

September 2013

PROVISION OF RESPITE IN THE COMMONWEALTH HOME SUPPORT PROGRAM - DISCUSSION PAPER

This paper provides recommendations to Government for the establishment of an integrated, flexible and responsive respite and carer support system within the Commonwealth Home Support Program (CHSP) which will commence operations from the 1st July 2015. In determining these recommendations NACA (the Alliance) has considered:

- Respite and carer support services delivered under the NRCP;
- Respite (currently delivered under HACC service group one);
- Centre-based day care (currently delivered under HACC service group four);
- Carer counselling, information and advocacy (currently delivered under HACC service group two); and
- The role and structure of residential respite care, as well as its interface with home and community based respite services and programs.

Section I – A Long-Term Vision for Home Support

The creation of the Commonwealth Home Support Program (CHSP) needs to be done with a long-term vision in mind so that initial design helps moves the service system in the right direction.

The Alliance's long term vision for home care is:

A single system for all home and community aged care services (incorporating CHSP and packaged care) that allows consumers to have continuity of care and access to whatever services they are assessed as needing, when they need them.

This approach will remove the artificial program barriers that currently prevent continuity of care. Some elements of the *Living Longer. Living Better* (LLLB) reforms start to move the system in this direction but they do not go far enough. This vision should be considered as part of the 5 year review of the LLLB reforms.

As part of this long term vision, the Alliance considers the specific needs of carers to access a range of different support services based on their specific needs at any given time crucial. This will require:

- A holistic assessment process; and
- The ability for carers who care for multiple people to combine and schedule respite services in order to fully meet their needs.

Individualised funding (based on assessed need) should be considered as part of this vision in order to:

- Meet the needs of consumers and carers by promoting both person and family centred care;
- Allow carers to build their own specific package of services and support;
- Assist carers of multiple people (particularly when one person is under 65 and one over than 65) to use funds from both the aged care sector and the disability sector (which

already utilises an individual funding model) and ‘line up’ their respite services in order to meet their needs;

- Assist older carers receiving aged care and their adult children receiving disability funds to ‘pool’ their resources in order to more effectively meet their shared needs. For example, this could mean that a carer could choose the same service provider for themselves as their son/daughter currently uses;
- Provide greater equity in service provision; and
- Complement the long-term vision of CDC models of service delivery for all home care.

Alliance members have differing views on the management of individualised funding. Some members are comfortable with the current package approach where funding is provided to organisations that deliver the services. Others support a “cashed-out” model with funding made available directly to the consumer who then purchases what they need.

Funding the full range of home care and respite services in this fashion, may require some separate ongoing block funding to remain attached to the services that have substantial infrastructure and capital costs. This would include transport services, centre-based services (including the provision of residential respite beds), as well as rural and remote services and other special needs services that provide a specific service type.

Recommendation 1: The vision of a single home care system (incorporating respite, CHSP and packaged care) should be considered as part of the 5-year review of the reforms. The Alliance will work with Government to develop an accountability framework for such a program.

Recommendation 2: To work towards the long term vision for home care and achieve optimum support for carers an individualised funding mode should be adopted. This should be combined with the continuation of separate ongoing funding to services with infrastructure costs such as transport, centre-based, rural and remote, as well as special needs services.

In the short to medium term the creation of the new Home Support Program needs to recognise and be structured in such a way as to enable the longer term vision to be achieved. The Alliance is developing a Home Support Program Design paper which will be released in September 2013.

The considerations and recommendations about respite care have been developed and framed with this longer term vision in mind but with due regard to what will be achievable in the short to medium term under the Commonwealth Home Support Program.

Section II – Current Arrangements

Current Respite Programs and Funding Arrangements for Carers of Older People

Currently respite services are funded through the:

- National Respite for Carers Program (NRCP) – including centre based and in-home day respite, individual and group community access respite, overnight in-home and cottage respite, Commonwealth Carer Respite Centres (CRCCs), the provision of information, carer support, counselling and emergency respite;
- Commonwealth Home and Community Care (HACC) Program;
- Residential care;

- Home Care Packages; and
- Programs funded by FACHSIA and State/Territory governments.

The HACC program includes a range of other services, (such as centre-based day care Service Group 4), which provide services to individuals, many of whom may also have a carer.

Current Respite Service Types

There are a number of respite service types, including:

- *Direct Respite* – services that provide the carer with quality alternative care for the person for whom they are the primary carer. Alternative care may be provided in the home, suitable temporary accommodation (including residential aged care) or an appropriate community setting;
- *Indirect Respite* – services that provide the carer with assistance which relieves the carer of tasks other than the caring role e.g. provision of a shopping or cleaning service;
- *Planned Respite* – services that are regular and delivered on an ongoing basis (e.g. ongoing provision of 4 hours of respite care weekly);
- *Unplanned Respite* - services that are required to respond to the outcomes of an unforeseen event. These are generally not ongoing services, and do not require a response within 24 hours; and
- *Emergency Respite* – services provided to meet an unexpected or unforeseen request for assistance, which are time-limited and required immediately – within 24 hours.

In addition to these, there are services which provide a respite effect. These services are primarily for the person receiving care. However, the provision of these services may also provide a short break from caring and therefore provides a respite effect for the carer (e.g. day centres).

Current Objectives and Target Groups for Respite Services

National Respite for Carers Program

The aim of the NRCP is to contribute to the support and maintenance of caring relationships between carers and the people receiving care by facilitating access to information, respite care and other support appropriate to individual needs and circumstances. It is part of a group of programs that provide support for carers of frail older people and people with moderate, severe or profound disabilities with the aim of assisting people to remain in their own homes for as long as possible. The NRCP also includes specific funding targeted towards employed carers. The target group for the NRCP is carers of:

- People with dementia;
- People with dementia and challenging behaviours;
- Frail older people (65 years or over, or 50 and over if Indigenous);
- Younger people (under 65, or under 50 if Indigenous) with moderate, severe or profound disabilities who are living at home; and
- People with a terminal illness in need of palliative care.

Commonwealth Home and Community Care Respite

Respite services provided under the HACC program are intended to strengthen and maintain the caring relationship by providing carers with a break from their caring responsibilities. This in turn contributes to the primary HACC objective of preventing premature or inappropriate admissions to long term residential care.

The target group for HACC services is the unpaid carers of people in the Australian community who, without basic maintenance and support services provided under the scope of the National Program, would be at risk of premature or inappropriate long term residential care, including:

- Older and frail people with moderate, severe or profound disabilities; and
- Such classes of people as are agreed upon, from time to time, by the Commonwealth Minister and the State Minister.

Residential Respite

Respite is provided in residential facilities with the primary purpose of giving the carer or person receiving care a short-term break from their usual care arrangement. While there is no minimum period for residential respite in the Aged Care Act, many approved providers will not take people for stays shorter than 14 days. The *Aged Care Act* allows for up to 63 days of subsidised respite in a year, with extensions available.

To be eligible for residential respite the person entering care must meet the general entry requirements for residential care as assessed by an ACAT.

Home Care Package Respite

A Home Care Package may provide in-home respite and arrange for social activities or other out-of-home services that help prevent social isolation for the person receiving care and their carer. Any form of respite accessed is considered to be within the scope of the services provided. A package may fund short term respite in response to an emergency or an unplanned event.

Any person receiving a package can access respite from their package if funding is available:

- CACPs are targeted towards those who would otherwise be eligible for at least low level residential care;
- EACH care is specifically targeted towards those who would otherwise be eligible for high level residential aged care; and
- EACHD care is specifically targeted towards those who experience behaviours of concern and psychological symptoms associated with dementia which impact on the ability of the person receiving care to live independently in the community.¹

These different programs and respite types all have different definitions, objectives and target groups.

¹These are reflective of pre-reform programs and will be changed with the removal of the low/high care distinction in residential care, and the changes to the home care packages for 1/7/2013.

Section III – Respite Services in the New System

Establishing the new CHSP provides an opportunity to:

- Streamline arrangements;
- Ensure appropriate program planning and focus;
- Provide better services support for carers and the people receiving care; and
- Continue to improve respite services through monitoring data on demand, utilisation patterns and unmet needs or gaps.

The approach to, and design of, respite services is consistent with the broader Home Support Program design.

Respite in the Commonwealth Home Support Program

To ensure that both carers and the people receiving care can access respite that is appropriate to their individual and family needs, goals and preferences, the system of respite care needs to be streamlined and made more flexible.

As outlined above, the long-term vision is to have a single aged home care system. However, the LLLB does not support this and an interim approach needs to be developed that will not work against this aim.

In the short to medium term, the Alliance recommends that the CHSP should create a carer support stream which includes all respite specific funding comprising:

- The NRCP services for older people;
- Existing HACC funded respite services; and
- Residential respite.

Only services provided to older people with carers, specifically designed to provide relief, support or assistance to the care relationship, should be identified as respite services in the CHSP. This would include direct, planned, unplanned, and emergency respite services (e.g. in home respite under the current HACC program and all NRCP funded services). Indirect respite and services that have a “respite effect” (e.g. Day Centres, Day Therapy Centres, and Social Support Programs) should be funded through other, more appropriate, streams of the CHSP.

Residential respite will still be available through the CHSP for individuals who don’t have a carer but who need a break from caring for themselves.

The reduction or elimination of boundaries between types of respite services and programs should give consumers greater flexibility and choice. Funding flexibility for providers should also be increased to allow for shifting of funding from one type of respite to another type in order to meet the needs of consumers and prevent the underutilisation of less ‘popular’ respite services.

There are currently significant State and program variations in the flexibility of respite provision. It will be important to ensure that in bringing these programs together the “highest common denominator” is identified and adopted as the standard. In this way, the quality of respite service provision can be strengthened and improved.

Indirect Respite and Services that Provide a Respite Effect

The move to streamline the definition and provision of respite is designed to reduce artificial barriers and promote ease of access and continuity of care. It is not to discount the value of indirect respite or services that provide a respite effect, but to acknowledge that this is not their main aim. The dual role and outcome of these services should be captured, but the funding of these should be incorporated into a more appropriate service stream.

It is recommended that funds for indirect respite and for services that have a respite effect (e.g. Day Centres and Social Support Programs) should be placed within new streams within CHSP that captures social support and community engagement.

Additionally, it is recommended that the term indirect respite no longer be used to refer to services that relieve the carer of tasks other than the caring role.²

Eligibility for these streams should continue to allow people with and without carers to participate. Additionally, data from such services should capture where the older person has a carer who (as a result of their participation) may be receiving respite.

It should be made clear that these services will continue to exist and be funded through the CHSP regardless of whether or not the participants have a carer.

Recommendation 3: The CHSP should be established with a specific carer support stream which includes all respite funding from NRCP for carers of older people funding, HACC respite and residential respite beds.

Recommendation 4: Only services provided to people with carers, specifically designed to provide relief, support or assistance to the care relationship, should be identified as respite services in the CHSP.

Recommendation 5: In bringing together the different programs/packages the highest common denominator should be identified and adopted as the standard.

Recommendation 6: Services currently known as indirect respite, and services that provide a respite effect should continue to be funded, but be placed in more appropriate streams within the CHSP and target people with and without carers.

Objective and Definition of Respite

The **objective** of the respite services as part of the carer support stream in the CHSP should be to enable the³:

- Person receiving care to continue to live at home/in the community for as long as is appropriate; and
- The care relationship to continue for as long as is appropriate.

The recommended **definition** of a respite service is one which:

- Supports the carer in the caring role (including time away, ability to engage in other activities of choice and to maintain their relationship) knowing that the person they care for is receiving quality care;

² The placement of these services has been referred to the CHSP for consideration.

³ The core elements of these objectives are taken from the definitions developed by the Departmental Carer and Respite Working Group.

- Meets both carer and consumer preferences and what they identify as their needs; and
- Provides, opportunities for social engagement, companionship and stimulation in enjoyable, meaningful and appropriate activities delivered in a dignified and respectful way.

Recommendation 7: The above definition and objectives should shape the design and development of respite services.

Target Group

The new CHSP will require the target group to be restated. Particular attention needs to be paid to what happens to carers caring for people under the age of 65 with the introduction of Disability Care Australia (DCA). It is currently unclear whether funding for those carers caring for people under the age of 65 will be transferred to DCA in the future system. As further information becomes available the CHSP Advisory Group may need to make further recommendations about the inclusion of these carers in the target group for the CHSP.

The CHSP will have an overall target population of people over the age of 65 (over 50 for Aboriginal Peoples and Torres Strait Islanders) who require support and assistance to remain living at home. This target group will be inclusive of special needs groups (as defined under the Aged Care Act 1997 as amended). For respite services the only additional requirement will be that a carer is being supported to continue in their caring role.

Recommendation 8: In addition to the target group requirements for CHSP, respite services should also require that a carer is being supported to continue in their caring role.

Adopting a Consumer Direction Philosophy

In line with the fundamental system shift the LLLB reforms create, the Alliance has considered how the philosophy and principles of consumer⁴ direction should be incorporated in the CHSP design.

The policy context of the current implementation of CDC Home Care Packages has given the term 'consumer directed care' a set and specific policy meaning in Australia. However, the term consumer direction has a broader meaning and application both internationally and in Australia.

Consumer direction enables those receiving services to have maximum control and choice of the services and support provided to meet their needs. Examples of its application in a program such as Home Support would be that rather than going in each week or time of service and doing exactly the same thing each time there is a discussion with the client about what they want to do. For example rather than the standard weekly housecleaning service (dust, vacuum and cleaning the bathroom) when the worker arrives they consult with the client and undertake whatever the consumer felt was important for that week. It might be cleaning the fridge or the pantry or some other household requirement that deviates from the standard service. Or it might be that person needs assistance to prepare some meals or to do the shopping because they have been unwell and unable to get to the supermarket.

There are myriad things a consumer might want assistance with around the house and there should be flexibility for such assistance to be provided at the consumers direction.

This philosophy should be an integral part of the development and delivery of all CHSP funded services, including respite.

⁴The term consumer in this context incorporates both the carer and the person receiving care.

Recommendation 9: The philosophy of consumer direction should be incorporated into the overall design of the CHSP, including the provision of all respite services.

Recommendation 10: The implementation of formal CDC models of service delivery in the CHSP should be considered at the 5 year review.

Respite Service Elements

As outlined above, respite funding would include direct, planned, unplanned, emergency and residential respite. There are some additional considerations for some service elements:

Residential Respite in the CHSP

Currently, residential respite is funded and delivered through the residential aged care program. This means that respite care is delivered in the same way as ongoing residential care, which can deter both providers and consumers from utilising residential respite. It ties the funding and approach to the provision of ongoing, long term care. These include:

- *Administrative burdens.*
Consumers and residential facilities have to go through the same administrative process for residential respite as they do for permanent residential care, including the requirement for a full ACAT assessment.
- *Limited availability of respite beds in residential facilities.*
Providers only receive funding when a person is using a bed for respite or permanent care. This deters providers from keeping beds available for respite and limits the availability of residential beds for both ongoing and emergency respite use.
- *Social isolation and confusion.*
Any community services being provided to a person are suspended while residential respite is provided. Some elements of consumers' packages (e.g. personal and care services) are appropriately provided by the residential facility during this time. However, other services (e.g. social activities such as regular attendance to a day centre, or services that the consumer needs to keep their home living arrangements functioning, such as pet care) are also discontinued but are not provided by the residential facility. This can be disruptive, isolating and confusing for consumers and undermines the benefit of respite for both the carer and the consumer.

In reality residential care is changing in nature with people entering for shorter stays and the community looking for short term residential alternatives for transition and sub acute care, palliative care and respite services. Funding and administrative requirements need to be more flexible to support and encourage short term service provision in line with consumer demand and system development.

One way of addressing these issues would be to consider incorporating residential respite into the CHSP carer support stream. This would reduce and simplify administrative requirements and burdens making it easier to offer residential respite services for less than two-weeks and allowing ease of access for respite consumers. It may also reduce the fears currently experienced by some consumers that they may end up staying on in that facility permanently rather than returning home.

Beds could be block funded on an ongoing basis to help increase respite capacity and availability. However, incentives to keep respite specific beds occupied may be needed. Options for such incentives may include a dual funding model (empty/occupied bed rate) or a requirement to accept referrals from the Carer Support Centres when the needs of the person can be adequately and appropriately met by that facility.

The Alliance recommends further development work is undertaken in conjunction with residential care providers to determine the most effective funding and management approach, recognising that the main current role of residential care is long-term care of residents.

In addition consumers receiving community care should be allowed to continue to receive relevant services and support during their time in residential respite. This would help keep the person's routine in place as much as possible, reduce the experience of social isolation and confusion experienced by consumers and improve outcomes for both consumer and carer.

Currently, residential respite can be accessed by people who have no carer but who need a break from caring for themselves. This is an effective service and must continue to be provided within the CHSP.

This change will reflect the growing demand for short term service provision through residential care including sub-acute and rehabilitation.

Recommendation 11: Consideration and exploration of the inclusion of residential respite (regardless of whether the person has a carer or is their own carer) in the carer support funding stream of the CHSP in order to reduce administrative burdens.

Recommendation 12: Respite specific residential beds should be block funded, with incentives for occupancy built into the system.

Recommendation 13: Package consumers utilising residential respite should continue to receive relevant services and support during their time in residential respite in order to prevent social isolation and improve continuity of care.

Emergency Respite

Emergency respite provision is usually precipitated by a crisis situation that results in the sudden unavailability of the person's main carer, and is provided when no other options for the person's care are available. When residential respite is provided in this situation funding is made available to the provider immediately (from the day on which the care starts).

Adequate funding must be provided for all types of respite including community-based emergency.

Care must be taken in defining 'emergency' respite to ensure that non-emergency situations are not "pushed" into the emergency system due to a lack of other more appropriate services. For this reason, the following situations should not be classified as emergencies:

- A change in the level of a person's needs necessitating a move from a low to a high level of care;⁵
- No availability of a bed in a residential aged care facility; and
- Moving from an acute setting to another setting.

⁵The low/high care distinction will be removed from residential care from 1/7/2014.

Currently, the greatest constraints to providers' ability to respond effectively to emergency respite needs include:

- Uncertainty regarding the length of emergency respite required;
- Funding limitations; and
- A lack of appropriate available workforce.

Additionally, the lack of available services is compounded by the complexity of navigating the current system for the carer who is attempting to locate emergency respite at a point of crisis. Therefore, there should be an easily identifiable number to contact that:

- Provides information, referral and access to available services quickly;
- Makes the necessary arrangements so that the carer does not have to undergo the further stress involved in making numerous calls;
- Covers the full range of respite and carer services, including residential and community respite, as well as other required services at short notice;
- Has linkages with other emergency and respite contacts and can effectively refer/transfer enquiries if appropriate; and
- Is effectively marketed so that all the people who will need it (not just those already receiving respite services) know about it.

Once the Gateway and Carer Support Services are fully functional they could be utilised to perform these services, as well as providing an up-to-date listing of respite service availability.

Other key elements for the adequate and effective provision of emergency respite include:

- Adequate funding for appropriate emergency respite services;
- Ease of access to emergency respite;
- Flexibility in service provision to allow consumers to receive whatever form of respite is most appropriate to their emergency situation;
- Access to funds that can be used flexibly to respond to specific needs (including the utilisation of informal carers);
- The ability to tap into services offered by other providers; and
- Access to providers prepared and able to care for people with dementia, other behavioural problems or high care needs - this would need to include the time efficient collection of consumer information prior to the provision of services.

While adequate funding is needed for emergency respite provision, methods of decreasing the need for emergency respite, listed below, should also be supported:

- Comprehensive assessment of the need of the people in the care relationship, including carer health and wellbeing and access to formal and informal supports;
- Preparation for emergency respite as part of the general assessment/admission process and overall carer system so that planning for such situations is already in place;
- The identification of consumers most at risk of needing emergency respite and planning for/preventing this occurrence through adequate ongoing respite provision;

- The use of contingency funding both within Home Care Packages and the CHSP (initially in provider funding, and then on an individual basis once the move to individualised funding takes place) to ensure additional funds are available when needed;
- Understanding the causes of emergency respite, and providing early intervention wherever possible, including the adequate funding and provision of planned ongoing respite services and ensuring funding for, and availability of, other carer support services;
- Increased carer education on avoiding emergency situations through ongoing supports;
- Workforce planning to promote responsiveness to both ongoing and emergency needs;
- Use of IT to assist in identification of vacant capacity (operationalised through the Gateway or Carer Support Centres);
- Modelling of data on demographics, demand etc. to ensure that non-emergency respite service provision matches ongoing needs; and
- Monitoring and evaluating respite usage patterns (including carer and client profiles, settings and service types, cause of emergency respite etc.) and identification of service gaps in order to determine the suitability of funding and service models and allocation.

Development of emergency respite design and provision could be informed by data from, and any evaluation of, the Commonwealth Respite for Carers Centres (CRCC) experience.

Recommendation 14: A single contact number should be established to provide information, referral and access to available services quickly and make the necessary emergency service arrangements.

Recommendation 15: Timely, easily accessible, flexible, and adequately funded emergency respite services should be made available.

Recommendation 16: Comprehensive assessment, preventative respite service provision, other carer support services, contingency funding, and planning for emergency respite should be encouraged to avoid the necessity of emergency respite wherever possible.

Support for Employed Carers

Services need to be made available outside of current standard operating hours (for example some respite centres are only open between 10am and 3pm) to support carers who need/want to continue working or return to paid work.⁶

Recommendation 17: Flexible and extended hours of respite should be offered to support carers who need/want to continue working or return to paid work.

Other Services and Support for Carers

In addition to respite, carers require access to information, counselling and advocacy services. As part of the LLLB reforms a national Aged Care Gateway (comprising a contact centre and website) will be established along with a number of Carer Support Centres.

⁶ Design and development of the Gateway and Carer Support Centres is currently underway. The Alliance has released an advisory paper on the Aged Care Gateway, which can be viewed at www.naca.asn.au

These centres are being developed as one source of support for carers. Respite service provision should be closely linked with the timely provision of other carer support services, which are designed to meet carers' individual needs, goals and preferences, and which assists them to continue their caring role for as long as is appropriate. These carer support services should include (but should not be limited to) information, counselling, training, education, group support activities and advocacy. Carer Support Centres should also have a role in assisting carers to manage their respite and other services, including assisting carers of multiple people to 'line' up their respite services, even when they are accessed through both the aged care and disability sectors.

This respite paper will be shared with the Alliance Gateway Carer Support Sub-Group established to provide advice on the design and implementation of these Centres.

Recommendation 18: The provision of respite should be closely linked to the full range of carer support services. This work will be referred to the Alliance Gateway Carer Support Sub-Group.

Section IV – Equity of Resource Allocation

The multitude of current respite programs has created challenges to achieving equity of resource allocation.

There should be equitable resource allocation across geographic locations, between individuals and between new and existing respite consumers. This equity of service provision should take into account the level and urgency of the assessed need of both the carer and the person receiving care.

Geographic Equity

There should be equitable resource allocation across the country. To ensure this equity of service/funding allocation, there may be a need to engage a resource equity formula, which takes into account local demographic data and regional attributes.

It should be noted that the inclusion of residential respite in the carer support stream of the CHSP may address some of the geographic inequity concerns, particularly in smaller centres where there is a lack of service alternatives.⁷

Individual Equity and Equity between New and Existing Respite Consumers

Currently, there is some inequity in the amount of services available to, or being accessed by, individuals. In the current system, some individuals may receive large amounts of respite and others may receive very little or nothing at all.

In the long term, the allocation of funds to individuals would address this inequity as it would ensure that consumers receive funding for respite according to, and adequate for, their assessed needs.

Interim arrangements are required to ensure equity in the short term. Streamlining of respite programs is likely to reduce 'double-dipping' to some extent. Additionally, minimising the administrative burdens of accepting new clients may also help encourage equity between new and existing consumers.

However, these measures are unlikely to fully address the equity issues.

⁷ Geographic inequity specific to service delivery in rural and remote locations is discussed at page 19.

The Alliance believes that there should be enough respite provision to meet the needs of carers who need support. However the Alliance recognises that there are limits to the funding for services and suggests that there needs to be some way of addressing equity of access to services. One way of addressing equity of access issues would be to introduce limits (either hours or a funding amount) for individuals that still enables assessed need to be met. Consideration would need to be given to how residential respite would be treated in such a system.

Comprehensive assessment for the need for respite (through the existing aged care assessment process and in future through the *My Aged Care* Gateway) should take account of multiple factors, including:

- Person receiving care – factors include (but are not limited to) dementia, challenging behaviour, palliative situation, mental health issues, complex medication regime requiring administration, lack of mobility for toileting, and incontinence;
- Carer – factors include (but are not limited to) frail/unwell, high risk for carer role breaking down, multiple carer roles (e.g. younger people), non-resident carer/s providing daily support, and time available for essential non-care activities such as employment, getting adequate rest, addressing own health needs, shopping and social activities;
- Family – factors include (but are not limited to) lack of other family support in caring role, and level of contribution to care situation;
- Supports in use – factors include (but are not limited to) the level of support currently accessed through package care or other supports; and
- Impact of respite supports – factors include (but are not limited to) the ability to prevent entry to residential care, and ability to meet other goals of the carer and the person receiving care.

Additionally, if such a limit was introduced, a range of issues would need to be considered, including that:

- Level of need may change dramatically over time as the caring situation changes (including short-term high-levels needs due to specific circumstances) and any limit must be able to match changing levels of need;
- The use of the entire respite limit may indicate a greater service need for either the carer or the person receiving care and should be used as a ‘trigger’ for a reassessment of the level of aged care support provided (linkages with both Carer Support Centres and the Gateway will be crucial to support this referral and reassessment process); and
- Monitoring will be required to ensure that a limit system does not result in increased demand for emergency respite services.

The about to be developed Carer Support Centres will have a central role in emergency respite which needs further exploration.

Recommendation 19: A resource equity formula that takes into account local demographic data should be used to ensure geographic equity in service/funding allocation.

Recommendation 20: A limit placed on the hours of respite provided per consumer (based on assessed need) should be considered to help address inequity between all carers (new and existing). However, any such limit must be based on individual needs, flexible to respond to changes in consumer needs over time. The effectiveness and impact of the limit should also be carefully monitored.

Section V – Special Needs Groups

Issues in Respite Provision for Special Needs Groups and Groups with High Care Needs

Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI)

The *National LGBTI Ageing and Aged Care strategy* notes that, in addition to the current recognition as special needs group under the *Aged Care Act*, LGBTI people will be recognised as a special needs group under the Home Support program from 2015. This should include recognition of both the LGBTI person receiving care and LGBTI carer.

Eligibility as a person receiving care and carer within the LGBTI special needs group should not be limited solely to those with an LGBTI *identity* (i.e., those who use particular labels to describe themselves), but also include people with an LGBTI *history, expression or experience*, such as a person of any identity:

- Who has a history or experience of same-gender attractions and/or same-gender romantic/sexual relationships (whether or not the person also has a history or experience of mixed gender [i.e., woman/man] relationships);
- Whose gender identity is not typically associated with their assigned sex;
- Whose gender expression differs from societal expectation;
- Who has previously lived as a gender other than their current gender;
- Whose gender identity is not strictly ‘woman’ or ‘man’, such as sistergirls and kathoey; and/or
- Whose physical characteristics are not strictly ‘female’ or ‘male’.

This recognition beyond identity labels will provide a culturally sensitive approach to the privacy and disclosure management needs of older LGBTI people.

Due to the uniquely diverse nature of ‘family’ relationships within LGBTI populations, definitions of ‘family’ that prioritise biological ties are likely to discriminate against LGBTI families. Identification of known non-biological ‘chosen family’ and of family members who may be secret partners without formal relationship recognition as carers can be challenging, and many carers within this population group may not identify as a carer. People of intersex status and people of trans experience may have intimate care needs that are best met by other intersex and trans people who may not identify publicly as intersex or trans, and who may not identify publicly as carers.

LGBTI populations may also be concerned about perceptions of service providers and/or levels of LGBTI cultural sensitivity and inclusiveness. This may result in lower accessing of respite services due to perceived barriers of culturally appropriate services for LGBTI populations. This may also result in fewer people disclosing their LGBTI identity, history, expression or experience in respite services and in potential exclusions due to lack of identified eligibility as part of the LGBTI special needs group.

The Sex Discrimination Act (Sexual Orientation, Gender Identity and Intersex Status) 2013 bans discrimination against LGBTI people across Australia. In particular, an amendment passed with the Act prohibits discrimination by religious organisations on the basis of sexual orientation, gender identity or intersex status in the provision of federally funded aged care services.

Rural and Remote

Rural and remote areas face a number of service delivery difficulties:

- Low levels of available or appropriate respite services;
- Lack of available staff (particularly staff that are appropriately trained to deliver services to consumers with specific or high-level needs); and
- Additional costs of delivery (often travel related).

Culturally and Linguistically Diverse (CALD)

A common challenge for CALD consumers and carers is finding and accessing respite that is culturally and linguistically appropriate. There is currently a lack of CALD appropriate respite services and the new CHSP carer support stream needs to include the provision of a range of respite services that are responsive to the individual needs of CALD people including their beliefs, attitudes, preferences, ethnicity, religion and language.⁸

Aboriginal Peoples and Torres Strait Islanders

Provision of respite in Aboriginal and Torres Strait Islander communities poses specific challenges. Aboriginal Peoples and Torres Strait Islanders are more likely to take on unpaid caring roles, more likely to need assistance with aspects of day-to-day living and less likely to access services that support them in their caring role. It is also common for Aboriginal and Torres Strait Islander carers to have care responsibilities for multiple people of differing ages and care needs. This is partially due to:

- Cultural values and gender roles;
- Lack of awareness of available support;
- Unwillingness to self-identify as a 'carer';
- Unwillingness to relocate or travel long distances for care services; and
- Lack of culturally appropriate and locally available respite and carer support services.

The lack of appropriate respite services in these areas also places undue burden on health services that are not designed to provide respite.⁹

Existing respite models are not always appropriate for such communities and there seems to be a preference for accessing Aboriginal and Torres Strait Islander specific services/providers, which are in-home or social-support services. Aboriginal and Torres Strait Islander specific respite options also include what is sometimes referred to as 'reverse respite' which supports Aboriginal Peoples and Torres Strait Islanders to return to their place of birth and communities.

Methods for sourcing support workers within the Aboriginal and Torres Strait Islander communities may need to be developed along with the enhancement of intergenerational programs.

Other suggestions to improve provision of respite in Aboriginal Peoples and Torres Strait Islander communities include:¹⁰

⁸The National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse Backgrounds can be referred to for more information.

⁹ Carers Australia 2013 study "Practical ways to overcome isolation for Aboriginal and Torres Strait Islander Carers".

¹⁰ For a full list of suggestions see Carers Australia 2013 study "Practical ways to overcome isolation for Aboriginal and Torres Strait Islander Carers".

- Increased access to information and assistance navigating the respite service provision systems;
- Carer education programs;
- Policies and practices designed to ensure culturally safe and ethical service provision and environments;
- Simplified application processes;
- Cultural awareness training for staff;
- Recruitment and retention of Aboriginal and Torres Strait Islander care staff and managers;
- Utilising interpreters;
- Community consultation, participation and leadership;
- Developing informal support networks;
- Further support and development of flexible models;
- Targeted packages and projects; and
- Adequate funding and resource allocation to ensure sustainability of services.

High Support Needs and Cognitive Impairment

The rate of people with dementia living in the community that have carers is very high (92%). Half of these carers are also co-residents. This high level of need for respite services is exacerbated by the increased likelihood that people with cognitive impairment will not want respite services to be provided (30% compared to 13% for other people receiving care).¹¹

High support needs have been flagged as a common reason that appropriate respite services cannot be found or that consumers are refused respite service. Providing appropriate care for those with high support needs or cognitive impairments such as dementia should therefore be a priority.

Dementia raises specific challenges for the provision of appropriate respite services and requires a special approach that recognises that:

- Flexible responses are necessary because of the different stages of the disease process;
- Complex care is required to manage behavioural and psychological symptoms of dementia; and
- The social isolation and stigma that may result from dementia necessitates an approach that supports early take-up of respite together with other services.¹²

It has been recommended by Alzheimer's Australia that these problems are addressed through the:

- Increased use of the Dementia Behavioural Management Advisory Service (DBMAS) by family carers and respite services;
- Extension of the Dementia Supplement for Home Care Packages (10%) to the CHSP. It has been noted that due to the current block funding arrangement for HACC and the NRCP that this may only be possible through a grants subsidy or similar in the short term but would be supported as an individual supplement in the long term vision of the CHSP.

¹¹ Figures taken from the Alzheimer's Australia Respite Review Policy Paper, Paper 33, prepared for the Department of Health and Ageing, 2013.

¹² This is an excerpt from Alzheimer's Australia's 2009 paper 'Respite Care for People Living with Dementia It's more than just a short break'.

- Enhancement of dementia-specific approaches, including research into innovative respite models and respite services appropriate to consumers with dementia, in all types of respite.

The dementia supplement should be used to resource the development dementia specific respite services and provide subsidised training and education (both individual and organisational). Respite services providing services for individuals eligible for the supplement would be required to demonstrate that staff have undertaken appropriate training in dementia care.

Due to the difficulty experienced by many respite services in handling the behavioural and psychological symptoms of dementia (BPSD), respite services should also be required to show they have ongoing consultation with clinical specialists and appropriate staff to patient ratios required to support individuals with BPSD.

There is little understanding of how dementia respite is currently funded, including a lack of data showing the numbers of providers that are already applying for more funding to compensate for higher provision costs. This needs to be measured and understood (as outlined above) to ensure equity of resource allocation, and appropriate and adequate funding of dementia specific service provision.

Recommendation 21: In order to provide appropriate services for those with high care needs and those experiencing cognitive impairment there should be increased use of the DBMAS by family carers and respite services; an extension of the Dementia Supplement for Home Care Packages to all forms of respite; and an enhancement of dementia-specific approaches in all types of respite.

Alternative Approaches to Service Funding and Provision for Special Needs Groups

There are a range of special needs groups who, in order to achieve equitable outcomes, require additional effort and service variation. In some cases this equates to a higher cost of service provision and this should be acknowledged and these services adequately funded.

Providers need to develop strategies that meet the needs of their consumers, including consumers with special needs. The following approaches could be adopted to address the specific needs of special needs consumers:

Block Funding

For services that may struggle to remain financially viable, but that offer an essential service to special needs consumers or in rural and remote locations, the continuation of block funding models may need to continue to support infrastructure, capital and/or staffing costs.

Paying Informal Carers

While not generally supported by the Alliance, the provision of paid services by informal carers (family, friends or neighbours) for special needs groups or in locations where there is a lack of appropriate or available service options, may already occur and should continue to do so where there is no other workable alternative. However, a number of issues must be considered where such arrangements are, or need to be, in place:

- Elder abuse safeguards;
- Provider responsibility for service quality, including the need to include the informal carer in their employee/volunteer/sub-contractor systems;
- Legal responsibilities;

- Industrial implications;
- Insurance requirements;
- Workplace health and safety; and
- Qualifications and training required to provide certain types of care.

Funding that Reflects the Cost of Provision

The Productivity Commission Report Caring for Older Australians recommended moving to funding which was variable based on location of delivery (rural and remote areas) and/or for special needs groups where there is a higher cost structure for delivery. The Alliance believes this is the best approach to address the issues as it acknowledges the reality that it costs more to deliver services in some areas and for some people. This was not picked up as part of the LLLB reforms and the Alliance recommends that this be reconsidered and introduced to ensure equity of access.

Viability Supplements

The Alliance's preference would be for a funding approach that recognises and meets the costs of actual delivery. If this can't be implemented there has to be a viability supplement for the HACC,¹³ NRCP, Day Therapy Centres (DTC) or Assistance with Care and Housing for the Aged (ACHA) programs to ensure equity of access and outcomes.

Funding currently made available to providers of respite under the NRCP and HACC takes account of the need to cater for people from regional and remote areas, people from CALD backgrounds and people with high care needs and challenging behaviour. The amount provided is based on what the organisation included in their budgets to deliver services to their client group, including people from special needs groups.

There is very little information available on standard costs of services or additional financial claims to provide services to special needs groups.

It is recommended that data collection be undertaken to calculate standard costs of respite service provision as well as to understand how additional funds are currently used to meet the needs of special needs groups and in rural and remote locations.

The Alliance recommends that viability supplements be extended across CHSP services (including respite) and that they are available to meet the additional costs of providing services to special needs groups as well as in rural and remote locations. Viability supplements should be available for special needs specific services as well as for rural and remote service provision. They should be funded at a level that matches the real additional costs of delivering these services.

The Dementia and Veterans Supplement for Home Care Packages (10%) should also be extended to cover some service streams, such as respite care, within the CHSP.

Appropriate/Specialised Staff Mixes

The workforce is the key to being able to meet the needs of consumers. Strategies to ensure staff can do so include:

- Giving priority to recruiting personnel whose background and knowledge meet the cultural mix of the local community;

¹³ In the past some States had a resource equity formula which took rural and remote locations into account in distributing the quantum of growth funds.

- Recruiting bi-lingual and culturally competent staff;
- Making training available across the sector on:
 - Cultural awareness;
 - LGBTI awareness and sensitivity; and
 - The needs of consumers with cognitive impairment and dementia.

Additionally, those services that have completed special needs sensitivity and awareness training, as well as services which choose to identify as ‘specialist’ providers should be easily identifiable in information systems and this information should be made available on the My Aged Care website (when it becomes operational).

Recommendation 22: The Productivity Commissions recommendation from the Caring for Older Australians report to provide differential funding based on the actual costs of service delivery in different locations (particularly rural and remote areas) and for special needs groups.

Recommendation 23: Data collection should be used to calculate the standard costs of respite provision as well as how additional funds are currently utilised to meet the needs of special needs groups and in rural and remote locations.

Recommendation 24: Additional costs associated with service provision to special needs groups (including CALD, LGBTI, ATSI, rural and remote and those with cognitive impairment) should be adequately recognised to achieve service delivery equity. Viability supplements should be introduced/increased to reflect the real costs of providing services to these groups and in these areas.

Recommendation 25: Block funding, and sub-contracting to informal carers should continue in rural and remote areas and for special needs groups where it is required to meet consumer needs.

Section VI - Innovative Service Options

Providers should be supported and encouraged to use innovative service approaches to meet the diverse respite needs of all people and care relationships across the sector. However, given that service provision to special needs groups is a continual challenge, the use of innovative service options and the utilisation of technological advances are especially critical.

Data collection should support innovation and gather information on the trends, needs, and usage of different forms of respite, including accurate recording of rates of residential, community, and in-home forms of respite. Support for innovation is needed and the Alliance recommends the following:

- A scoping study should be undertaken to record existing innovative models and programs as well as best practice across the sector for all types of respite (including residential respite);
- The development of a clearing house of information should be established to allow providers to stay up to date with best practice and new innovations;
- Government should work with members of the special/specific needs communities and their advocates, carer organisations, researchers and service providers to identify achievable solutions to providing carer supports (including respite) that are appropriate and responsive to the individual needs of people in special/specific needs groups;
- Funding should be made available to implement the existing innovative models already

- developed for carers of people with dementia;
- Government funding should explicitly be able to be used to research, trial, implement and expand innovative service programs. Funding models could be a percentage of ongoing funding dedicated to innovation, innovation subsidies or grants-based block funding for innovation;
- Further funding should be directed toward more innovative trials particularly for Aboriginal and Torres Strait Islander and CALD specific services (a comparatively under developed area);
- A system for sharing staff with specific skills across agencies should be developed to make the best use of existing resources; and
- A focus on respite at the Aged Care Standards Accreditation Agency better practice forums and awards, particularly when the Agency takes responsibility for home care.

Recommendation 26: Innovative service provision should be a priority and be supported through the establishment of a clearing house of information for providers; the provision of dedicated funding for research, trialing, implementation and expansion of effective innovative service models; and the extension of the Aged Care Standards Accreditation Agency's better practice forums and awards to include respite service provision.

Section VII –Interfaces

It is important to note that once services are in place, the carer is generally not concerned about which level of government or which program funds the service and that HACC providers of respite have indicated that the aged care split for respite had little, if any, impact on carers. However, there are a range of interface issues that need to be addressed in the design of the CHSP.

Implementation of the long term vision outlined in this paper would prevent the majority of issues relating to interface arising. However, in the short term, program barriers and silos will limit what people can access and the flexibility with which services can be offered. The largest impact from the interface will be for providers who have to manage two separate funding streams and different program philosophies. Given these differences, effective interface systems will be needed.

The CHSP, Gateway and Carer Support Centres

The Gateway is currently envisioned to involve Carer Support Centres (CSC). This rationale is based on role of CSC as acting as a first point of contact for carers. However, given their important role in providing services to carers the interface between the CHSP and the Gateway/CSC functions will be crucial. This interface needs to be seamless in order to allow carers to access the full range of services they need, when they need it.

The CHSP and the Disability Sector

Previously, respite care could be provided under the HACC program and NRCP regardless of the age of the person receiving care.

As part of the National Health Reforms, the Council of Australian Governments (COAG) agreed that from 1 July 2012, the Australian Government will take full funding and program responsibility for basic maintenance, support and care services for older people previously delivered through the HACC Program. This applies to people aged 65 years and over and Aboriginal Peoples and Torres Strait Islanders aged 50 years and over.

State and territory governments are responsible for managing and contributing funding to programs to provide care and support services for younger people with a disability and their carers. The implementation of the DCA through launch sites will increase the Commonwealth contribution to disability care and change the way funds are accessed and managed to provide disability services for people under 65.

Therefore, the Aged Care Gateway will need to be informed and able to make a 'guided referral' to the disability system as it operates in the relevant region. Additionally, the disability service system will need to be able to make a 'guided referral' to the aged care system. This will ensure that the needs of carers, regardless of the age of the person for whom they care, can be met.¹⁴

- Younger Onset Dementia (YOD)

Service barriers for those with YOD may be exacerbated by the introduction of the 65 age limits for the NRCP, which are in addition to the existing age split between HACC services in disability and aged care. Steps must be taken to ensure an effective interface between these systems exists in order to provide accessibility and continuity of care for these consumers.

Since the announcement of the introduction of the DCA much of the focus has been on how things will work once the DCA is fully operational. However, this is not planned until 2018 and there are serious concerns regarding the eligibility of, and access to services for, people with YOD during the transition period.

The Home Care Packages Program Guidelines do not have any age requirements for access while noting that the program is targeted at frail older people. However, the ability for people with YOD to access the CHSP is currently unclear.

It is recommended that people with YOD be given flexibility to access services from the most appropriate source for their needs, regardless of whether that be through the disability or aged care sector. To allow this, the eligibility requirements/target group of the Home Care Packages and the CHSP must be inclusive of individuals with YOD.

- Carers of Multiple People

The interface of respite with the disability sectors also raises particular issues for carers who care for more than one person. In 2009, 21% of all those who identified as primary carers were also caring for at least one other person. Additionally, the total number of people who were providing care was 6.3% or 2.6 million people and a significant proportion of this broader group is also likely to be providing care to more than one person.

Carers who care for a person under 65 as well as another person over 65 would need to align their respite services from the aged care and disability sectors in order to receive full respite that is age appropriate for the person they care for. This also applies to older parents of adults with a disability where the parent receives aged care services and the son or daughter receives disability services. This scenario requires effective dovetailing of government service provision and/or merging and brokering of carer support in both the aged care and disability sectors.

It should be noted that the additional flexibility given to carers (through individualised funding in the long term vision as outlined above), would allow carers to access appropriate services through both the aged care and disability systems as appropriate to meet their needs with more ease.

¹⁴ There will be a NACA Interface Advisory Group working on the aged care/NDIS interface.

Recommendation 27: Effective interface arrangements between the CHSP and home care packages, as well as the Gateway and Carer Support Centres will be needed to prevent artificial program barriers and silos, and ensure flexibility and continuity of care.

Recommendation 28: In the short term, effective linkages between the aged care and disability sectors will be needed to ensure that the needs of carers, regardless of the age of the person for whom they care, are met. In the long term, the move towards individualised funding will allow carers to more easily use their resources and to access respite services through both the disability and aged care sectors in order to fully meet their needs.

Recommendation 29: To ensure the needs of people with younger onset dementia are adequately met the eligibility requirements of the CHSP should be inclusive of individuals with younger onset dementia.

Section VII – Summary of Recommendations

This paper presents the Alliance's advice on the provision of respite within the new CHSP for consideration by the Alliance's Commonwealth Home Support Advisory Group. The ideas and views on the respite provision may continue to develop as further details of the CHSP design are discussed and finalised by the Advisory Group.

In summary The Alliance's recommendations are:

Recommendation 1: The vision of a single home care system (incorporating respite, CHSP and packaged care) should be considered as part of the 5-year review of the reforms. The Alliance will work with Government to develop an accountability framework for such a program.

Recommendation 2: To work towards the long term vision for home care and achieve optimum support for carers an individualised funding mode should be adopted. This should be combined with the continuation of separate ongoing funding to services with infrastructure costs such as transport, centre-based, rural and remote, as well as special needs services.

Recommendation 3: The CHSP should be established with a specific carer support stream which includes all respite funding from NRCP for carers of older people funding, HACC respite and residential respite beds.

Recommendation 4: Only services provided to people with carers, specifically designed to provide relief, support or assistance to the care relationship, should be identified as respite services in the CHSP.

Recommendation 5: In bringing together the different programs/packages the highest common denominator should be identified and adopted as the standard.

Recommendation 6: Services currently known as indirect respite, and services that provide a respite effect should continue to be funded, but be placed in more appropriate streams within the CHSP and target people with and without carers.

Recommendation 7: The above definition and objectives should shape the development of respite program, package, and service design.

Recommendation 8: In addition to the target group requirements for CHSP, respite services should also require that a carer is being supported to continue in their caring role.

Recommendation 9: The philosophy of consumer direction should be incorporated into the overall design of the CHSP, including the provision of all respite services.

Recommendation 10: The implementation of formal CDC models of service delivery in the CHSP should be considered at the 5 year review.

Recommendation 11: Consideration and exploration of the inclusion of residential respite (regardless of whether the person has a carer or is their own carer) in the carer support stream of the CHSP in order to reduce administrative burdens.

Recommendation 12: Respite specific residential beds should be block funded, with incentives for occupancy built into the system.

Recommendation 13: Package consumers utilising residential respite should continue to receive relevant services and support during their time in residential respite in order to prevent social isolation and improve continuity of care.

Recommendation 14: A single contact number should be established to provide information, referral and access to available services quickly and make the necessary emergency service arrangements.

Recommendation 15: Timely, easily accessible, flexible, and adequately funded emergency respite services should be made available.

Recommendation 16: Comprehensive assessment, preventative respite service provision, other carer support services, contingency funding, and planning for emergency respite should be encouraged to avoid the necessity of emergency respite wherever possible.

Recommendation 17: Flexible and extended hours of respite should be offered to support carers who need/want to continue working or return to paid work.

Recommendation 18: The provision of respite should be closely linked to the full range of carer support services. This work will be referred to the Alliance Gateway Carer Support Sub-Group.

Recommendation 19: A resource equity formula that takes into account local demographic data should be used to ensure geographic equity in service/funding allocation.

Recommendation 20: A limit placed on the hours of respite provided per consumer (based on assessed need) should be considered to help address inequity between all carers (new and existing). However, any such limit must be based on individual needs, flexible to respond to changes in consumer needs over time. The effectiveness and impact of the limit should also be carefully monitored.

Recommendation 21: In order to provide appropriate services for those with high care needs and those experiencing cognitive impairment there should be increased use of the DBMAS by family carers and respite services; an extension of the Dementia Supplement for Home Care Packages to all forms of respite; and an enhancement of dementia-specific approaches in all types of respite.

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Recommendation 28: In the short term, effective linkages between the aged care and disability sectors will be needed to ensure that the needs of carers, regardless of the age of the person for whom they care, are met.

Recommendation 29: To ensure the needs of people with younger onset dementia are adequately met the eligibility requirements of the CHSP should be inclusive of individuals with younger onset dementia.

The National Aged Care Alliance is the representative body of peak national organisations in aged care including consumer groups, providers, unions and professionals.

