive outcomes for the social and economic participation of participants and carers by improving their opportunities for engagement with institutions and community activities. Both participants (Arksey et al., 2004) and carers (Cramer and Carline, 2008) report that respite offers opportunities to participate in social and recreational activities, to reduce feelings of isolation (Cotterill et al., 1995) and to build social and life skills (Canadian Healthcare Association, 2012), including connectedness to the community. Carers who participated in work or further education reported that respite supported them in managing and completing these activities: their caring and work responsibilities (Arksey et al., 2004), and continue in and complete their education (Hamilton and Adamson, 2013).

Personal relationships

Respite can also provide positive outcomes for the personal relationships of participants and carers, ensuring greater longevity of the caring relationship and providing opportunities to cultivate or strengthen their relationships with family or friends (VON Canada, 2002).

Carers report using the time offered by respite to spend time with friends, sustain existing friendships (Cotterill et al., 1995) and build new friendships (Arksey et al., 2004). Carers also report using the time to work on family relationships (Arksey et al., 2004) and in particular, they identified

the importance of having time to spend with their partners and other family members (Cramer and Carline, 2008). Families also report better relationships and cohesion as a result of having access to periods of respite (Cotterill et al., 1995; Canadian Healthcare Association, 2012). Carers reported that respite offered an opportunity to strengthen the care relationship, both by providing the carers and participants with a short break from the intensity of the caring relationship and by providing opportunities for them to do things together, such as joint or family respite activities like recreational days or holidays (Arksey et al., 2004; Cotterill et al., 1995). The benefits offered by respite, including the sense of 'shared responsibility' it offers, meant that many carers report that it enables them to continue in their caring role (Arksey et al., 2004, Laragy and Naughtin, 2009; VON Canada, 2002).

Participants also report that respite can have positive outcomes for their personal relationships. They report enjoying the company, the sense of belonging and activities that respite offers, including being part of a group and the opportunities to meet new people, develop new friendships, develop confidence and provide a sense of interdependence and solidarity (Arksey et al., 2004; Cramer and Carline, 2008).

Community capacity and support

Research also suggests that respite can create positive outcomes for the community. For example, it shows that respite can foster community activities or cultivate a volunteer workforce and build relationships in the community (for example through host family respite). There are also wider social and economic benefits to the community associated with respite such as supporting the carer and participant to remain living in the community and delaying the entry of a frail older person into a residential aged care facility (Cotterill et al., 1995; Arksey et al., 2004), or reducing carers' and participants' need to use other community services (Arksey et al., 2004).

Respite as an outcome in itself

The above four categories of outcomes are in a sense indirect outcomes of respite, that is, positive outcomes that emerge from the feelings or activities that the carer and participant experience or participate in while they are having a break. However, respite is also an outcome in itself that can be defined as a break, a 'short interval of rest', a temporary interruption to the intensity or routine of a caregiving relationship (Canadian Healthcare Association, 2012) that is a positive outcome in its own right. That is, the break itself can be a positive outcome, regardless of what the carer or participant do during this time or what they feel.

This suggests that the focus should not just be on the outcomes of the break but on the nature of the break itself, including the conditions under which it is made available, how long it is, and whether it is at a time that is suitable and convenient for the service participant. The literature suggests that this is of particular importance to carers. Carers report that in order to meet these 'indirect outcomes' (such as improving emotional wellbeing, facilitating participation in work or recreational activities, or strengthening family relationships), respite must be available when they need it, for the appropriate duration and easily accessible (Arksey et al., 2004). Carers emphasise "the importance of carers being able to use the time and space that respite services offered as they wished, whether this was to work, relax, catch up on sleep, do domestic tasks or keep in touch with family, friends and outside interests" (Arksey et al., 2004, p. 100). Carers also report that it is the quality, not the quantity, of the time away (VON Canada, 2002), suggesting that it is the extent to

which the carer can enjoy the break and use the time in the way that they wish that is important for creating the positive outcomes.

Negative outcomes

While the emphasis in the above sections is on the positive outcomes associated with respite, its provision can also affect carers and participants in negative ways (Cotterill et al., 1995). For example, carers sometimes feel guilty or anxious about whether the person they care for will be looked after (Laragy and Naughtin, 2009). Some carers report that the use of respite feels like a personal failure (Arksey et al., 2004). Participants have also reported negative outcomes of respite, including feeling alone, excluded, unsafe, and anxious about being in respite, particularly if the service was unfamiliar (Arksey et al., 2004). In a study on people with dementia, sometimes the change to the routine created by respite triggered behavioural difficulties that were troubling for both the participant and the carer (Laragy and Naughtin, 2009). The research suggests, however, that negative outcomes were often a result of inadequate, inappropriate or poor quality respite services. Some reports, for example, stated that the complexity of organising respite added more stress, or that carer stress was actually increased when the respite service was perceived to be inadequately addressing the needs of the participant (Arksey et al., 2004, Laragy and Naughtin, 2009).

What are respite services?

Respite care is provided or organised by respite services and takes a number of forms. This section discusses who provides respite and in what form, and informs the *outputs* section of the service framework. The international and Australian literature suggest that respite services are usually characterised by the *setting* in which the care is provided and the possible *duration or timing* of service use (Bamford et al., 2009). Respite services are also distinguished based on the *activities or level of care* that is provided (Cotterill et al., 1997) and by who provides the care, such as health professionals, personal care workers, host families, and volunteers. There is great variation across these different forms as to the character of the respite provided (Cotterill et al., 1997).

Broadly, respite services can be categorised according to several types: in-home respite; out-of-home respite and other forms of respite that can be provided either inside or outside of the home.

In-home respite

In-home respite is provided in the home of the participant. This can be in several forms and is most often short term. It can be a therapeutic visit from a health care provider, a day or a night sitting service provided by a care worker, nursing assistant or a befriending service or more recently, ‘video respite’. This is an in-home resource designed initially for people with Alzheimer’s disease and their carers that involves the provision of specially designed interactive videos that the participant may engage with for a short time and which may provide a short break for the carer or other family members (Canadian Healthcare Association, 2012; Arksey et al., 2004).

Out-of-home respite

Out-of-home respite takes diverse forms. It can include centre-based day care, which is generally provided in specialist facilities, community buildings and sometimes hospitals or residential facilities. The focus of centre-based day care can be on meeting the therapeutic needs of the

participant, or on providing social or recreational activities (Bamford et al., 2009). It is generally short term (up to a day) but can be regular, such as several days a week (Canadian Healthcare Association, 2012). Out-of-home respite also includes residential or cottage respite that is generally overnight or over a period of nights or weeks. Residential respite is provided in a specialist facility (Bamford et al., 2009; Canadian Healthcare Association, 2012), which can also include involvement by the participant or the carer in clubs, interest or activity groups that focus on a particular activity or group of service users (i.e. people with dementia or young carers). This can be in a range of locations, depending on the activity (Bamford et al., 2009).

Host-family respite, another form of out-of-home-respite, is when the participant (or a group of participants) has a short visit or overnight stay in the home of a host family, where the more informal support is provided by a family member who is a paid or volunteer carer (Arksey et al., 2004; Bamford et al., 2009).

More recently, respite services have diversified to provide breaks or holidays for participants, carers or families (Kirkley et al., 2011). These may be in the form of 'traditional' holidays in hotels or holidays in specialist camps or recreational centres with support staff available (Bamford et al., 2009). In some instances, breaks or holidays are provided to the whole family so that the emphasis is not on members of the family having a break from each other but on the family taking a break from their everyday routine and enjoying a holiday together. Family-based breaks or holidays can be for the day, overnight, for a weekend or longer (Cramer and Carline, 2008).

Other forms of respite

There are several other forms of respite that do not fall neatly into in-home or out-of-home categories because they can be provided in either and can be more flexible in form. This includes emergency and flexible respite, which is often unplanned, at short notice or during irregular hours.

Respite outputs and respite outcomes

The type and nature of respite services is therefore diverse, with a great deal of variation according to the *setting* or *location* of the respite, duration and timing of the respite, and the *activities or type of care* that the respite involves. These categories provide a useful way of understanding respite outputs and are adopted as output categories in the service framework below.

Another important category for understanding respite outputs is the clients that they service, including their capacity to reach different groups of participants and carers. Research suggests that different carers and participants value and need different types of respite services in different settings (Arksey et al., 2004). For example, Canadian research suggests that the main users of in-home respite are the spouses and adult children of seniors (Canadian Healthcare Association, 2012). Research also suggests that different kinds of respite services produce different kinds of outcomes. For example, research on carers of people with dementia has found that catching up on sleep is a highly valued outcome of respite, which means that residential, overnight respite services are one way to organize this outcome for carers in this group (Arksey et al., 2004). Hence, understanding the service user 'reach' of different types of respite services is important in understanding respite outputs, and maintaining a diversity of respite outputs that are accessible to multiple service user groups is important to ensuring that the range of respite outcomes are met.

Service framework for understanding respite outcomes and outputs

Drawing on the Australian and international literature on the outcomes of respite this section sets out a service framework. This is a conceptual tool for understanding continuity and change in respite outputs and outcomes in the new policy context. In order to be able to fulfill this function, the service framework attempts to use language that is neutral and transferable across disability and aged care service systems, participant and carer groups, and the current and future service contexts being examined.

To be transferable across sectors and service users, the service framework had to be 'abstracted', or independent from, specific service arrangements in Australia and the other countries surveyed. To create an abstracted framework, the research team underwent the following process:

- It compiled a list of (positive and negative) outcomes of respite that were raised in the literature (see previous section).
- It developed these into broader outcome categories, such as 'enhancing autonomy and independence' and 'strengthening care relationships'.
- It grouped these outcome categories into higher level 'outcome areas', such as 'individual health and wellbeing', and 'social and economic participation'.
- It compiled a list of respite outputs that emerged in the literature, including service types and characteristics of service provision (see previous section).
- Because of the aim to create a framework that is abstracted from actual service outputs, so that it can be used to understand changes to respite services as they have traditionally been conceived, types of respite were not listed as outputs. Instead, more abstract output categories were developed that were capable of capturing respite outputs that are not necessarily called respite, such as quantity and timing, and location. These output categories are also more neutral for participant and carer groups than the term respite.
- The framework was refined through consultations with respite service providers on the project's Service Leadership Group and with reference to the service mapping exercise. Two additional output categories were also added to capture two important additional elements of respite outputs in the service infrastructure: region, or the geographical distribution of respite outputs across areas with different levels of remoteness; and transport.

The framework was therefore strongly informed by user perspectives, drawing on research with participants and carers about the positive and negative outcomes of respite. The team then placed the framework alongside the purported outputs and outcomes of the NDIS and CHSP to ensure that the framework is capable of capturing changes transpiring in respite outputs and outcomes in the current Australian context. The framework of respite outputs and outcomes appears in Table 1 below.

Table 1 Service framework

Respite outputs	Respite outcomes
Location In home Centre-based Host-family home Community-based (e.g. recreational locations) Therapeutic/health-based location (e.g. specialist offices, hospital)	**Individual wellbeing** Improving emotional wellbeing, reducing stress, depression, anxiety Improving physical health Providing time for self-care Enhancing autonomy and independence Offering a period of enhanced 'freedom' or 'choice' in tasks/ activities
Activities Therapeutic Social Recreational Family-based activities Personal care	**Social and economic participation** Creating opportunities for participation in recreational activities Improving choices/opportunities for participation in work Improving choices/opportunities for participation in education Maintaining links to the community
Quantity and timing Number of hours Time of day/week (day, overnight, weekend) Flexible respite Emergency respite	**Personal relationships** Strengthening care relationships Strengthening other family relationships Providing opportunities to spend time with friends Providing opportunities to cultivate new relationships
Reach Participants under 65 Participants over 65 Carers of people under 65 Carers of people over 65	**Workforce capacity and conditions** Workforce size Employment security Employment conditions Opportunities for training and capacity building
Region Metropolitan Outer metropolitan Regional Remote	**Community capacity and support** Fostering community activities Cultivating volunteer workforce
Transport	**Respite as outcome in itself**

4. What might policy changes entail for respite in Australia?

Main points

- Consumer directed care (CDC) typically involves the provision of cash or vouchers to consumers so that they can select and purchase services directly and receive them where they prefer in their homes and communities.
- CDC can take many forms, including personalisation, self-directed care, direct payments, individual budgets (piloted in England from 2005 to 2007), personal budgets (introduced into English social care policy in 2007), and 'cash-for-care'.
- Results from the 2011 and 2013 English POET surveys found that:
  - Personal budgets had a positive impact on the life of both personal budget holders and carers, including control of their support, wellbeing, physical health, and relationships with family members and finance, support to continue caring, quality of life and physical and mental wellbeing for carers.
  - Carers of older people were more likely to report an improvement in their ability to do paid work, although this was not the case for most personal budgets holders and carers (in the second survey, 41 per cent of the carers were over 65).
- CDC markets prioritise the goals and preferences of service users. When this entails a primary focus on the person with disability (or the older person in the context of aged care services), the challenge arises in continuing to recognise and meet the needs and preferences of the carer.
- In the guidelines for carers' support under the NDIS, carers' goals and aspirations are recognised, for example to go back to education or employment. However, there is no formal assessment process.
- In the UK, carers' needs are assessed independently of the needs of service users. In the US, needs of all members of the family are assessed at once.
- International evidence suggests that the introduction of a CDC
  - can limit the choice of services available to some participants, e.g. those using resource-intensive services, such as day centres, or services with niche demand
  - shape the choices of services that people buy, e.g. in the UK, direct budget holders were more likely to spend their budgets on personal care than social or leisure activities
  - require high levels of support at set-up and planning stages and resources to purchase more than basic personal care for older people to benefit fully from cash-for-care schemes such as individual budgets
  - can be augmented with the introduction of the option of paying relatives, acquaintances or 'unaffiliated workers' for providing care to create a more flexible care workforce. However, this raises policy questions in relation to employment regulations, quality controls and monitoring of the services purchased, and cost coverage, that is, the proportion of the costs of care which is covered by the cash-for-care payment and by families
  - can generate personal assistance-management services, such as recruitment, payroll. In the Netherlands, a third of budget holders outsource these tasks.

The previous sections have set out the policy reform processes in Australia that are likely to change the way that respite is conceived, organised and delivered, before setting out a conceptual service framework for understanding these changes. The framework is a method of exploring and evaluating how respite outputs may be altered as a result of the changing service context, including possible alterations to the *character* of respite (location and activities, including transport), the *amount and availability* of respite (quantity and timing), and *who has access* to respite (geographical distribution and reach, or accessibility to different groups). It also provides a method of understanding the implications of these alterations for respite outcomes across different groups of participants and carers.

This section explores the possibilities for change resulting from the policy reform processes of the NDIS and the CHSP. It sets out what might change in the way that respite is conceived in a new context dominated by a CDC model of service provision more generally, before setting out in more detail what we might expect to change in the organization and delivery of respite in Australia. To answer these questions, the section combines a literature review of the international experience of the transition to CDC markets, and a policy and stakeholder analysis, which draws on consultations with the project's Service Leadership Group (a group of representatives from respite services in Australia). It also provides a review of legislation and policy documents associated with the policy changes, and position papers and submissions by relevant stakeholders to explore in more detail the possible implications that the complex policy changes in the NDIS and CHSP may have for respite in Australia.

4.1 International experience: The emergence of consumer directed care markets

The shift to a CDC model in disability and aged care services poses several broader challenges to the way that *all* services in the two sectors are conceived and delivered, including respite. For example, one major challenge is the capacity of services to maintain a dual focus on the needs of both the participant and the carer in a model that is fundamentally underpinned by a primary focus on the participant. Another challenge posed by a shift to CDC has been the viability of some services in a changing funding model whereby the consumer plays a much greater role in selecting where and how the money is spent. These challenges are important in the Australian context in the shift to the NDIS and (to a lesser extent) the CHSP.

Australia is not the first country to meet these challenges. Over the last few decades, a number of countries internationally have introduced CDC markets into their disability and aged care sectors as well as some other community services sectors such as child care (Sipila et al., 2010). Consumer directed care takes many forms, and it includes personalisation, self-directed care, direct payments, individual budgets, and 'cash-for-care'. Typically, however, it involves the provision of cash or vouchers to consumers so that they can select and purchase services directly rather than receive them in kind in their homes and communities (Arksey and Kemp, 2008). This section draws on a review of the international literature to explore the international experience of managing the challenges associated with introducing CDC markets to the disability and aged care sectors. Drawing on this evidence, it explores the outcomes of the shift to CDC markets for participants, carers and service providers. It discusses the experience of several countries in more detail to provide 'case studies' of the experiences of countries with similar welfare regime types to

Australia: England, the United States and Canada, before discussing several other European examples.

England

Individual and personal budgets have been a central element of the personalisation agenda for reforming the delivery of adult social care in England (Glendinning et al., 2009; Jones et al., 2014). Individual budgets brought together local authority social care, housing-related support services, adaptations and equipment budgets into a single individual budget to be spent flexibly according to individual priorities and preferences (Glendinning et al., 2008, 2009; Jones et al., 2014). Although they were successfully piloted in 13 English local authorities from the end of 2005 until the end of 2007, the complications associated with administering funding streams from different agencies and authorities led the English Government to replace individual budgets with personal budgets that consisted only of one stream of social care funds.

Individual budgets: Individual budgets aimed to give more choice and control to older people and people with disability over their support needs. An independent evaluation of the pilot was undertaken using a Randomised Controlled Trial design, which entailed randomly allocating service users to either the individual budget group or a comparison group consisting of users of standard social care services (Glendinning et al., 2008). Findings from 263 structured interviews and 40 semi-structured interviews with older people from the independent evaluation of the pilot showed that "older people spent their individual budgets predominantly on personal care, with little resources left for social or leisure activities" (Moran et al., 2013, p. 826). Older people receiving individual budgets "had higher levels of psychological ill-health, lower levels of wellbeing, and worse self-perceived health than older people in receipt of conventional services" (Moran et al., 2013, p. 826). Potential advantages of individual budgets for older people included "increased choice and control, continuity of care worker, and the ability to reward some family carers" (Moran et al., 2013, p. 826). However, older people reported anxieties about the responsibility of organising their own support and managing their budget (Moran et al., 2013). Overall, the literature suggests that high levels of support at set-up and planning stages and resources to purchase more than basic personal care are needed for older people to benefit fully from cash-for-care schemes such as individual budgets (Moran et al., 2013; Netten et al., 2011). Netten et al. (2011) raised the question of what the potential for achieving better outcomes through personalisation is in a financial climate that necessitates cuts in expenditure on social care, particularly in relation to the possibility of employing professionals who can sustain the flexible and creative approaches needed to support different groups in achieving their desired outcomes.

The individual budget pilot study focused primarily on service users, so a separate but linked study was set up to evaluate the impact and outcomes of individual budgets on carers (Glendinning et al., 2009; Jones et al., 2014). The study found that carers of individual budget users scored higher than carers of people using standard social care services in relation to measures of quality of life, social care outcomes and psychological wellbeing, although the difference between the two groups of carers was statistically significant only in relation to carers' quality of life. Jones et al. (2014, pp. 171-172) report that "occupation was the social care outcome domain where most impact was identified", suggesting that individual budgets were able to support carers to have "a life of their own". Jones et al. (2014) report that these outcome gains were achieved despite no higher costs; in fact, the cost of the support plan was slightly lower in the individual budget group than the

service package for the comparison group. However, on average, carers of individual budget users appeared to spend more time on care-related tasks (81 hours) than carers supporting someone in the comparison group (72 hours), entailing that "the opportunity costs for carers of individual budget users constituted a higher proportion of the overall costs of care for the individual budget group" (Jones et al., 2014, p. 173). In addition, only a small minority of carers received any payment from the service users for their care-related responsibilities. These two findings suggest that "the slightly lower costs of individual budgets compared with standard social care support may be offset by greater inputs of time – and the associated opportunity costs – on the part of informal carers" (Jones et al., 2014, p. 173). However, Jones et al. (2014) caution that this conclusion needs to be treated with extreme caution because there were no statistically significant differences between individual budget and comparison groups in levels of formal resource inputs to the service users, and sample numbers were relatively small. Overall, the carers' evaluation found that "the participation of carers in the planning of social care services to be received by a service user can have a positive impact on carers' outcomes" and stressed "the importance of assessing and meeting the needs of disabled and older people and those who support them, and the interdependency of their respective outcomes" (Jones et al., 2014, p. 173).

Personal budgets: Personal budgets aim to promote greater choice and control over support arrangements among social care service users (Glendinning et al., 2008; Prabhakar et al., 2010). Disabled and older people are encouraged to play an active role in the assessment of their support needs through a system called the Resource Allocation System (RAS).[1] A personal budget is then estimated based on the assessment, which generally discounts the help given by informal carers if they are willing and able to continue providing the same level of support (Glendinning et al., 2009). Personal budgets were introduced into English social care policy in 2007 following the Individual Budget Pilot programme 2005-7, with a view to extending them to all those eligible for ongoing council-funded social care. However, the recognition of carers' needs and the development of services to meet those needs evolved along rather separate lines from policies for disabled and older people (Glendinning et al., 2009; Mitchell et al., 2014).

A partnership by In Control (a charity who pioneered self-directed support for service users in the UK) and Lancaster University undertook two national surveys, the 'POET surveys', on the outcomes and experiences of people using personal budgets and their family carers (Hatton & Waters, 2011; Hatton & Waters, 2013). The first survey was completed by a total of 2,064 respondents, of which 1,114 were personal budget holders and 950 were carers (Hatton & Waters, 2011). It found that most personal budget holders reported that the budget had a positive impact on 10 of the 14 life dimensions explored in the survey,[2] including:

> …being supported with dignity and respect (76 per cent reporting a positive impact); people staying as independent as they want to be (75 per cent); people being in control of their support (72 per cent); people having control over the important things in life (68 per

[1] The Resource Allocation System (RAS) consists of a points based formula that measures a person's level of dependency and awards money accordingly based on what the person might have received using traditional services.

[2] These were: physical health, mental wellbeing, being in control of life, being independent, being in control of support, getting needed support, being supported with dignity, feeling safe, choose where/who to live with, getting/keeping paid job (not measured for older people), volunteering and helping community, relations with family, relations with friends, relations with paid supporters.

> cent); people's relationships with those paid to support them (67 per cent); people's mental wellbeing (63 per cent); people's physical health (59 per cent); people's relationships with family members (58 per cent); people feeling safe both inside and outside their home (57 per cent) and people getting the support they need when they need it (72 per cent) (Hatton & Waters, 2011, pp. 2-3).

However, most personal budget holders reported personal budgets making no difference in the following aspects of their lives:

> …people getting and keeping a paid job (68% of working age adults reporting no difference) and people volunteering and helping their local community (77% of adults of any age); people choosing where they live/who they live with (60% of all adults); and people's relationships with friends (52% of all adults) (Hatton & Waters, 2011, p. 3).

Positive experiences were also reported by most carers although to a lesser extent compared to personal budget holders. Most carers reported a positive impact of the personal budgets held by the person they cared for in about three out of the nine life domains that were explored.[3] In particular, the majority of carers reported a positive impact on "support for them to continue caring (68 per cent); their quality of life (60 per cent); and their physical and mental wellbeing (55 per cent)" (Hatton & Waters, 2011, p. 3).

Carers were relatively evenly split on whether personal budgets for the person they care for had a positive impact or made no difference in relation to their finances, social life, relationships with the person cared for and/or other family/friends, and their sense of choice and control over their own lives (Hatton & Waters, 2011). Similarly to personal budget holders, most carers (68 per cent) reported that personal budgets for the person they care for had no impact on their own capacity to get and keep a paid job (Hatton & Waters, 2011). Nevertheless, 87 per cent of carers reported that their views were very much or mostly included in the personal budget holder's support plan.

Only a small number of personal budget holders (between 3 per cent and 8 per cent) and carers reported that personal budgets had a negative impact on the life domains that were explored in the survey. In particular, just more than ten per cent of carers reported that personal budgets had a negative impact "on their physical and mental wellbeing (13 per cent), their social life (12 per cent), their quality of life (11 per cent) and their choice and control over their own lives (11 per cent)" (Hatton & Waters, 2011, p. 3).

Similar findings were reported in the second survey, which included over 3,300 respondents (2,022 personal budget holders and 1,386 carers). The bigger sample of the second survey allowed comparisons between older people, working age adults with learning disabilities, working age adults with mental health issues, and working age disabled adults (Hatton & Waters, 2013). The analysis showed an equal impact across groups in eight of the 14 life domains explored: physical health, being as independent as you want to be, getting the support you need and want, being supported with dignity, feeling safe in and outside your home, choosing where to live/who to live with, getting and keeping a paid job (working age adults) and relationships with family. However, personal budgets were less likely to make a difference for older people in relation to their mental

[3] The nine areas were: support for them to continue caring; quality of life; physical wellbeing; mental wellbeing; finances; the carer's social life; the carer's relationships with the person cared for; the carer's relationships with other family/friends; the carer's sense of choice and control over their own lives.

wellbeing, control over important things in life, control over their support, volunteering, relationships with friends, and relationships with paid supporters (Hatton & Waters, 2013).

More than half of the carers reported that having a personal budget for the person they cared for improved their life in four of the nine areas which were explored in the second survey: finances (52 per cent), having the support you need to continue caring and remain well (69 per cent), quality of life (60 per cent) and physical and mental wellbeing (53 per cent). However, having a personal budget for the person they cared for made no difference to the carers' relationships with other people who were important to them (51 per cent) and to their ability to do paid work (69 per cent, although 41 per cent were over 65). Carers of older people were least likely to report improvements in all but one of the eight life domains that were explored for carers, i.e. ability to do paid work (Hatton & Waters, 2013).

Overall, the two surveys show that personal budget holders and carers reported positive experiences of the impact of personal budgets on their lives, although experiences of the personal budget process varied across councils. According to Hatton and Waters (2013), a limitation of their study is the over-representation, compared to the national picture, of direct payment users in both the 2011 and 2013 National Personal Budgets Surveys (Hatton & Waters, 2013), and this criticism is picked up by Slasberg, Beresford and Schofield (2012a, pp. 1030-1031), who criticise the POET study for being unrepresentative. Slasberg et al. (2012b) distinguish three key elements of the UK social care reform:

- personalisation of support to give people greater control over their lives and overcome services informed by a 'one size fits all' culture
- personal budgets to enable purchase of support and services most appropriate to the individuals
- self-directed support, which is calculated through Resource Allocation System (see above) and entails that the personal budget is given 'up-front' to the individuals to empower them as consumers.

Slasberg et al. (2012b) suggest that the 'self-directed support' element is failing to adequately support the goals of personal budgets and personalization and suggest reforming this component of CDC in the UK. They report evidence from a freedom of information request to a number of councils which shows that, on average, the upfront budget figure that is given to the participant is considerably different to the actual budget that is allocated to them once their support planning is developed. Slasberg et al. (2012b) argue that this difference in the 'up-front' budget and the budget actually given creates uncertainty for participants (with a disempowering rather than an empowering effect) and service providers. Slasberg et al. (2012b) also analysed data from the National Adult Social Care Information Service (NASCIS) showing that local councils, who administer self-directed budgets in the UK, significantly increased staffing levels after the introduction of the self-directed support reform while at the same time, the volume of support delivered was reduced. Slasberg et al. (2012b) suggest a reduction of around 20 per cent in productivity, with more staff delivering less work.

Wilberforce et al. (2011) discuss the (early) impact of individual budgets on service providers and their workforces. They report data from 16 interviews with managers of social care providers and seven commissioning managers, which were undertaken as part of the independent evaluation of

the individual budgets pilot study. Wilberforce et al. (2011) found that many service users, particularly older people, had simply not requested anything different from their service providers. However, some providers reported that "service users were developing greater expectations about what providers should deliver (choice of 'when' was most strongly demanded, especially with regards to short-notice care)" (Wilberforce et al., 2011, p. 608). Wilberforce et al. (2011) report that many providers felt that budget holders were being unrealistic and aimed to temper their aspirations when discussing options with them. Most managers raised issues about the viability of some services in the new service context, with specific reference to day services. Wilberforce et al. (2011, p. 608) report evidence on changes in demand from the wider individual budget evaluation and other sources, which suggested that "holders of budgets in learning disability services spent 28 per cent fewer days in day centres than previously". This suggests an alteration in the patterns of support use among participants and that the viability of day services can be at risk as holders of budgets spend fewer days in day centres. Wilberforce et al. (2011, p. 608) raise an important issue of equity and stability in relation to this potential outcome of individual budgets:

> …if a day service closes because a sufficiently large number of users – empowered by greater choice – elect to leave the service, the remaining users may find their choice restricted and be forced to find alternative arrangements. In short, IBs may not reach a Pareto optimal solution in that greater choice for some may occur at the expense of lesser choice for others.

However, Wilberforce et al. (2011) report that, overall, providers were broadly unthreatened by the prospect of fewer people using their services because of the prospect of opportunities for new business to compensate for this. In particular, the provision of more PA-management services, such as recruitment and payroll, may prove a lucrative area for service provision; Wilberforce et al. (2011) also report that, in the Netherlands, a third of budget holders have outsourced these tasks.

Finally, the majority of the homecare providers interviewed had direct experience of, or concern about, the administrative consequences of individual budgets (Wilberforce et al., 2011). This issue has also been expressed by Australian providers, who identified sources of potential higher cost burdens, including investment in new IT systems; processes for invoicing and chasing non-payment; recruitment costs to replace care workers who leave to become personal assistants; costs of developing new service options; and retraining care workers to work in new flexible ways, including how to respond to unanticipated risks (National Disability Service, 2009).

Alongside the shift towards individual budgets, the UK has seen a concurrent introduction of a policy framework for assessing carers' needs independently of the needs of the participants. This has involved the introduction of a carer's right to a 'carer assessment', or the right to have their needs assessed and addressed by local service providers through referral to appropriate support services (Seddon and Robinson, 2001). During the assessment of their support requirements, the carer's wishes and needs regarding education, training and employment must be taken into consideration (AHRC, 2012). After research found a number of carers missing out on an assessment and inadequacies and inconsistencies in the assessment process (Yeandle et al., 2007; Mitchell et al., 2014), legislation was introduced, most recently the UK Care Act (2014), which significantly improved the carer assessment process. Improvements have involved extending and strengthening the carers' entitlement to have their needs assessed and met by services, and decoupling the right to a carer assessment from the needs of the care recipient, so

that the participant does not need to be receiving services in order for the carer to have their needs assessed. This is a significant step forward in recognising the needs of the carer as independent from those of the participant.

Other European countries

A number of other countries in Europe offer cash-for-care programs to people with disability or older people, including Austria, France, Germany, Italy, the Netherlands and Sweden (Canadian Healthcare Association, 2012). These schemes tend to share similar overarching goals, including improving the choice available to the participant, constraining costs of services, cultivating family or informal care, and developing care markets (Canadian Healthcare Association, 2012). Timonen, Convery and Cahill (2006) compared cash-for care programs in four countries: Ireland (Home-Care Grants), the England (Direct Payments), Finland (Service Vouchers), and the Netherlands (Personal Budgets). They argue that while the four countries' cash-for care schemes have similar goals, their relative importance and the design and operating principles of the programs differed substantially in each country. The reforms in the four countries shared the following goals:

- increased freedom of choice
- independence and autonomy for care recipients
- compensation for gaps in existing services
- creation of jobs in personal-care services
- efficiency gains or cost savings through reduced overheads and increased competition among providers
- shifting care preferences and utilisation from institutional to domiciliary care.

Despite these similarities, the relative importance of these goals varied in each of the four countries discussed. Timonen et al. (2006) note that cash-for-care programs in England, Finland and Ireland were introduced to compensate for (perceived) deficiencies in, or a lack of, direct service provision whereas others were focused on reducing cost or increasing competition in services. Overall, the most important differences across the schemes in the four countries are:

- their levels of commodification, that is the possibility to 'commodify' informal care work by employing relatives as care workers. This is possible in the Netherlands and in England, but not in Finland and Ireland (Timonen, et al., 2006).
- their employment regulations, which refer to the degree to which the employment created and the care purchased through the scheme is part of the mainstream, taxed and regulated economy. For example, this is the case in England, the Netherlands and Finland, but less so in Ireland.
- the cost coverage, which refers to the proportion of the costs of care which are covered by the cash-for-care payment. This is high in Finland and the Netherlands, moderate in England, and in most cases low in Ireland. This entails that "the Irish and the English schemes place more responsibility for costs on individuals (and families)" (Timonen, et al., 2006, p. 467).

- the quality controls, which refer to the monitoring of the services purchased with the cash entitlement. Timonen et al. (2006, p. 467) report that “there are some quality controls in England, and comprehensive monitoring takes place in Finland and the Netherlands”, whereas “the quality of services purchased with the cash entitlement is only haphazardly monitored in Ireland”.

Several of these countries also provide a form of carer assessment or brokerage resembling that of the UK, which offer mechanisms for recognising carers’ needs. For example, Sweden has a system of carer assessments that refers the carer to respite and counselling support, and the Netherlands has a “system of ‘care brokers’ targeted at working carers, in which carers are provided with a case manager to help them navigate the service infrastructure and co-ordinate the range of health and social care services”, reducing their time spent on ‘care management activities’, and in some instances to negotiate with the employer on the carer’s behalf (AHRC, 2012).

In several European countries, e.g. Italy, Spain, Greece, Austria, Germany and Ireland, public cash for care schemes providing benefits to dependents have driven an increase in the employment of migrant care workers (Di Rosa, Melchiorre, Lucchetti, & Lamura, 2011). In Southern European countries, foreign-born workers often consist of unskilled, mainly live-in domestic workers, primarily women, who are often employed by families in a grey economy characterised by illegal immigration and/or work status. In Northern European countries, they are more likely to consist of long-settled migrants who are employed by formal care service providers (Di Rosa et al., 2011).

United States and Canada

Throughout the 1960s and 1970s in the US and Canada, community-based programs and rehabilitation services were based on the so called ‘continuum model’ (Hutchinson, Lord, & Salisbury, 2006). This provided a range of services from the most restrictive, such as a large residential care home, to the least restrictive, such as a supported independent living apartment (Hutchinson, et al., 2006). The assumption behind this approach was that “people would be able to progress through the continuum relatively quickly and that no one would get ‘stuck’ at the more restrictive end” (Hutchinson, et al., 2006, p. 49). Key characteristics of the traditional community service delivery system included: ”funding for disability supports was available only to agencies and not directly to individuals; services were provided in congregate settings, rather than being individualised; the development of supports was typically professionally driven; many community services were rehabilitation-oriented and played a major role in people’s lives; services were usually poorly coordinated, and duplication, misutilisation, or gaps in services were common” (Hutchinson, et al., 2006, p. 50).

In the early 1980s, in disability services, consumer/user movements of people with disability drew attention to the limitations of the continuum model and the rehabilitation approach as foundations for the provision of disability support. Many people became isolated and trapped at the ‘restrictive end of the continuum’, with little community engagement and few prospects for independent living (Hutchinson, et al., 2006, p. 49).

It is in this context that individualised planning and direct funding became a core component of a new paradigm of disability supports in the US and Canada, which Hutchinson et al. (2006, p. 50) describe “as a move from service and placement towards capacity building and participation”. Such

a paradigm shift and policy change was driven primarily by local initiatives and state/provincial projects. Hutchinson et al. (2006) point out that, unlike Britain, in North America there has not been a national policy direction or national legislation to enable people to access direct payments. This lack of a federal policy framework has affected the extent to which direct payments could develop and flourish in the United States and Canada (Hutchinson, et al., 2006, p. 52). As a consequence, only a few states or provinces have put in place direct funding policies or systems. Despite some success among the pilot self-determination projects funded in 19 US states in the 1990s, few states have developed more comprehensive approaches to direct funding based on these pilots. Similarly, despite some positive features, the individualised funding reform introduced by the Canadian province of Alberta in 1995 had limited results, primarily because "there was no infrastructure support for person-centred planning and facilitation" (Hutchinson, et al., 2006, p. 52).

For Hutchinson et al. (2006) and Lord and Hutchison (2003), there are four key issues in the transformation of services that is underway in North America. First, they identify the importance of values and principles to the success of direct payments. These include commitment to self-determination and community participation, with people with disability supports viewed as citizens with the same rights as others. Second, they describe the importance of policy frameworks to guide planning and implementation of funding initiatives. Policy frameworks entail building mechanisms to strengthen choice and control for consumers, developing social networks with individuals and families and expanding community connections (Lord & Hutchison, 2003). Third, they stress that the planning support for individuals and families should be independent from the service provision itself. Hutchinson et al. (2006) and Lord and Hutchison (2003) stress that independent planning support is not just about allocating cash. Hutchinson et al. (2006) discuss three main US case studies and emphasise how these show that the introduction of new planning and capacity building roles take time to get used to for both families and service providers. Families have traditionally experienced compliance and clienthood, and need time to learn how to best interact with independent planners and facilitators who act in very different ways to traditional service providers. Independent planners and facilitators aim to help people with disability to begin "to create a real life beyond services in the community" (Hutchinson, et al., 2006, p. 58) by "listening, assisting individuals to dream and express their own voice, supporting familiy involvement, and being skillful about planning and implementation of those dreams and goals" (p. 58). Finally, in the future development of direct payments in these countries, Hutchinson et al. (2006) and Lord and Hutchison (2003) draw attention to the challenge of building larger service systems that reflect the values and principles delivered by states and provinces.

As in the disability sector, CDC projects for older people have increased in the US in response to the ageing population and the declining availability of informal carers in the community (Simon-Rusinowitz, et al., 2010). In their study of the impact of CDC markets on the 'carer workforce', Simon-Rusinowitz et al. (2010) argue that consumer directed markets can expand the carer workforce by including sources of labour unavailable to agencies, such as relatives, friends, and unaffiliated workers, that is, directly hired personal assistance workers who are not employed through an agency and are not family members or close friends. Simon-Rusinowitz et al. (2010) found that while unaffiliated workers earned higher wages than their peers, they were less satisfied with these wages and benefits than other directly hired workers. Simon-Rusinowitz et al. (2010) conclude that in order to inform worker recruitment and retention strategies and expand the supply

of direct care workers in a consumer directed setting, it is important to understand the experiences and needs of unaffiliated workers.

Indeed, research in the US has found that in the case of the *Cash and Counselling Demonstration and Evaluation*, a pilot CDC program in three states which provided the option for participants to pay family members or acquaintences for care and support, participants frequently hired relatives and acquaintances (Keigher, 2007). Some research, however, has raised potential difficulties associated with this, such as the professionalism and training of family members, and possible difficulties resolving client-care provider conflicts (Keigher, 2007). Thus, the potential to use personal budgets to hire family members (inlcuding people who were previously in an informal caring role) has a range of potential implications for carers, participants and services.

4.2 What are the implications for respite?

The international evidence suggests that the shift to CDC markets in disability and aged care can have several important implications for service delivery in these sectors and for the outcomes for participants and carers. Despite the relative lack of research that explores the impact of this shift for respite specifically, these findings about implications for services more generally point to some important implications for respite.

International evidence suggests that the shift to CDC markets can give both participants and carers a greater say in how their needs are met (Glendinning et al., 2009) and can improve outcomes for all groups: people with disability, older people and carers (Mitchell et al., 2014; Caldwell and Heller, 2003). In the UK, for example, participants and carers reported positive outcomes associated with personal budgets (participants with disability experienced greater satisfaction with direct payments than older people). Many carers reported positive outcomes for their personal wellbeing and for the sustainability of the care relationship, but were mixed in their views on whether direct budgets improved the extent to which they could pursue and meet their own needs, such as participating in social activities, engaging in work, and having a sense of control over their lives (Hatton & Waters, 2011).

Internationally, organisations delivering services to participants and carers have faced challenges in meeting the needs of all groups in CDC markets. In the UK and some US states, the shift towards CDC for people with disability and frail older people has more recently been accompanied by a shift towards individualised budgets for families and carers (Caldwell, 2007; Seddon and Robinson, 2001). Organisations providing these services must now reconcile different forms of individual budgets to meet the service needs of participants and their families.

In the UK, CDC markets that focus on the needs of participants and carer assessments that focus on the needs of carers have emerged and operate separately at the policy level. This has created challenges for organisations working in the sector and ‘tensions for practitioners in identifying and responding to the separate needs’ of the two groups (Mitchell et al., 2014: 5). Evidence in the UK suggests that organisations have grappled with the extent to which a carer’s needs are taken into consideration in the assessment of the needs of the participant. The lack of clear policy and practice guidelines means that there is great variation in how this is done with varying outcomes for carers (Mitchell et al., 2014). Some organisations in the UK manage different funding sources in complex ways in attempts to meet the service needs of both the participant and the carer and experiment with ways in which breaks for both parties can be funded from different revenue

streams (Glendinning et al., 2009). Some have recommended that outputs and outcomes could be improved by coordinating the assessment of the needs of participants and carers in planning support (Mitchell et al., 2014). Indeed, in some instances, this has taken place in the US where some research points to the proliferation of consumer directed family support programs that assess the needs of *all* members of the family at once, suggesting that these have resulted in positive outcomes for both participants and carers (Productivity Commission, 2011).

CDC markets, and the focus on person-centred care that underpins them, therefore raise issues about how we conceptualise what has traditionally been called respite, and how respite is funded and delivered. CDC markets prioritise the goals and preferences of service users, or participants, and when 'participant' is understood to mean the person with disability (or the older person in the context of aged care services), the challenge arises in continuing to recognise and meet the needs and preferences of the carer (Mitchell et al., 2014).

International evidence also suggests that the introduction of a CDC model in disability and aged care can have an impact on the services that are available to participants. The model can limit what service providers are willing to offer in a flexible market – particularly more resource-intensive services (such as day centres) or services with niche demand – limiting the choice of services available to some participants. It can also shape the nature of the services that people choose to buy. For example, research in the UK found that direct budget holders were more likely to spend their budgets on personal care than social or leisure activities (Moran et al., 2013), which has potential implications for participants, carers, and service providers. For example, a shift in service expenditure away from social or leisure activities may have implications for the nature of, demand for, and therefore viability of respite services.

Finally, international evidence suggests that the introduction of the option of paying relatives, acquaintances or 'unaffiliated workers' (see above) for providing care has the potential to create a more flexible care workforce. However, it also has potential issues for participants and carers in the context of family and job market relationships. In particular, the possibility of paying relatives and hiring unaffiliated workers to deliver care raises important policy questions in relation to employment regulations. These include worker recruitment and retention strategies, quality controls and monitoring of the services purchased with the cash entitlements, and cost coverage, that is, the proportion of the costs of care which are covered by the cash-for-care payment and by families. The literature shows that in some European countries, often unaffiliated workers consist of unskilled migrant workers who tend to be hired at low cost and operate in a grey economy characterised by lack of controls and illegal work or immigration status. Although Australia has different migration policies and patterns, the issue of quality control and monitoring of care workers in an expanded and more flexible care workforce requires attention. Similarly, while paying family members is discouraged in the NDIS except in particular circumstances, this option does have potential implications for respite services. For example, the assumption underpinning the NDIS is that the scheme will reduce many carers' responsibilities, providing a respite effect, and this assumption is complicated considerably by the possibility of a participant paying a family carer.

4.3 Policy and stakeholder analysis

This section draws on the consultations with the project's Service Leadership Group, the review of legislation and policy documents associated with the policy changes, position papers and submissions by relevant stakeholders in order to identify further possible implications of the recent policy reforms for respite in Australia. Whereas the previous section focused on the broad implications for disability and aged care services resulting from the shift to CDC markets, and on what *has happened* in the international context, this section focuses more specifically on the Australian policy reform processes currently being phased in, and their *potential implications for respite* in the Australian context.

The policy and stakeholder analysis suggests that the changes to disability, aged care, and carer support services through the NDIS and the CHSP have implications for the way in which respite is conceived and provided in Australia, including:

- changes to the *conceptualisation* of respite services
- changes to the *organisation and delivery* of respite services

4.4 Conceptualisation of respite services

The shift towards consumer directed care in the NDIS and CHSP has the potential to alter the way that respite is conceived in Australia. This has two elements; it has the potential to change both the *principles underpinning* the provision of respite outputs and outcomes, and the way that respite is *described and discussed*.

Principles underpinning the provision of respite services

Like other models of personalised support or CDC that are in operation in Australia and internationally, the focus of the NDIS and to a lesser extent the CHSP, is on identifying and meeting the needs of the consumer, where the 'consumer' is defined as the person with disability or the older person. This is not to say that families and carers are excluded entirely from this model. To the contrary, the NDIS and the CHSP, like the schemes in the UK, Canada and other countries, recognise the important role of families and carers. The NDIS in particular as well as the CHSP recognise the important role of carers in the support of people requiring care, and the need for carers to be involved in identifying and meeting the needs of that person. However, the focus of both schemes on meeting the needs of the '*consumer'* (hereafter, the 'participant') means that neither provides a process of identifying and meeting the needs of the *carer*. References to the provision of support to carers exist only insofar as the support improves the care that they can provide to participants (i.e. training for the carer in managing the participant's specific condition in the NDIS) or the support that sustains the care relationship, rather than on carers' needs in their own right. This focus means that, where respite is provided through the funding for either of these programs, the principles underpinning it are likely to differ from what has traditionally included a strong focus on the importance of meeting carers' needs in their own right.

This principle has informed the proposed outputs and outcomes frameworks of the two major policy reform processes. Table 2 below sets out the proposed outputs and outcomes of the two schemes. The framework of the CHSP, which has the 'care relationship' as a key outcome, has significantly greater potential to meet the needs of carers.

Table 2 Conceptualising respite outcomes and outputs in the new policy landscape

NDIS outputs	NDIS outcomes	CHSP outputs	CHSP outcomes
Support services relating to:	Participating in learning and education (for the participant)	Domestic assistance	Assistance at home
Health	Workforce participation (for the participant)	Personal care	Social participation
Mental Health	Independent living (for the participant)	Home maintenance	Care relationships
Early childhood development	Health and wellbeing (of the participant)	Social support	Increased independence
Child protection and family support		Centre-based day care	Nutrition
School education		Flexible respite	Access to the community
Higher education and vocational education and training		Cottage respite	Sector support and development
Employment		Emergency and short term respite	
Housing and community infrastructure		Nursing	
Transport		Allied health and therapy	
Justice		Home modification	
		Goods and equipment	
		Food services	
		Meals	
		Transport	

Table 2 developed by the report authors with material drawn from publicly available policy documents

As is evident in Table 2, in the NDIS, the original focus of the outcomes was entirely on the outcomes for the participant. The outcomes included (assisting participants to) *participate in learning and education*, *participate in the workforce*, *achieve independent living*, and *improve health and wellbeing*. Respite for the *participant* could contribute to achieving these outcomes and may therefore be funded under the NDIS. In a speech at the National Carer Conference in November 2014, NDIA Chairman Bruce Bonyhady announced an outcomes framework for the NDIS that includes a series of five outcomes for families and carers: families/carers have the support they need to care; families and carers know their rights and advocate effectively for the person they are caring for; families and carers are able to gain access to desired services, programs and activities in their communities; families and carers have succession plans; parents

and carers enjoy health and well-being. However, within the outcomes framework of the NDIS, at this stage, there is only scope to provide respite to *families and carers* insofar as it improves the four outcomes for participants. The prospect of respite being provided to families and carers to meet their own needs is very limited. Turning to the list of NDIS outputs in Table 2, the only category in which the stipulations allow for the potential for respite to be provided to families and carers is the output type 'child protection and family services'. According to the *NDIS Supports for Participants* rules:

> The NDIS will be responsible for: supports for children, families and carers, required as a direct result of the child's disability, that enable families and carers to sustainably maintain their caring role, including community participation, therapeutic and behavioural supports and additional respite and aids and equipment (p 16).

In making a decision about whether a service can be funded under this stipulation, CEOs of services must take into account "the desirability of supporting and developing the potential contributions of informal supports and networks within the community" (NDIS Supports for Participants p. 9) They must also consider, for a participant who is a child: "That it is normal for parents to provide substantial care and support for children" and "the extent of any risks to the wellbeing of the participant's family members or carer or carers" (NDIS Supports for Participants p. 9). Hence, the guidelines suggest weighing up what is reasonable to expect the family to provide in terms of care and support and the extent to which the wellbeing of the family members is at risk. For participants who are not children, CEOs must consider: any risk to the participant arising from reliance on carers or family members; the 'suitability' of carers or family members to provide the required care, including the age and capacities of the carer and other family members; the intensity of support required and the extent of risk to the wellbeing of any family members (NDIS Supports for Participants p. 9). The extent to which respite can be made available to family members under these conditions is therefore unclear. It appears limited and based on a number of discretionary decisions of service providers and is therefore in need of further exploration.

Turning to the outputs and outcomes of the CHSP, the outputs resemble more closely respite as it is traditionally conceived. There is significantly more scope in the CHSP than in the NDIS for the provision of respite services to carers. For example, the outcome 'care relationships' in the CHSP explicitly includes funding for 'flexible respite (incorporating in home day, in home night, host home day, host home night, individual community access and mobile respite), emergency respite, and cottage respite' and the outcome 'social participation' explicitly encompasses respite for 'centre-based day respite, residential day respite and group community access respite' (DSS, 2014). However, the outcomes framework in the CHSP is nonetheless focused on the outcomes for the participant and the care relationship and does not include specific outcomes for the carer.

At this stage, there is no separate process in Australia for identifying and addressing the specific needs of carers. A number of stakeholders have called for a carer assessment process of the kind that exists in the UK as an important concurrent process to the NDIS and CHSP, alongside a separate suite of carer support services (Carers NSW, 2014; National Respite, 2014; Anglicare, 2014; Carers Australia, 2013; ARAFMI, 2014). In the guidelines for carers' support under the NDIS, carers' goals and aspirations are recognised, for example to go back to education or employment. However, there is no formal assessment process (Consumer Reference Group).

Describing respite: A consequence of the new outputs and outcomes frameworks may be a change in the way that respite is described and discussed by governments, service providers, participants and carers. Moreover, the language used when describing respite may need to change in order to fit within the new output and outcomes categories. In the case of the NDIS, it is possible that the term 'respite' may disappear from the service vocabulary entirely. For example, according to the NDIS Guidelines on Pricing and Payment of Supports:

> The names of the supports used under the NDIS aim to better reflect the participant's experience of receiving the support and be clearer about what is included in a participant's plan. Some supports on the list may have been renamed to be more participant centred.
>
> For example, the term respite is not used in the NDIS list, but many supports for participants will have a flow on effect of providing participants' families and carers with time away from caring. These activities may include activities in the 'assistance with daily life tasks in a group or shared living arrangement', or 'participation in community, social and civic activities' (NDIS website).

These sentiments that are built into the NDIS are likely to have a flow-on effect on the way in which services describe their respite products to their clients. For example, some services already refrain from using the word respite to describe their respite outputs and some are considering new ways of framing and marketing what they traditionally called respite (Service Leadership Group Roundtables 1, 2 and Consumer Reference Group).

There is some concern that changing the language used to describe respite so that it fits into outcomes categories like 'social participation' will shift the focus to a respite effect for carers rather than respite in itself (Service Leadership Group Roundtable 1). Moreover, support for the person with disability that involves the participation by the person in social or community activities may provide the carer with a break from their caring responsibilities, having a 'respite effect', but this does not mean that it is meeting the needs of the carer (Carers NSW, 2014). According to the literature review above, for respite to be most effective for carers, it needs to be at a time and under circumstances that suit them (Arksey et al., 2004), rather than being an incidental consequence of the participation of the person they care for in other activities. According to Carers NSW, in an issues paper on the trial of the NDIS, a service that provides a 'respite effect' is a valuable service but is not the same as respite (Carers NSW, 2014).

In the CHSP, the term respite is much more heavily embedded into the policy language concerning the introduction and implementation of the scheme and is therefore likely to continue to be an operational term. In the CHSP, the changes to the nature of respite are more likely to be in the form of alterations to the way it is organised and delivered rather than the way in which it is conceived and described.

The organisation and delivery of respite services

The shift towards CDC in the NDIS and CHSP has the potential to alter the way that respite is organised and delivered in Australia. This has two elements; it has the potential to change *who* has access to respite in Australia, and the *type of services* to which they have access.

Who has access: Prior to the recent reform processes that have involved a shift to CDC, respite services to people with disability, older people and carers were provided through a number of

programs at the state and Commonwealth levels. State governments funded respite services for people with disability and their carers as part of a suite of disability services. The jointly state- and Commonwealth-funded Home and Community Care Program provided respite services for older people and their carers; the Commonwealth-funded National Respite for Carers Program (NRCP) provided respite to carers both of people with disability and older people, and a range of other smaller programs at the state and Commonwealth levels provided respite to specific groups of participants and carers. Such programs included young carers respite and information services, mental health respite carer support, and emergency respite, which are currently accessed through the Commonwealth Respite and Carelink Centres.

The changes under the NDIS and CHSP will alter who is entitled to respite under which funding stream, and who may have access to respite in the future. The main changes that will affect which groups are entitled to receive respite include the following:

- Supports under the NDIS are only available to people with a *permanent and significant disability* and their families and carers, and supports to families and carers are limited to those that ultimately meet the needs of the participant (or person with disability).
- The HACC and NRCP programs have been rolled into the CHSP, which means that only people *aged 65 and over* (or Aboriginal and Torres Strait Islander peoples aged 50 and over) and their carers are entitled to receive supports under these schemes.
- The CHSP only provides services to older people with *basic* needs and their carers; the intention is that older people in need of more intensive support will receive care through community aged care packages or in residential aged care facilities.
- It is not yet clear what will happen to the disability services currently provided by the states, but it appears likely that many states will roll their state funding for these services into the NDIS.

This has a number of implications for who is entitled to receive respite, with particular implications for several groups.

Older people with 'basic' or low level needs and their carers will receive support under the Commonwealth Home Support Program, including access to respite services under the scheme. Older people with higher care needs who receive a community aged care package, and their carers, should continue to receive respite within their funded package. However, there are several groups of older people and their carers who may miss out on the respite services that they need. First, there are some higher needs older people who are eligible for a community aged care package but for whom a package is not available due to the short supply of packages (National Respite, 2014). These older people and their carers may not have access to respite through either the CHSP or a package. There are also a number of older people with high care needs and their carers who choose not to apply for a package and who choose instead to rely on services through the NRCP. Due to their high care needs, these people (and their carers) will become ineligible for support through the NRCP, now part of the CHSP, and must apply for a package in order to receive support, including respite (Carers Australia, 2013). Some older people with higher needs will have access to care packages and as a consequence, their carers may have access to respite as part of the package. However, these carers will be ineligible for respite provided under the CHSP (because the older person must be eligible for support under the CHSP in order for the

carer to be eligible). This means that if the respite they receive as part of the package does not meet their needs, they will no longer be able to supplement this respite with the more flexible and diverse respite options available under the NRCP (Carers Australia, 2013). Because the entitlement of the carer to support is dependent on the assessed need and entitlement of the older person, carers of older people who choose not to access any aged care services will not be eligible for respite under the CHSP or a care package.

Hence, the CHSP will offer respite to many older people and their carers. However, rolling the HACC and NRCP into the CHSP has meant that these two programs, which used to offer respite to people of all ages and their carers, are now only available to people aged 65 and over. People with a disability or chronic illness under the age of 65 – and their carers – are no longer eligible for respite under these schemes. This creates significant implications for the respite options available to people with disability or chronic illness under the age of 65 and their carers.

Some people with disability will be entitled to support under the NDIS and this may include access to respite, although the 'respite' they receive may be conceived differently and the term 'respite' not used. However, the respite options available to *carers* under the NDIS are limited, as carer-specific support is provided only insofar as it sustains the informal care arrangements for the participant and are not provided to the carer in their own right (Carers NSW, 2014).

In addition, support under the NDIS is only available to people with a *permanent and significant disability* and their families and carers. It is estimated that NDIS-funded support will be available to around 460,000 Australians but this is estimated at only 10 per cent of Australians with a reported disability, leaving most people with disability without access to an individual disability package, including respite, under the NDIS (Carers NSW, 2014). There is also a group of people with chronic illnesses and palliative care needs who will not be eligible for support, including respite, under the NDIS (Carers Australia, 2013). This leaves a large group of people with disability, chronic illness, or palliative care needs under the age of 65, *and their carers*, without access to respite either through the NDIS, HACC or the NRCP. This includes people who had previously been assessed as eligible for support through the NRCP, who receive respite through the program and who will as of July 2015 no longer be eligible (Anglicare, 2014).

It is still unclear whether the needs of these groups excluded from receiving services under the NDIS and CHSP will have access to support through state disability services. However, it seems likely that the funding for state disability services in most states will be rolled into the NDIS by the time it is fully rolled out in 2018, so the future of respite for this large group of Australians is unclear (Anglicare, 2014).

There are also concerns about the extent to which a person's geographical location will affect their access to respite under the new schemes. Several stakeholders have expressed concern that in a competitive consumer directed market, the continued provision of adequate services, including respite, in regional and remote areas will become difficult (NACA, 2013; Service Leadership Group Roundtable 1 and Consumer Reference Group). Several stakeholders have recommended maintaining block funding for services in regional and remote areas in order to ensure that services in these areas remain strong (NACA, 2013; NDS, 2014).

Type of services: In addition to raising questions about the capacity of the new policy context to meet the respite needs of all groups of consumers, the raft of policy changes also raises some

possible implications for the *nature* of the services that are available and delivered. This includes possible effects on the type of respite service, the location and activities involved, and the amount of respite available. The policy and stakeholder analysis suggests that the shift from block to individualised funding in particular may have an impact on the nature of the respite services available. First, the change may affect the viability of respite services with high infrastructure and capital costs, such as centre-based care (NACA, 2013; Service Leadership Group Roundtable 2 and Consumer Reference Group) and the provision of transport to support respite. This was particularly important in rural and remote areas where services provided transport for staff who may have to travel long distances and for participants. The change may also affect respite that involves service provider organised family support by volunteers. In the new individualised funding model, the sources of capital available to services to cultivate and coordinate these volunteer-run supports, including host family respite, for example, will be lost and supports of this kind may no longer be sustainable (NDS, 2014; Service Leadership Group Roundtable 1 and Consumer Reference Group). There are also concerns that the shift to a consumer directed market in care service may make some services for which there is little demand unsustainable. This includes highly specialised respite services on which a small number of people are reliant (NACA, 2013; NDS, 2014). At the more general level, as in the international experience, participants may choose to spend their budgets on services other than direct respite (Service Leadership Group Roundtable 1, 2, and Consumer Reference Group), which may have implications for the demand and therefore sustainability of respite services. Finally, the policy changes are likely to have an impact on the number of hours of respite available to participants and their families. According to the NDIS Operational Guidelines, there is a restriction placed on the number of respite hours that can be provided, with the greatest number available in the case of participants with high needs capped at the equivalent of 28 days (NDIS Operational Guidelines, 2014).

Hence, the changes to disability, aged care, and carer support services through the NDIS and the CHSP have implications for the way in which respite is conceived and provided in Australia, including the principles underpinning respite, the way in which it is discursively framed, and the ways that it is organised and delivered. This is likely to create significant changes in respite outputs, most particularly, on who is able to access respite services and on the type of respite service that is available to them. The changes to respite *outputs* have the potential to have considerable implications for respite *outcomes*, particularly among some groups of Australians. These potential changes are mapped out alongside the respite outputs in the framework in Table 3 below.

Notably, Table 3 does not include the potential changes to the support labour force resulting from the reform processes, as the service framework does not include the character or composition of the labour force as an ‘output’. However, these important potential changes to the labour force will be captured as an *outcome* of the reform processes in the next stage of the project.

Table 3 Changes to respite output categories under the NDIS and CHSP reforms

Respite outputs	Possible changes
Location In home Centre-based Host-family home Community-based (i.e. recreational locations) Therapeutic/health-based location (i.e. specialist offices, hospital)	May be a challenge to the sustainability of services with: • high capital expenditure • specialised functions • involvement of volunteers
Activities Therapeutic Social Recreational Family-based activities Personal care	May have an impact on the types of activities that participants choose to spend their budgets on - may select more personal care and less social and recreational
Quantity and timing Number of hours Time of day/week (day, overnight, weekend) Available at short notice (i.e. emergency, flexible)	May limit the number of hours of respite that can be funded in an NDIS package
Reach Participants under 65 years Participants over 65 years Carers of people under 65 years Carers of people over 65 years	May limit access to respite for: Older people with high level care needs, and their carers Carers of people with disability who receive services under the NDIS People with disability, chronic or mental illness, or palliative care needs who are under 65 years and not receiving services under the NDIS, and their carers
Region Metropolitan Outer metropolitan Regional Remote	May create difficulties for viability and range of services in regional and remote areas
Transport	May reduce accessibility to respite care by people living in rural and remote areas where services currently provide transport as part of the service

5. Service mapping

Main points

- An estimated 312,539 people with disability accessed disability support services in 2012–13 in Australia of which about 12% (38,072) received respite services.
- People with intellectual and learning disability were more likely to use respite services (18 per cent) compared to people with other types of disability.
- Between 2008/09 and 2012–13, respite services increased by 8 per cent.
- In 2012/13, the majority of the service outlets (54 per cent, n=884) consisted of flexible respite services, followed by centre-based respite/respite homes (29 per cent, n=476), own home respite (10 per cent, n=169), other respite (4 per cent, n=64) and host family/peer support respite (2 per cent, n=37).
- Expenditure on disability support services, adjusted for inflation, has increased by 4 per cent from 2011/12 to 2012/13, and by 23 per cent since 2008/09.
- Between 2011/12 and 2012/13, expenditure for respite services increased at about double the rate of other disability support services: an 8 per cent increase for respite compared to a 4 per cent increase for all disability support services.
- The combined level of fully unmet and partly met need is similar across states; however, some states and territories have a higher number of service users per outlets than others, e.g. Victoria, suggesting a risk for a potential shortage of services, particularly in light of the constant increase in the number of users of respite services in Australia.
- In 2012/13, 93 per cent of service users of respite services reported having an informal carer compared to other service users. Users of respite services (85 per cent) and community support (84 per cent) were more likely to have a co-resident carer than users of other service groups.
- Admissions for permanent and respite residents over a year are of similar magnitude: between 1 July 2010 and 30 June 2011, there were 58,172 persons admitted to permanent residential care and more than 43,533 admitted to respite care.
- Most primary carers (89.1 per cent; the person who provides the most ongoing care for the person with disability) never used respite care (2012 Survey of Disability and Carers, SDAC, 2012).
- Most primary carers (54.8 per cent) reported that they did not use respite because they did not need it (SDAC, 2012). However, 10.5 per cent of primary carers who did not use respite reported that they needed it.
- Reasons for not using respite included: the care recipient did not want to use respite (10.7 per cent), the carer was unaware of the available services (8.5 per cent), the carer did not want it (7.2 per cent), and the services were unavailable, unsuitable or unaffordable (3.6 per cent). This finding requires further exploration, given that research with carers consistently suggests that they would like more opportunities to participate in employment or social activities.
- Respite or time-out is the third most used form of coping strategy among informal carers according to the Carers NSW 2012 Carer Survey.

The final part of the report is a synthesis of the main outputs and trends in the use of respite services in disability support services, aged care services and among informal carers in Australia. Its purpose is to provide a service baseline for understanding the potential impacts of changes to respite provision. It presents a synthesis of the main outputs and trends in the use of respite services in disability support services, aged care services and among informal carers. It is organised in three main sections: disability services, aged care services and informal carers. It draws on six sources:

- Disability Services National Minimum Data Set (DS NMDS), which collected data on disability support services provided under the National Disability Agreement (NDA) in 2012–13.
- Survey of Disability, Ageing and Carers (SDAC) 2012, which is the seventh comprehensive national survey conducted by the Australian Bureau of Statistics (ABS, 2013) to measure disability.
- Home and Community Care Minimum Data Set (HACC MDS), which collects data on clients that received HACC services.
- Australian Government *Report on Government Services* (2014) (Aged Care Services)
- Australian Institute of Health and Welfare *Residential aged care in Australia 2010–11: A statistical overview* (2012)
- Carers NSW 2012 Carer Survey

4.5 Disability services

An estimated 312,539 people with disability accessed disability support services in 2012/13 in Australia (AIHW, 2014c) of which about 12 per cent (38,072) received respite[4] services (Table 4[5]). Overall, in Australia, there was a general increase in the number of service users between 2008/09 and 2012/13: by 12 per cent respectively for all services and by 8 per cent for state and territory services; respite services increased by 8 per cent. Nevertheless between 2011/12 and 2012/13 there was a general trend towards a slight decrease in the number of serve users– respectively by ~2 per cent for all services and ~1 per cent for state and territory services (Table 9), Unlike this national trend, between 2011/12 and 2012/13 users of respite services increased by 3 per cent.

Table 5 shows that people with intellectual and learning disabilities were more likely to use respite services (18 per cent) compared to people with other types of disability. People with disability may require support to perform activities in different areas of their lives (‘life area’ activities). Most service users required at least some assistance in one or more of the three broad life areas

[4] Respite is here defined as “services that provide a short-term and time-limited break for families and other voluntary care-givers of people with disability, to assist in supporting and maintaining the primary care-giving relationship, while providing a positive experience for the person with disability” (AIHW, 2014c, p. 3). See Appendix A for a definition of types of respite services.

[5] Tables report the trends in use of respite services in comparison with the total number of state- and territory- delivered services (which include respite, accommodation support services, community support services and community access services) and the grand total of state and territory services plus the Australian Government delivered employment services.

identified in the Disability Services National Minimum Data Set (DS NMDS), which includes three main categories that group nine data items on some of the functional needs of service users across these life areas, which are grouped into three main categories: 'activities of daily living' (ADL), 'activities of independent living' (AIL) and 'activities of work, education and community living' (AWEC).: the activities of daily living (55 per cent); the activities of independent living (64 per cent); and the activities of work, education and community living (61 per cent). Users of respite services were the most likely to 'always' or 'sometimes' need assistance to perform activities in all three broad life areas comparatively to users of accommodation support, community support, community access and employment services, which entails a high level of dependency.

Table 15 shows that the combined level of fully unmet and partly met need[6] is similar across states; however, some states and territories, such as for example Victoria[7], have a higher number of service users per outlets than others, suggesting a risk for a potential shortage of services, particularly in light of the constant increase in the number of users of respite services in Australia (Table 9). Table 14 shows that Tasmania has a slightly higher fully unmet need for all persons with a disability compared to the other states and territories, whereas Queensland and Western Australia have a slightly higher unmet need for people aged 65 and over.

In 2012/13, respite services were delivered by 1,630 respite service outlets[8], with an average of 23.4 service users per respite service outlet in the 7-day reference week preceding the end of the reporting period in 2012/13 (Table 13). The majority of the service outlets (54 per cent, n=884) consisted of flexible respite services, followed by centre-based respite/respite homes (29 per cent, n=476), own home respite (10 per cent, n=169), other respite (4 per cent, n=64) and host family/peer support respite (2 per cent, n=37) (see Table 6 and Appendix A for a definition of types of respite). Table 6 shows the number of respite service outlets by state and territory, and Table 7 shows their geographical distribution. Table 8 shows that an estimated total of 498,403 hours of respite services were delivered in 2012/13. Table 13 shows that there was a mean of 97.5 paid staff hours and a mean of 8.8 unpaid staff hours per outlet in the reference week, with an average 0.1 full-time equivalent staff per user[9].

[6] Calculated as the sum of needs partly met and needs not met at all (see Table 14 for a breakdown of the extent to which needs are met for all persons with a reported disability by state).

[7] The higher number of service users per outlets in Victoria might be related to the fact that there was a change in service type classification, whereby an activity previously classified under 'community access' was amalgamated under 'community support' from 2012–13 onwards.

[8] A service type outlet is the unit of the funded agency that delivers a particular NDA service type at or from a discrete location. For example, if a funded agency provides both accommodation support and respite services, it is counted as two service type outlets.

[9] FTE staff numbers are based on a 38-hour working week.

Table 4 Number of respite service users by state and territory, 2012/13

Service	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	%
Own home respite	9	1,114	789	435	473	69	12	4	**2,905**	**10**
Centre-based respite/ respite homes	3,999	4,890	2,606	1,181	1,005	234	210	93	**14,197**	**29**
Host family/peer support respite	279	1,160	75	—	102	6	—	40	**1,662**	**2**
Flexible respite	7,931	11,017	2,555	2,260	369	198	141	131	**24,581**	**54**
Other respite	—	688	400	338	296	—	—	1	**1,723**	**4**
Total respite	**10,580**	**16,042**	**5,041**	**3,549**	**1,876**	**471**	**327**	**250**	**38,072**	**100**
Total state/ territory services	*53,128*	*72,170*	*27,583*	*17,187*	*18,386*	*6,547*	*4,673*	*2,757*	***201,675***	
Total services	**91,802**	**98,948**	**51,289**	**24,857**	**29,055**	**9,166**	**6,187**	**3,244**	**312,539**	

Notes. The column and row totals do not tally because people can use services in more than one state over the year.

Table 5 Percentage of respite service users by primary disability group, 2012/13

Disability group	Per cent using respite services
Intellectual/ learning	18.2
Physical/ diverse	9.5
Sensory / Speech	3.2
Psychiatric	4.7
All service users	12.2

Notes. Adapted from Table 7.1 in (AIHW, 2014c, p. 21). 'Intellectual/learning' includes the categories of 'intellectual', 'specific learning/attention deficit disorder', 'autism', and 'developmental delay'; 'physical/diverse' includes the categories of 'physical', 'acquired brain injury', and 'neurological'; 'sensory/speech' includes the categories of 'deaf-blind', 'vision', 'hearing' and 'speech'.

Table 6 Number of respite service outlets by state and territory 2012/13.

Service type	NSW	Vic(a)	Qld	WA	SA	Tas	ACT	NT(b)	Total
Own home respite	2	28	59	39	30	5	2	4	169 (10)
Centre-based respite/respite homes	117	106	123	30	73	9	8	10	476 (29)
Host family/peer support respite	11	10	7	—	6	1	—	2	37 (2)
Flexible respite	445	166	110	88	36	24	5	10	884 (54)
Other respite	—	8	18	13	24	—	—	1	64 (4)
Total respite	**575 (35)**	**318 (20)**	**317 (19)**	**170 (10)**	**169 (10)**	**39 (2)**	**15 (1)**	**27 (2)**	**1630 (100)**

Note. Adapted from Table B4 in (AIHW, 2014b, p. 13). Percentage in parenthesis.

Table 7 Respite services by remoteness area, Australia, 2012/13

	Major cities		Inner regional		Outer regional		Remote		Very remote		Not known		Total	
Service group	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Respite	885	54.3	478	29.4	202	12.4	46	2.8	18	1.1	1	—	1,630	100
Total	**9,529**	**60.9**	**4,067**	**26**	**1,665**	**10.6**	**248**	**1.6**	**147**	**1.6**	**4**	**1.6**	**15,659**	**100**

Note. Adapted from Table B8 in (AIHW, 2014b, p. 18)

Table 8 Estimated number of hours in each type of respite

Type of respite services	Total number of users in Australia in 2012/13[1]	Estimated total number of hours in a week[2]
Own home respite	2,904	38,042
Centre-based respite/ respite homes	14,196	185,968
Host family/peer support respite	1,662	21,772
Flexible respite	24,560	321,736
Other respite	1,720	22,532
Total respite	**38,046**	**498,403**

Notes. [1] Created using information from Table B37 AIHW, 2014b, p. 58. [2] Based on 13.1 mean hours of respite services received per user in a specified week during 2012/13 (Table B26 in AIHW, 2014b, p. 44).

Table 9 Number of respite services users, 2008/09 to 2012/13

Service group	2008/09	2009–10	2010–11	2011–12	2012–13	Percentage change 2008/9 to 2012/13	Percentage change 2011/12 to 2012/13
Respite	34,331	35,978	36,266	37,015	38,072	10.9	2.9
Total state/territory services	*186,961*	*193,218*	*204,226*	*203,371*	*201,675*	*7.9*	*-0.8*
Total	**279,301**	**295,024**	**314,252**	**317,616**	**312,539**	**11.9**	**-1.6**

Notes. Adapted from Table 5.2 in AIHW, 2014c, p. 17.

In 2012/13, expenditure on disability support services was $7.2 billion, of which $6.7 billion was allocated directly to service delivery. Expenditure on disability support services, adjusted for inflation, has increased in recent years—by 4 per cent between 2011/12 and 2012/13, and by 23 per cent since 2008/09 (Table 10). Expenditure for respite services seemed to increase less compared to all disability support services between 2008-09 and 2012/13 (there was a 15 per cent increase for respite compared to a 23 per cent increase for all the disability support services). However, over the last three years (i.e. between 2011/12 and 2012/13), expenditure for respite services has increased at about double the amount (there was about an 8 per cent increase[10] for respite compared to about a 4 per cent increase for all disability support services). Similarly, average expenditure per service user has generally increased, although expenditure per service user for respite services has increased less than the national average (by 3 per cent from 2008/09 to 2012/13 as opposed to a national increase by 10 per cent; Table 10).

Table 10 Expenditure ($ million) on respite services and per service user 2008/09 to 2012/13 (constant prices in 2012/13 dollars)

Service group	2008/09	2009–10	2010–11	2011–12	2012–13	Percentage change 2008/09 to 2012/13	Percentage change 2011/12 to 2012/13
Expenditure on respite services							
Respite	372.1	392.4	386.0	394.3	424.3	14.0	7.6
All disability support services	5,817.9	6,207.0	6,419.3	6,893.5	7,151.8	22.9	3.7
Expenditure per service user							
Respite	11,575	11,703	11,369	11,329	11,911	2.9	5.1
All disability support services	19,370	19,340	18,963	19,966	21,329	10.1	6.8

Note. Extract from Table 1.2, AIHW, 2014, p. 6

On average, service users used 1.3 service groups and 1.4 service types each. The most commonly combined service groups were community support and community access, with 21,954 service users using this combination of services. This combination was used by 16 per cent of

[10] The increase by 8% between 2011-12 and 2012/13 could be related to a change in service type classification in Victoria as part of an output structure review whereby an activity previously classified under 'community access' was amalgamated under 'community support' from 2012–13 onwards.

community support users, and by 40 per cent of community access users. Other common combinations were community support with respite (20,421 service users), accommodation support with community support (20,232 service users), and accommodation support with community access (16,924 service users). Users with the highest level of need for assistance in the activities of daily living were more likely to use multiple service types and to use services across more than one service group than service users with less-frequent or no need for assistance in this life area.

In 2012/13, 136,325 (67 per cent) service users had an informal carer (AIHW, 2014c, p. 19). This was an increase of 24 per cent from the estimated 110,082 service users with an informal carer in 2008/09, and a slight decrease from the 136,794 service users with an informal carer in 2011/12. Service users of respite services were those most likely to report having an informal carer (93 per cent). Accommodation support service users were the least likely to have an informal carer (40 per cent), particularly those living in institutional accommodation (16 per cent).

Eighty two percent of service users with an informal carer had the informal carers living (co-resident) with them (AIHW, 2014c, p. 19). Users of respite services (85 per cent) and community support (84 per cent) were more likely to have a co-resident carer than were users of other service groups.

Table 11 reports the mean hours of service provided by respite services in a typical week and in the 7-day reference week preceding the end of the reporting period in 2012/13. Table 12 shows the mean number of hours of respite services received per service user.

Table 11 Mean and median hours of service provided by respite services during the 7-day reference week and preceding the end of the reporting period and a typical week, Australia, 2012/13

Service type	Number of service type outlets		Mean hours per outlet		Median hours per outlet		Mean number service users with hours received	
	Reference week	Typical week	Reference week	Typical week	Reference week	Typical week	Reference week	Typical week
Own home respite	88	102	72.2	77.6	36	38.5	14.4	-
Centre-based respite/respite homes	319	351	645.1	665.5	459	255	19.2	-
Host family/peer support respite	13	27	438.1	164.5	202	79	53.2	-
Flexible respite	489	681	193.1	251.5	63	74	18.1	-
Other respite	40	51	130.1	104.9	52.5	43	19.7	-
Total respite	949	1,212	334.5	348.6	100	93	18.7	-
All services reporting hours	**3,956**	**5,710**	**273.4**	**243.2**	**93**	**70**	**23.3**	**-**

Note. Adapted from Table B9 and B10 in (AIHW, 2014b, p. 20)

Table 12 Mean hours of respite services received per service user[1], Australia, 2008/09 to 2012/13

Service	2008/09	2009/10	2010/11	2011/12	2012/13
Respite	13.3	8.4	9.3	19.7	13.1
Total[2]	16.6	12.7	12.7	16.7	13

Notes. Adapted from Table B26 (AIHW, 2014b, p. 44)

[1] Includes service users who received zero (0) hours of support from the service type category during the reference week, but excludes service users where the number of hours of support received from the service type category during the reference week was missing.

[2] Total of the following selected service categories: Non-residential accommodation support; Case management, local coordination and development; Community access; Respite.

Table 13 Mean hours worked in the reference week by paid and unpaid staff for respite disability support service type outlets, Australia, 2012/13

Service group	Mean paid staff hours per outlets		Mean FTE(a) paid staff per outlet		Mean unpaid staff hours per outlet		Mean FTE(a) unpaid staff per outlet		Total mean FTE(a) staff per outlet		Service users(b) per outlet		Mean FTE staff per user[1]	
	Reference week	Typical week	Reference week	Typical week	Reference week	Typical week	Reference week	Typical week	Reference week	Typical week	Reference week	Typical week	Reference week	Typical week
Respite	97.5	155.4	2.6	4.1	8.8	10.6	0.2	0.3	2.8	-	23.4	-	0.1	-
All services	165.6	228.5	4.4	6.0	5.4	10.3	0.1	0.3	4.5	-	20	-	0.2	-

Note. Adapted from Table B10 and Table B11 in (AIHW, 2014b, p. 21), (a) Full-time equivalent. (b) Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. [1]FTE staff numbers are based on a 38-hour working week.

Table 14 Estimates and proportions of the extent to which needs are met for all persons with a reported disability by state

States	All persons			0-64 years			65+ years		
	Fully met	Partly met	Not met at all	Fully met	Partly met	Not met at all	Fully met	Partly met	Not met at all
NSW	484.6[1] (37.4)[2]	272.5 (21.0)	16.5 (1.3)	260.9 (33.3)	167.6 (21.4)	11.4 (1.5)	223.3 (43.8)	107.5 (21.1)	5.1[3] (1.0)
Victoria	400 (37.6)	256.2 (24.1)	15.3 (1.4)	220.2 (33.9)	151.2 (23.3)	8.3[3] (1.3)	177.4 42.9	105.8 (25.6)	6.5[3] (1.6)
Queensland	281.3 (35.3)	172.1 (21.6)	11.6 (1.5)	159.3 (31.9)	107.3 (21.5)	5.7[3] (1.1)	122.3 (41.1)	64.8 (21.8)	6.6[3] (2.2)
SA	125 (37.2)	80.6 (24.0)	4.6[3] (1.4)	72.3 (34.8)	50.1 (24.1)	1.7[3] (0.8)	51.7 (40.3)	29.7 (23.1)	1.8[3] (1.4)
WA	114.5 (31.6)	81.7 (22.5)	6.6 (1.8)	67.1 (28.8)	49.8 (21.4)	3.9[3] (1.7)	48.8 (37.5)	30.2 (23.2)	2.8[3] (2.1)
Tasmania	46.7 (39.0)	25.4 (21.2)	2.7 (2.2)	-	-	-	-	-	-
Northern Territory	6.1 (36.8)	3.2 (19.5)	0.2[3] (1.0)	-	-	-	-	-	-
ACT	21.5 (37.6)	12.9 (22.6)	0.8[3] (1.5)	-	-	-	-	-	-
Australia	147(60.7)	904(37.1)	56.4(2.3)	824.5(58.3)	552.2(39.1)	34.1(2.4)	652.9(63.7)	349.9(34.2)	21.7(2.1)

Notes. Adapted from Table 14.1 and Table 14.2 of the data cubes of the 2012 Disability, Ageing and Carers Survey (ABS, 2013).
[1] Estimates ('000). [2] Proportions (per cent). [3] Estimates have a relative standard error of 25 per cent to 50 per cent and should be used with caution.

Table 15 Distribution of service users per outlet and extent to which needs are met by state

State	Respite service users	Respite service outlets		Service user per outlet[1]	Needs partly met / not met at all
		n	per cent		
NSW	10,580	575	35	18.4	22.3
Victoria	16,042	318	20	50.4	25.5
Queensland	5,041	317	19	15.9	23.1
SA	1,876	169	10	11.1	25.4
WA	3,549	170	10	20.9	24.3
Tasmania	471	39	2	12.1	23.4
Northern Territory	250	27	2	9.3	20.5
ACT	327	15	1	21.8	24.1
Australia	**38,072**	**1630**	**100**	23.4	**39.4**

Notes. Data from Tables 4, 6 and 14. [1]Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. [1] FTE staff numbers are based on a 38-hour working week

4.6 Aged care services

The AIHW (2012) report, which offers an overview of Australian Government funded aged care, shows that, at 30 June 2011, there were 169,001 residents in mainstream residential aged care services. This is an increase of 1.6 per cent over the previous year. Of these, 165,032 (98 per cent) residents were receiving permanent care, and 3,969 (2 per cent) were receiving respite care (AIHW, 2012). However, the AIHW (2012, p. 30) report stresses that 'the total number of people accessing residential respite care over a year will be much greater than this number. Admissions for permanent and respite residents over a year are of similar magnitude'. In fact, between 1 July 2010 and 30 June 2011, there were 58,172 persons admitted to permanent residential care and more than 43,533 admitted to respite care[11] (AIHW, 2012). The majority of these residents had been living in a house or flat before admission (76 per cent of permanent residents and 84 per cent of respite residents). Around 11 per cent of permanent residents and 9 per cent of respite residents had been living in independent units, that is, a self-care, individual residence situated within a retirement village or aged care facility (AIHW, 2012).

At 30 June 2011, there was a slightly higher proportion of residents (1.2 per cent) who identified as Aboriginal and Torres Strait Islander in respite services than in permanent aged care services (0.7 per cent).

Residents receiving respite care at 30 June 2011 had a younger age profile than permanent residents, with just under half being aged 85 and over (AIHW, 2012). The proportion of older residents has been increasing over the past decade (AIHW, 2012). There was some variation in the marital status of men, with 44 per cent of men receiving permanent residential aged care being married or in a de facto relationship, compared to 58 per cent among men receiving respite care. There was no variation among women by marital status.

[11] Residents are 'admitted' each time they enter residential aged care, so if an individual leaves care for a period of time (for example, to go to hospital), then on return to care they are 'admitted' again (AIHW, 2012, p. 37).

Between 1 July 2010 and 30 June 2011, there were 118,178 admissions to residential aged care: just over 58,900 for permanent care and 59,276 for respite care (Table 14). The age distribution of permanent and respite residents was similar (AIHW, 2012). The majority (74 per cent) of residents admitted to permanent care in 2010–11 were aged 80 and over. The most common age group was 85–89, accounting for 29 per cent of permanent admissions and 28 per cent of respite admissions (AIHW, 2012).

The Report on Government Services (2014) reports that during 2012/13, 'the number of older clients (aged 65 years or over and Indigenous Australians aged 50–64 years) who received either high or low care in a residential aged care facility was 218,906 nationally for permanent care and 46,792 nationally for respite care[12]' (p. 13,19).
Respite services are also offered through:

- the HACC Program, which offers essential community care services to frail aged people and younger people with disability and their carers. The HACC Program's main objective is to promote and enhance the independence of people in these client groups. It provides basic maintenance and support services, including allied health care, assessment, case management and client care coordination, centre-based day care, counselling, support, information and advocacy, domestic assistance, home maintenance, nursing, personal care and respite care, social support, meals, home modification, linen service, goods and equipment and transport.
- the Australian Government (DVA) Veterans' Home Care (VHC) Respite services (see Table 20). The VHC program targets veterans and war widows/widowers with low care needs. There were 67,471 people approved for VHC services in 2012/13. The program offers veterans and war widows/widowers who hold a Gold or White Repatriation Health Card home support services, including domestic assistance, personal care, home and garden maintenance, and respite care.

Table 16 to Table 22 show the number and percentage of instances of assistance, distinct clients, hours of services received and average hours received per service user by age and geographical location for HACC services in 2012/13. The 2012-2013 appropriation for in-home and emergency respite was $23.8 million.

[12] The AIHW report (2012, p. 79) defines high-care residents as 'permanent residents who are assigned to classification levels 1–4 using the RCS or who is appraised as ACFI high care'. Low-care residents are 'permanent resident who are assigned to classification levels 5–8 using the RCS or who is appraised as ACFI low care'.

Table 16 Number and percentage of respite admissions, age at admission, by state/territory, 1 July 2010 to 30 June 2011

Age	NSW		Vic		Qld		WA		SA		Tas		ACT		NT		Australia	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	NT	%	n	%
<65	830	3.6	544	3.5	383	4.7	182	4.3	203	3.9	92	4.9	39	5.1	75	19.8	2,348	4.0
65-69	867	3.7	622	4.0	312	3.8	221	5.2	159	3.0	96	5.1	15	2.0	58	15.3	2,350	4.0
70-74	1,574	6.8	1,121	7.3	661	8.1	347	8.1	316	6.0	143	7.6	50	6.5	67	17.7	4,279	7.2
75-79	2,830	12.2	2,022	13.1	1,106	13.6	604	14.2	652	12.4	292	15.4	79	10.3	49	12.9	7,634	12.9
80-84	5,433	23.5	3,744	24.3	1,809	22.3	1,057	24.8	1,237	23.5	389	20.6	184	24.0	60	15.8	13,913	23.5
85-89	6,723	29.0	4,361	28.3	2,222	27.4	1,025	24.0	1,576	29.9	521	27.5	259	33.7	34	9.0	16,721	28.2
90-94	3,700	16.0	2,346	15.2	1,233	15.2	615	14.4	897	17.0	276	14.6	107	13.9	27	7.1	9,201	15.5
95+	1,192	5.1	677	4.4	392	4.8	212	5.0	230	4.4	83	4.4	35	4.6	9	2.4	2,830	4.8
Total	**23,149**	**100.0**	**15,437**	**100.0**	**8,118**	**100.0**	**4,263**	**100.0**	**5,270**	**100.0**	**1,892**	**100.0**	**768**	**100.0**	**379**	**100.0**	**59,276**	**100.0**

Note. Adapted from Table A3.2 in AIHW (2012b)

Table 17 HACC instances of agency assistance and hours of HACC services received by state/territory, 2012/13

States / territories	Instances of agency assistance[1]	Number of distinct clients	% of distinct clients[2]	Hours of services received by younger HACC clients[3]	Average hours received[4]
NSW	8,324	272,811	3.1	889,431	106.9
Vic	9,289	286,632	3.2	650,565	70.0
Qld	11,456	188,062	6.1	687,889	60.0
WA	1,823	70,814	2.6	135,478	74.3
SA	3,298	103,602	3.2	260,240	78.9
Tas	703	29,093	2.4	69,714	99.2
ACT	361	14,261	2.5	40,116	111.1
NT	14	1,817	0.8	708	50.6
Total Australia	**35,268**	**967,092**	**3.6**	**2,734,141**	**77.5**

Notes. Adapted from Table A15, Table A16 and Table A17 in (Australian Government, 2014a). [1] Instances of agency assistance represent the number of distinct clients that received each assistance type on an agency by agency basis. This results in some duplication in cases where a client received the same type of assistance from more than one agency. [2] Percentages represent the proportion of distinct HACC clients that accessed that particular assistance type. [3] Younger HACC clients include all HACC clients aged 0-49, plus Non-indigenous HACC clients aged 50-64 and HACC clients aged 50-64 whose Indigenous status is unknown. [4] Average services received per client are calculated by dividing hours of assistance received by instances of agency assistance.

Table 18 HACC instances of agency assistance and hours of HACC respite services received by age, 2012/13

States / territories	Instances of agency assistance[1]	Hours of services received	Average hours received[4]
Older Persons[2]	16,894	931,248	55.1
Younger persons with a disability[3]	18,013	1,768,995	98.2
Unknown age	361	33,898	93.9
Total Australia	**35,268**	**2,734,141**	**77.5**

Notes. Adapted from Table A18, Table A19 and Table A20 in (Australian Government, 2014a) [1] Instances of agency assistance represent the number of distinct clients that received each assistance type on an agency by agency basis. This results in some duplication in cases where a client received the same type of assistance from more than one agency. [2] Older HACC clients include all HACC clients aged 65 years or more, plus Indigenous HACC clients aged 50-64 years. [3]Younger HACC clients include all HACC clients aged 0-49, plus Non-indigenous HACC clients aged 50-64 and HACC clients aged 50-64 whose Indigenous status is unknown. [4] Average services received per client are calculated by dividing hours of assistance received by instances of agency assistance.

Table 19 Hours of respite services received by HACC clients, 2012/13

Number of hours	n	%[1]
<13	8,518	25.8
13-52	9,200	27.9
53-208	12,290	37.2
209-365	2,146	6.5
>365	862	2.6
Total	**33,016**	**100**

Note. [1] Percentages calculated as a proportion of the raw total, n=number of people using this number of hours

Table 20 People receiving residential care respite services

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total Australia
All clients (number)									
Residential care - respite	19,511	12,378	6,296	3,315	4,615	1,477	555	207	48,182
Number of older clients, aged 65 years or over, and Indigenous 50–64 years, by aged care program (rate per 1000 people in parenthesis)									
Residential care - respite	18,923 (16.6)	12,057 (14.3)	6,112 (9.4)	3,206 (9.9)	4,498 (15.9)	1,424 (15.6)	541 (12.3)	200 (9.1)	46,792 (13.8)
Residential care – respite by Age groups. Number of older clients per 1000 people aged 65 years or over, and Indigenous 50–64 years (in parenthesis)									
65-69	748 (2.1)	423 (1.6)	272 (1.2)	164 (5.9)	165 (1.5)	58 (1.9)	27 (2.0)	28 (1.8)	1,880 (4.0)
70-74	1,221 (4.7)	743 (3.8)	461 (3.0)	242 (3.2)	281 (4.5)	102 (4.8)	33 (3.3)	25 (6.5)	3,086 (4.0)
75-79	2,309 (11.6)	1,538 (10.3)	781 (7.2)	413 (7.5)	525 (10.7)	184 (11.9)	62 (8.5)	40 (19.6)	5,832 (10.0)
80-84	4,197 (27.4)	2,768 (24.0)	1,329 (16.8)	756 (18.6)	1029 (26.4)	315 (27.3)	108 (20.8)	32 (27.4)	10,496 (23.5)
85-89	5,579 (55.6)	3,648 (48.2)	1,735 (35.0)	813 (32.2)	1,352 (50.1)	424 (58.4)	156 (40.8)	19 (35.5)	13,685 (47.3)
90+	4,844 (94.3)	2,925 (76.1)	1,518 (58.9)	785 (59.9)	1,138 (81.7)	340 (92.7)	155 (101.3)	17 (68.7)	11,680 (78.8)

Note. Adapted from Table 13A.4 in Australian Government (2014b, pp. 1-3 of Table 13A.4 and p. 7 of Table 13A.4)

Table 21 Hours of HACC respite services received per 1,000 people aged 65 years or over and Indigenous Australians aged 50–64 years, total number and break down by geographical location

States / territories	Total number per 1000 people	Major cities	Inner regional areas	Outer regional areas	Remote areas	Very remote areas
NSW	232	258	177	697	992	1,085
Vic[1]	189	205	156	454	177	-
Qld	485	501	416	2,217	1,926	1,488
WA	176	197	120	438	214	362
SA	389	442	278	1,096	456	597
Tas	259	-	263	1,060	207	-
ACT	35	35	-	-	-	-
NT	30	-	-	251	5	20
Total Australia	**274**	**290**	**231**	**1,102**	**754**	**738**

Notes. Adapted from Table 13A.46, Table 13A.48, Table 13A.49, Table 13A.50, Table 13A.51 and Table 13A.52. Data in these tables represent HACC services received by people aged 65 years or over and Indigenous Australians aged 50-64 years, divided by people aged 65 years or over and Indigenous Australians aged 50-64 years. Actual service levels will be higher than those reported here (see notes a to f of Table 13A.48 in Australian Government, 2014b).1 Validation process for the Victorian Data Repository (VDR) and the HACC MDS differ and actual service levels may be up to 6 per cent higher or lower than stated.

Table 22 Australian Government (DVA) Veterans' Home Care (VHC) Respite services

States / territories	n	Hours / year
NSW	3,046	122
Vic	2,496	122
Qld	1,821	115
WA	504	109
SA	497	113
Tas	643	108
ACT	142	120
NT	8	78
Total Australia	9,133	119

Note. Adapted from Table 13A.13 in Australian Government (2014b, p. 1 of Table 13A.13)

4.7 Informal carers

According to the ABS Survey of Disability and Carers (SDAC) 2012, while 29.1 per cent of 'primary carers' (i.e. the person who provides the most ongoing care for the person with disability) were satisfied with the quality of the formal services they received, 62.1 per cent said that they had never received assistance from formal services. Only 5.7 per cent of primary carers reported receiving respite care for the person they cared for in the three months prior to the SDAC survey and a further 5.4 per cent reported using respite, but not in the previous three months. This means a very high 89.1 per cent of primary carers reporting that they had never used respite care. Of those primary carers who had used respite in the past, 5.3 per cent said that they needed more. Of those who had never used respite, 10.5 per cent reported that they do not use it but need it. Reasons for not using respite included: the care recipient did not want to use respite (10.7 per cent), the carer was unaware of the available services (8.5 per cent), the carer did not want it (7.2 per cent), and the services were unavailable, unsuitable or unaffordable (3.6 per cent). A fairly high proportion of primary carers (54.8 per cent) reported that they did not use respite because they did not need it. This finding requires further exploration given that research with carers consistently suggests that they would like more opportunities to participate in employment or social activities.

NSW Carers Australia (2012) asked informal carers about their coping strategies. The most used coping strategy was talking to friends and family (chosen by three quarters of the 1,919 respondents), followed by exercise/relaxation techniques (45 per cent) and respite/time-out (42 per cent). One quarter of respondents selected stress or anxiety medication while 15 per cent selected alcohol or drugs.

NSW Carers Australia (2012) also asked carers what they thought would most improve their mental health and wellbeing. The most common response was regular breaks from caring (61 per cent), followed by more financial support, more practical support and more support from services, selected by almost half of respondents. The strong desire for the opportunity for regular breaks from caring reflects similar concerns in the 2010 Carer Survey, where one third of respondents selected 'increase in funding for respite services' as the single most important issue that they would like the NSW Government to focus on (NSW Carers Australia, 2012, p. 20).

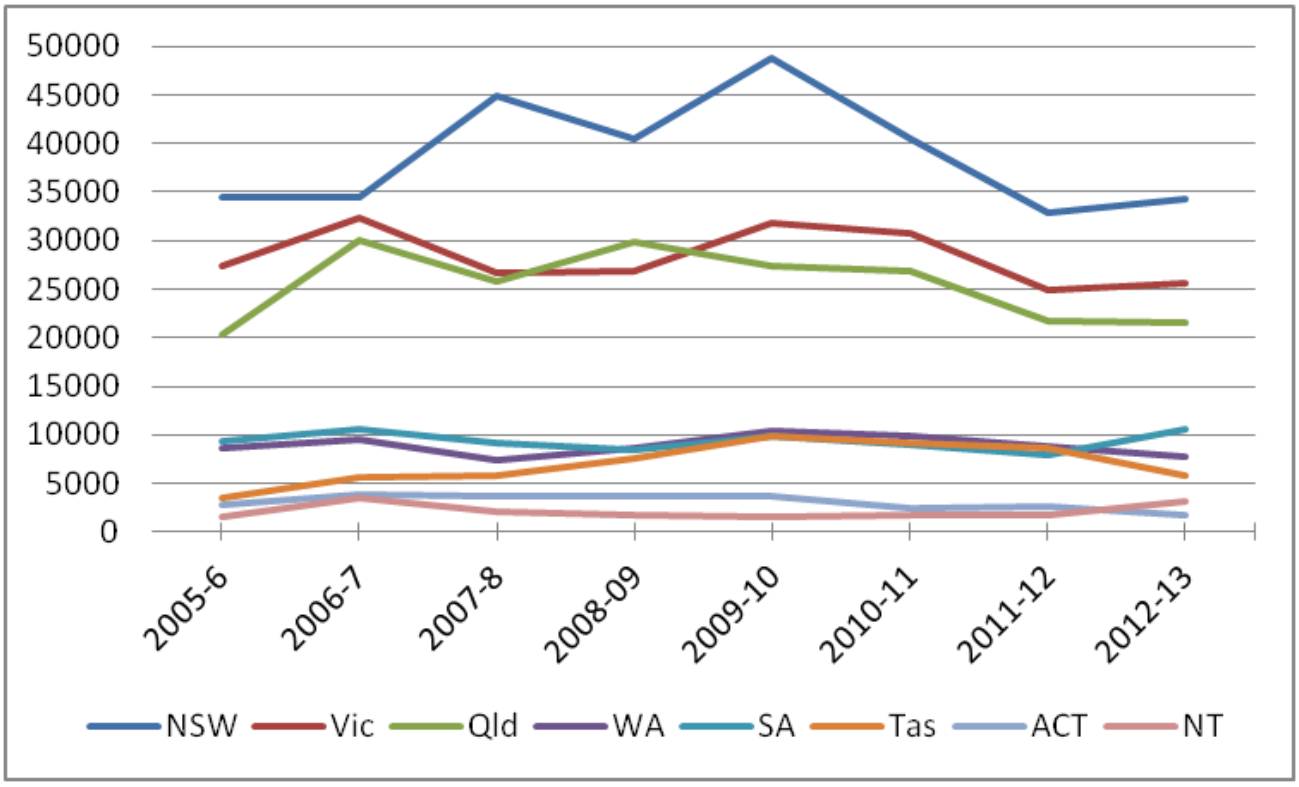
Table 23 shows the number of carers assisted through the National Respite for Carers program (see Appendix C). Figure 1 shows the trends in the numbers of people assisted through the NRCP from 2005/06 to 2012/13.

Table 23 Government expenditure on National Respite for Carers (NRCP), 2012/13 ($ million)

States / territories	Number of people assisted	Expenditure in $ million
NSW	34,262	62.9
Vic	25,646	44.9
Qld	21,491	34.5
WA	7,697	17.1
SA	10,514	17.6
Tas	5,843	6.3
ACT	1,787	4.3
NT	3,131	5.4
Other[1]	-	13.7
Total Australia	**110,371**	**206.6**

Note. Adapted from Table 13A.15 in Australian Government (2014b, p. 4 of Table 13A.15)

Figure 1 Number of people assisted by the National Respite for Carers program, 2005/06 to 2012/13



Note. Adapted from Table 13A.15 in Australian Government (2014b)

6. Conclusions

The international and Australian literature reviews and policy analysis reveal that the move towards consumer directed markets are likely to lead to changes in the way that respite care is understood and implemented in Australia. While this movement offers opportunities for increasing the choices and power of people with disability and older people, the lack of a clear focus in Australia on the needs of carers raises some important issues for governments, respite care providers, participants and carers. The evidence above suggests that CDC markets, and the focus on person-centred care that underpins them, have the potential to alter the way we conceptualise and describe what has traditionally been called respite so that the focus falls more heavily on the needs and activities of participants, shifting the focus from 'respite' to a 'respite effect'. This change does not necessarily meet the simultaneous needs and preferences of the carer, which also indirectly benefit the participant.

The evidence also suggests that the introduction of a CDC model in disability and aged care can affect the character of the services that are available to participants. The model can restrict what services the providers are able to offer in a flexible market and can crowd out niche services that do not have high demand but nonetheless meet essential needs of fewer participants. It may also create inequalities in the amount and nature of respite that participants and carers who are eligible for respite can access. While there is considerable support for CDC models, the parallel policies in some overseas countries to recognise the needs of carers in their own right is currently not evident in the Australian Government policy frameworks of the NDIS or CHSP. Although carers' goals and aspirations are recognised in the guidelines for carer support under the NDIS, there is no formal assessment process for carers.

Overall, this study has highlighted five main issues that require policy attention. These include the lack of mechanisms to:

1. assess carers' needs and provide support to them in their own right
2. plan and generate a dialogue between key stakeholders and policy developers about the goals of the primary support participants and those of the carers to avoid goal conflicts and mismatches
3. preserve useful flexibility in respite services, including those for informal, volunteer, family and paid support carers
4. fund strategies to seek innovation for gaps in care provision, for example in the case of young carers and carers for people with dementia or younger onset dementia
5. address how in the CDC approach to respite care the needs of small groups requiring respite can still be met, particularly in rural and remote areas.

References

ABS (Australian Bureau of Statistics) (2013) Disability, Ageing and Carers, Australia: Summary of Findings, 2012, available at: www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012?OpenDocument.

AHRC (Australian Human Rights Commission) (2013) *Investing in Care: Recognising and valuing those who care*, Vol 2 Technical Papers, AHRC.

AIHW (2012). *Residential aged care in Australia 2010–11: A statistical overview. Aged care statistics series no. 36. Cat. no. AGE 68*. Canberra: Australian Institute of Health and Welfare

AIHW (2014a). *Disability Services National Minimum data set. Data guide* Canberra: Australian Institute of Health and Welfare

AIHW (2014b). *Disability support services: Appendix 2012–13.* Canberra: Australian Institute of Health and Welfare.

AIHW (2014c). *Disability support services: Services provided under the National Disability Agreement. Bulletin no. 122.* Canberra: Australian Institute of Health and Welfare.

ARAFMI (2014) Policy brief: Involving carers and family members in the NDIS, ARAFMI.

Arksey, H; Jackson, K; Croucher, K; Weatherly, H; Golder, S; Hare, P; Newbronner, E; Balwin, S (2004) 'Review of Respite Services and Short-Term Breaks for Carers for People with Dementia', Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO), NCCSDO.

Arksey, H and Kemp, P (2008) Dimensions of Choice: A narrative review of cash-for-care schemes, Working Paper No DHP 2250, Social Policy Research Unit, York.

Arunachalam, I (2013) Transition Guide: A practical A practical guide for not-for-profit disability service providers in their journey to a person-centred and individualised support system of DisabilityCare Australia, IntegratedLiving.

Ashworth, M and Baker, A (2000) ''Time and space': carers' views about respite care', Health and Social Care in the Community 8(1), 50–56

Australian Government (2014a). Home and Community Care program Minimum Data Set. 2012/13 Annual Bulletin, from https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/for-providers/hacc-governance/hacc-mds-annual-bulletin/2012-2013-hacc-mds-annual-bulletin

Australian Government (2014b). Report on government services 2014. Chapter 13: Aged care services: Australian Government. Productivity Commission.

Bamford, C; Arksey, H; Poole, M; Kirkley, C; Hughes, J; Corner, L; Bond, J (2009) Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models, Report for the National Institute for Health Research Service Delivery and Organisation programme, HMSO.

Bellamy, J; Paleologos, Z; Kemp, B; Carter, S; King, S (2014) Caring into old age: The wellbeing and support needs of parent carers of people with disabilities, Anglicare Diocese of Sydney, Social Policy and Research Unit, October 2014.

Caldwell, J (2007) Experiences of families with relatives with intellectual and developmental disabilities in a consumer directed support program, Disability & Society, 22(6), 549-562

Caldwell, J & Heller, T 2003, 'Management of respite and personal assistance services in a consumer directed family support programme', *Journal of Intellectual Disability Research*, 47(4/5), 352-366.

Canadian Healthcare Association (2012). Respite care in Canada. Ottawa: Canadian Healthcare Association.

Carers Australia (2013) Submission in Response to Questions Contained in the Key Directions for the Commonwealth Home Support Program (CHSP) Discussion Paper, June 2013, Carers Australia.

Carers NSW (2012). *Carers NSW 2012 Carer Survey*. Sydney: Carers NSW.

Carers NSW (2014) 'The NDIS one year in: Experiences of carers in the Hunter trial site', *Carers NSW Issues Paper*, September 2014, Carers NSW, Sydney.

Cotterill, L; Hayes, L; Flynn, M; Sloper, P (1997) Reviewing Respite Services: Some lessons from the literature, Disability & Society, 12:5, 775-788

Cramer, H and Carline, J (2008) Family-Based Short Breaks (Respite) for Disabled Children: Results from the Fourth National Survey, British Journal of Social Work 38, 1060–1075

Di Rosa, M., Melchiorre, M. G., Lucchetti, M., & Lamura, G. (2011). The impact of migrant work in the elder care sector: Recent trends and empirical evidence in Italy. *European Journal of Social Work, <http://dx.doi.org/10.1080/13691457.2011.562034>*.

DSS (Department of Social Services) (2014) *Key Directions for the Commonwealth Home Support Program: Discussion Paper*, Australian Government.

DSS (Department of Social Services). (2015a). 2015 Budget fact sheet - Support for carers. from https://www.dss.gov.au/about-the-department/publications-articles/corporate-publications/support-for-carers

DSS (Department of Social Services) (2015b, 13 May 2015). Carer support services - National carer gateway. from https://www.dss.gov.au/disability-and-carers/news/2015/carer-support-services-national-carer-gateway

Fifield. Senator the Hon. Mitch (2015). Paper presented at the National Carer Conference, Gold Coast, November 2014, Goald Coast.

Glendinning, C., Arksey, H., Karen, J., Moran, N., Netten, A. and Rabiee, P. (2009) The individual budgets pilot projects: Impact and outcomes for carers *Working Paper*, York: Social Policy Research Unit, University of York.

Glendinning, C., Challis, D., Fernández, J.-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008) Evaluation of the individual budgets pilot programme, York: Social Policy Research Unit, University of York.

Hamilton, M and Adamson, E (2013) 'Bounded agency in young carers' life course-stage domains and transitions', *Journal of Youth Studies*, 16(1) pp101-117.

Hatton, C. and Waters, J. (2011) National personal budget survey (POET), London: Think Local Act Personal.

Hatton, C. and Waters, J. (2013) The second POET survey of personal budget holders and carers 2013, London: Think Local Act Personal.

Hutchinson, P., Lord, J., & Salisbury, B. (2006). North American approaches to individualised planning and direct funding. In J. Leece & J. Bornat (Eds.), *Developments in direct payments* (pp. 49-62). Bristol: The Policy Press.

Joint Standing Committee on the National Disability Insurance Scheme (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, Commonwealth of Australia: Canberra.

Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H. and Moran, N. (2014) Can individual budgets have an impact on carers and the caring role?, *Ageing & Society*, 34, 01, 157-175.

Keigher, S (2007) 'Consumer directed in an 'Ownership Society': An Emerging Paradigm for Home and Community Care in the United States', in Ungerson, C and Yeandle, S (eds) Cash for Care in Developed Welfare States, Palgrave Macmillan, Houndmills UK.

Kirkley, C; Bamford, C; Poole, M; Arksey, H; Highes, J; Bond, J (2011) The impact of organisational culture on the delivery of person-centred care in services providing respite care and short breaks for people with dementia, Health and Social Care in the Community 19(4), 438–448

Laragy, C and Naughtin, G (2009) 'Increasing consumer choice in aged care services: A position paper', Brotherhood of St Laurence, Fitzroy.

Lord, J., & Hutchison, P. (2003). Individualised support and funding: Building blocks for capacity building and inclusion. Disability & Society, 18(1), 71-86.

Mitchell, W., Brooks, J. and Glendinning, C. (2014) Carers' roles in personal budgets: Tensions and dilemmas in front line practice, *British Journal of Social Work*.

Moran, N., Glendinning, C., Wilberforce, M., Stevens, M., Netten, A., Jones, K., Manthorpe, J., Knapp, M., Fernandez, J.-L., Challis, D. and Jacobs, S. (2013) Older people's experiences of cash-for-care schemes: Evidence from the English individual budget pilot projects, *Ageing & Society*, 33, 05, 826-851.

NACA (National Aged Care Alliance) (2013) Provision of Respite in the Commonwealth Home Support Program - Discussion Paper, September 2013, NACA.

National Disability Service (2009) Individualised funding: What it requires to work.

National Respite (2014) Key Directions for the Commonwealth Home Support Programme Discussion Paper, Submission to DSS, National Respite.

NDIS (2014) Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Sustaining Informal Support, Available at: http://www.ndis.gov.au/sites/default/files/documents/og_plan_assess_supports_sustaining_informal.docx

NDIS website 'Pricing and payment for supports', Available at: http://www.ndis.gov.au/providers/pricing-and-payment-supports

NDS (National Disability Services) (2014) 'The case for some block funding in the NDIS', *National Disability Services (NDS) Policy Paper*, June 2014, NDS.

Netten, A., Jones, K., Knapp, M., Fernandez, J.L., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M. and Wilberforce, M. (2011) Personalisation through individual budgets: Does it work and for whom?, *British Journal of Social Work*.

NSW Carers Australia (2012). *Carers NSW 2012 Carer Survey*. Sydney: Carers NSW.

Prabhakar, M., Thom, G. and Rhian, J. (2010) Individual budgets for families with disabled children Final evaluation report: The IB process, London: Department for Education.

Productivity Commission (2011) *Disability Care and Support*, Productivity Commission Inquiry Report Vol 1, No. 54, Productivity Commission.

Robinson, C (1994) 'Making the break from 'respite care'', *British Journal of Learning* Disabilities 22, 42-45.

Seddon, D and Robinson, C (2001) Carers of older people with dementia: assessment and the Carers Act, *Health and Social Care in the Community* 9(3), 151–158

Simon-Rusinowitz, L., Loughlin, D. M., Chan, R., Mahoney, K. J., Garcia, G. M., & Ruben, M. (2010). Expanding the consumer directed workforce by attracting and retaining unaffiliated workers. *Care Management Journals, 11*(2), 74-82.

Sipila, J; Repo, K; Rissanen, T (2010) *Cash-for-Childcare: The Consequences for Caring Mothers*, Edward Elgar Publishing Ltd, Cheltenham UK.

Slasberg, C., Beresford, P. and Schofield, P. (2012a) Can personal budgets really deliver better outcome for all at no cost? Reviewing the evidence, costs and quality, *Disability & Society*, 27, 7, 1029-1034.

Slasberg, C., Beresford, P. and Schofield, P. (2012b) How self directed support is failing to deliver personal budgets and personalisation, *Research, Policy and Planning*, 29, 3, 161-177.

Timonen, V., Convery, J., & Cahill, S. (2006). Care revolutions in the making? A comparison of cash-for-care programmes in four European countries. Ageing & Society, 26(3), 455.

VON Canada (2002) *Caregiver Focus Group Report*. Ottawa: VON Canada. Available at: http://www.von.ca/english/Caregiving/CaregiverManual/Guideline/Part6_Recommendations.pdf

Wilberforce, M., Glendinning, C., Challis, D., Fernandez, J.-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A. and Stevens, M. (2011) Implementing consumer choice in long-term Care: The impact of individual budgets on social care providers in England, *Social Policy & Administration*, 45, 5, 593-612.

Wilson, Karen (Branch Manager Disability and Carers Policy DSS). (2015). Paper presented at the National Carer Conference, Gold Coast, November 2014, Goald Coast.

Yeandle, S; Bennett, C and Buckner, L (2007) Carers, Employment and Services in their Local Context, Carers, Employment and Services Report Series No. 4, UK.

Appendix A

Respite services are one of the seven 'service group' categories into which the 34 individual service types funded under the NDA can be grouped. The other six categories are: accommodation support; community support; community access; employment; advocacy, information and alternative forms of communication; and other support services (AIHW, 2014a). Respite services "provide a short-term and time-limited break for families and other voluntary care givers of people with disability, to assist in supporting and maintaining the primary care giving relationship, while providing a positive experience for the person with disability" (AIHW, 2014a, p. 25).

Five main types of respite services are funded under the NDA (AIHW, 2014a, p. 25):

4.01 Own home respite

Respite care provided in the individual's own home location.

4.02 Centre-based respite/respite homes

Respite care provided in community setting similar to a 'group home' structure and respite care provided in other centre-based settings. This service type includes respite care provided in any of the accommodation settings: large residential/institutions (>20 places); small residential/institutions (7-20 places), Hostels, Group homes (usually <7 places)

4.03 Host family respite/peer support respite

Host family respite provides a network of 'host families' matched to the age, interests and background of the individual and their carer. Peer support is generally targeted at children or young adults up to 25 years of age and matches the individual with a peer of similar age and interests, usually for group activities. It is usually provided on a voluntary basis.

4.04 Flexible respite

Respite services that offer any combination of own home and host family/peer support respite (service types 4.01 and 4.03). Flexible respite includes respite where day outings and camping trips are taken (this service type is distinguished from service type 3.02 'Recreation/holiday programs' because the primary purpose is respite). Flexible respite to meet an individual's needs may include brokerage for respite only when the funding dollars come from respite resources. Outlets providing centre-based respite services should be recorded separately under service type 4.02 and not under this service type.

4.05 Other respite

Respite services other than those outlined above (that is, other than 4.01–4.04), including:

- crisis respite
- holidays for the person with the disability where the primary intention of the service is to provide respite support (rather than primarily a holiday experience) and the service user is generally separated from their usual support arrangements, for example, family

Appendix B

Residential aged care: permanent (AIHW, 2012, p. 13)

‘Permanent residential aged care is offered to people who can no longer be supported living in the community. Depending on a person’s assessed needs, permanent care is currently offered at two levels: low care and high care (DoHA 2006, 2008). Assessments focus on a person’s physical, medical, psychological, cultural and social needs. Permanent residents receiving low-care require accommodation and personal care, and residents receiving high-care require 24-hour nursing care in addition to their low-care needs’.

Residential aged care: respite (AIHW, 2012, p. 13)

‘Residential respite care is short-term care in aged care facilities. It is available on a planned or emergency basis to older people who intend returning to their own home yet need residential aged care on a temporary basis. It supports older people in transition stages of health as well as being used by carers to provide them with a break from their caring duties. Residential respite care is provided on either a low-care or high-care basis. This kind of care is also an example of the dynamic nature of the relationships between levels of care; for example, respite care may be provided concurrently with a community aged care package’.

Appendix C

Service overview (Australian Government, 2014b, pp.13.2-13.3)

Services for older people are provided on the basis of frailty or disability. Government funded aged care services covered in this chapter include:

- assessment and information services, which are largely provided under the Aged Care Assessment Program (ACAP)
- residential care services, which provide permanent high and low level care, and respite high and low level care
- community care services, including home-based care and assistance to help older people remain, or return to, living independently in the community as long as possible. These services include:
    - HACC program services
    - Community Aged Care Packages (CACP)
    - flexible care packages provided under the Extended Aged Care at Home (EACH) and the EACH-Dementia (EACH-D) programs
    - services provided by the Department of Veterans' Affairs (DVA) under the Veterans' Home Care (VHC)1 and Community Nursing programs
- community care respite services, which include HACC respite and centre-based day care services and services provided under the National Respite for Carers Program (NRCP). NRCP includes expenditure on Respite services and Commonwealth Carer Respite Centres and Demonstration Day Respite.
- services provided in mixed delivery settings, which are designed to provide flexible care or specific support:
    - flexible care services, which address the needs of care recipients in ways other than that provided through mainstream residential and community care — services are provided under the Transition Care Program (TCP), Multi-Purpose Service (MPS) program, Innovative Care Pool and National Aboriginal and Torres Strait Islander Flexible Aged Care Program
    - specific support services, which are provided to address particular needs such as those under the Community Visitors Scheme and in Day Therapy Centres.

The formal publicly funded services represent only a small proportion of total assistance provided to older people. Extended family and partners are the largest source of emotional, practical and financial support for older people.