# Carers Australia submission in response to questions contained in the Key Directions for the Commonwealth Home Support Program (CHSP) Discussion Paper (June 2013)

**Preamble**

Carers Australia would like to acknowledge the valuable, expert input to this submission of Anne Muldowney of Carers Victoria and Louise Bradley of Carers NSW, as well as comments received from other of state and territory Carer Associations.

**1. Are there any other key directions that you consider should be pursued in the development of the Commonwealth Home Support Programme from July 2015?**

## 1.1 Carer Recognition

The paper frequently refers to 'clients' or 'older people' without a reference to carers. Given that the amalgamation of the NRCP and the HACC program is a key element of the new CHSP it is important that carers are always referenced alongside the term clients. Recognition of and support for carers is in accordance with the Carer Recognition Act 2010 (the Act) and must be reflected throughout the new CHSP. This can be achieved by embedding the principles contained in the Act, specifically items 5 through 8 in the Statement for Australia's Carers as these are most relevant to the obligations of CHSP providers towards family and friend carers:

- Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
- The relationship between carers and the persons for whom they care should be recognised and respected.
- Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
- Carers should be treated with dignity and respect.

**Recommendation 1**:
Carers Australia recommends that the opening statement includes the following:
It is proposed that the Commonwealth Home Support Program will:

- Consider carers as partners in care as well as individuals with their own needs.

their **Recommendation 2:**
Carers Australia recommends that in accordance with the Carer Recognition Act, the CHSP key directions include the following obligations:
CHSP providers must ensure that:

(a) their board, management, staff and contractors have an awareness and understanding of the Statement for Australia's Carers; and
(b) their board, management, staff and contractors take action to reflect the principles of the Statement in developing, implementing, providing or evaluating care supports.

## 1.2 CHSP as a Basic Support Program

The term 'basic' is used constantly throughout the document as the defining characteristic of the CHSP program. The description of 'basic' on page 18 is:

- low intensity levels of support
- delivered as individual interventions with limited coordination.

Carers Australia urges caution in equating basic costs/minimal service delivery with basic needs. Carers Australia questions the average level of annual HACC subsidy per client at $2,300 given the absence of a central client record and the lack of inclusion of any spending on NRCP or other funded support services on behalf of these same clients. Some clients and carers will have higher cost/higher intensity short term service delivery needs, especially in the context of a restorative care program. In particular the need for carer support and respite care is related to a range of factors in the care relationship, not just to the functional limitations of the person receiving care.

Whilst agreeing that those people needing ongoing case management and care coordination or more intensive ongoing support should be referred for assessment for a home care package, any moves to cap CHSP service delivery to a set dollar amount for existing clients during the transition to the new program should be avoided. Carers Australia supports Alzheimer's Australia's position on grand- parenting arrangements for existing higher level service usage clients for a minimum of three years. This is especially needed whilst demand for higher level service provision continues to be well in excess of the supply of Home Care Packages.

The CHSP would be better described as the foundation level of an end-to-end aged care system, offering a wide range of service types. Whilst short term services may be higher intensity, ongoing services are low intensity with limited coordination.

However, carers of older people with higher needs should not be denied access to the flexibility and range of respite care services currently available under NRCP. Carers must continue to have access to CHSP funded respite services as well as residential respite care based on their assessed need. Carer needs should be independently assessed to ensure that a need for respite care that exceeds the provision of consumer directed services within an individual client's Home Care Package is able to be accommodated.

**Recommendation 3:**
Carers Australia recommends that carers haveaccess to the suite of respite care services within the CHSP as well as the residential respite care program based on their assessed need when the person they care for receives a Home Care Package that is fully expended on meeting own needs.

## 2. How should restorative care be implemented in the new programme?

### 2.1 Change Management

There is much to be learned from the WA and Victorian government's experience of implementing restorative care in the HACC program. A change management approach must focus on supporting and building both workforce capacity and client and carer empowerment. Any restorative care program must also subscribe to a social model of health, emphasising and promoting good emotional and mental health and social connectedness as much as physical wellbeing.

The Victorian Department of Health has employed a range of strategies to implement wellness and reablement. Provider and consumer buy-in is a critical success factor. Key strategies include:

- Workforce transition to a more qualified and skilled workforce
- Whole of workforce training in the principles, philosophy and practice of wellness and reablement
- Access to allied health, in particular occupational therapy
- Regional networks to support service improvement and practice change
- Sector support to implement organisational and workforce practice change
- Embed the approach in quality systems
- Consumer communication strategy, focusing on new service users
- Review and evaluate the implementation

**Recommendation 4:**
Carers Australia recommends that achieving client and carer goals is at the centre of a restorative care program rather than health professional or organisational goals. These are more likely to be broad wellbeing goals, for example to improve their capacity for participation in family, social and community events; reduce social isolation; improve confidence and emotional wellbeing.

### 2.2 Carer health and wellbeing

Caring often has adverse effects on the health and wellbeing of carers. The Australian Bureau of Statistics' 2009 Survey of Disability, Ageing and Carers (SDAC) found that about one-third (32%) of carers said that their 'overall physical and emotional wellbeing' had changed due to their caring role.

Some specific adverse effects of caring on primary carers include:

- feeling weary or lacking in energy (32% of primary carers)
- frequently feeling worried or depressed (30%)
- being diagnosed with a stress-related disorder (11%)
- sleep interruption (45%).

These effects increase with the amount of supervision and assistance with core activities required of the carer.

Data from the 2011 Census indicate that 5% of informal carers aged 15 and over needed help with core activities themselves. The rate of need for such help increased with the age of carers, with carers aged 65 and over being 75% more likely to have a core activity limitation than those between 16 and 64.

There are many examples all over Australia of services using HACC and NRCP funding to provide comprehensive support for carers using a wellness and restorative approach. Services commonly include:

- Counselling
- Education and training
- Peer support
- Social outings, retreats and activities with a respite effect
- Information and advocacy

**Recommendation 5:**
Carers Australia recommends that DSS ensure that existing models of good practice in promoting carer health and wellbeing using a restorative approach are retained during the transition to the CHSP.

Carers are also at risk of incurring physical injuries from their caring role. A survey undertaken by the Independent Living Centre in Western Australia in 2005 on the physical impact of caring found that:

- 43% of carers said they had been physically hurt or injured as a result of providing care
- 63% reported that caring had a medium to very large impact on their physical health
- carers reported a higher level of orthopaedic or spinal problems, cardiovascular problems and emotional or mental problems after becoming a carer
- most of the injuries sustained were back injuries generally caused by lifting, lowering or carrying
- 42% said they had to get extra assistance to continue to provide care
- the average age of carers and care recipients who participated in the survey was 59, with the predominant group being 50-69.
  (Independent Living Centre of WA, Family Carers and the Physical Impact of Caring – Injury and Prevention, 2006)

We are advised by NACA members providing allied health services that carers who have injuries as a result of their caring responsibilities constitute a significant proportion of their clientele.

**Recommendation 6:**
Carers Australia recommends that the CHSP guidelines make explicit that the restorative care principles apply to carers as well as clients and that in particular, carers need access to CHSP allied health services such as physiotherapy to address the physical health impacts of the caring role as well as access to specialist carer support services.

**3. Are these proposed client eligibility criteria appropriate? Should the eligibility criteria specify the level of functional limitation?**

## 4. Carer Eligibility

Carers Australia shares NACA's concern about the lack of consistent understanding in relation to eligibility of carers within the Commonwealth HACC program. The Alliance recommends that the CHSP eligibility criteria should seek to redress this by making carer eligibility clear in the following ways:

- Amend 'aims' to recognise a carer as a client in their own right (p27)
- Amend 'target group' eligibility of carers, to clarify that carers do not need to be above the age of 65 in order to access the CHSP by inserting the words "of any age".
- Affirm in eligibility or program manual that a carer may be eligible for CHSP even where the eligible person they care for is not receiving a service themselves.

As mentioned under Question 1, in the context of incorporating NRCP into CHSP, Carers Australia is cautious about the program offering a 'basic service/low level of support' and the impact this could have on access to a range of respite care services.

Carers Australia supports Alzheimer's Australia in recognising that having a limit on respite services may help address current inequities in access to supports by people in care relationships. However any limit must be in line with assessed need and should be flexible to respond to changing needs over time. Considerations include:

- The needs and circumstances of people in care relationships can change significantly in a short period of time (such as a carer being unwell) that will create a need for a high intensity of service that would exceed an imposed limit, but is only needed short term.
- Imposing a limit may increase the demand for emergency respite.

Reaching a respite limit may indicate a greater service need and should be a trigger for reassessment. This would be more easily facilitated if carers are recognised and assessed in their own right under the CHSP.

**Recommendation 7:**
Carers Australia recommends that DSS make explicit the eligibility of people in care relationships, regardless of the age of the carer. Carers may be eligible on the basis of their caring role at any age. They may also be eligible as a CHSP client in their own right if they are aged 65 and over and have an aged care need.

**Recommendation 8:**
Carers Australia recommends that the eligibility criteria should not specify the level of functional limitation as this could have the effect of excluding those clients and carers who may benefit most from a restorative approach.

**5. Are the circumstances for direct referral from screening to service provision appropriate?**

It is essential that carers are able to access carer support services directly as well as through My Aged Care based on the 'no wrong door' principle. Carers Australia supports the suggestion in the discussion paper that where a need is episodic or temporary (such as carer absence) there would not necessarily need to be a face to face assessment. In some cases this could present as a barrier and lead to a situation worsening, for instance if there is a need for emergency respite. The circumstances listed should be amended to specifically include emergency respite, so that waiting for an assessment does not prevent access to respite at a critical time. However, there should still be a face to face assessment of the older person and their carer, although this may need to occur after receiving initial services. Given that the need for emergency respite indicates a crisis situation it is likely that the carer and the older person have other needs which also need to be identified and addressed.

**Recommendation 9:**
Carers Australia recommends that carers are able to access carer support services in a variety of ways:

- Independently of My Aged Care or CHSP
- Direct referral following phone based screening
- Guided referral as a result of face to face assessment of their needs.

**6. Are there particular service types that it would be appropriate to access without face to face assessment?**

Carers Australia agrees that referrals direct to clinical services such as nursing and allied health can be appropriate without an initial face to face assessment. Those health professionals who identify other unmet needs during their specialist assessment or service delivery should then refer the client or carer for subsequent face to face assessment via the My Aged Care provider portal.

Where services are needed immediately such as meals or transport a direct referral to service provision is appropriate. However the need for a follow up assessment will depend on the client and carer circumstances identified at screening and the length of time that they will need services for.

We also note that face to face assessments can be difficult to achieve in some rural and remote communities and that phone assessment which thoroughly explores the circumstances of older people and their carers will need to suffice until other communications technology such as videoconferencing is more widely available.

**Recommendation 10:**
Carers Australia recommends that referral pathways for clients and carers from My Aged Care for other service types should be considered according to their individual circumstances not according to the service type.

**7. Are there any other specific triggers that would mean an older person would require a face to face assessment?**

## 6.1 Carer Needs Assessment

The paper refers to a process of a two-way conversation between the client and the My Aged Care assessor. A two-way conversation can be had over the phone and the limitations of this approach, particularly in articulating carer needs have been acknowledged. It is important to make explicit that this may in fact be a three-way conversation including the client and the carer and that the assessor will need to exercise appropriate judgement about engaging with the carer via phone or email before, during and/or after the face to face assessment.

Face to face assessment enables an acknowledgement that carers have needs both within and separate to the care relationship and can help make these clear to all parties. It also has the capacity to generate appropriate and timely referrals for carer support services, enabling earlier intervention and prevention of the some of the negative impacts on carer health and wellbeing. Further specialist assessment of carer needs for emotional and practical support in their caring role would take place within carer support services.

**Recommendation 11:**
Carers Australia recommends that a face to face assessment should always be made available when a care relationship has been identified through the screening process.

**Recommendation 12:**
Carers Australia recommends that the domains for face to face assessment should include:

- Caring tasks and responsibilities
- Carers other responsibilities – employment, study, care for others
- Carer physical and emotional health status
- Access to formal and informal support
- Sustainability of the care relationship
- Carer goals

In addition to face to face assessment, the option for face to face eligibility screening should be available to clients and carers who are unable to complete this step over the phone. Clients and carers that may require face to face screening include those who identify with one of the special needs groups; have communication, speech or hearing difficulties in taking part in this process over phone; or have a cognitive impairment or mental illness.

**8. Are there better ways to group outcomes?**

Sector Support and Development is not a client or carer related outcome and would be better represented as both an overarching activity across all the other outcome areas and as an activity that helps to connect and link the diverse service delivery outcomes.

**9. Are there specific transition issues to consider?**

## 8.1 Existing clients and carers with higher needs

Carers Australia has identified a number of transition issues which must be considered when planning for the introduction of the CHSP, which can be summarised as:

- Many NRCP and HACC clients have higher needs
- Disincentives to transition to packaged care
- NRCP for carers of people under 65
- Unfunded support services
- Integration with NDIS and other programs including carer support, health services and state funded programs

This section includes unpublished results from a recent survey conducted by the Victorian State-wide NRCP Network and completed by 79 respondents representing a range of different respite service types.

Many carers and older people who are currently supported by HACC and NRCP would be ineligible if the CHSP is restricted to those who have needs that do not exceed a basic support programme. According to the Victorian NRCP survey, the majority of respondents estimate that at least half of care recipients have high care needs. The survey also shows that many older people and their carers access multiple programs and many clients have been receiving support for more than 12 months.

Another key issue is that many older people and their carers have declined packaged care and chosen to remain with the NRCP and/or HACC program. 61.5% of respondents in the NRCP survey said they know of carers who have refused a Home Care Package because they felt that they would be disadvantaged. In many cases this is because of increased costs and at times decreased services. Others chose not to accept a package because they were told they would no longer be eligible for respite through NRCP or they did not want to lose staff with whom they have developed a relationship.

As the new CHSP aims to cater for people with a lower level of need for formal services, the reasons why carers and older people have chosen to remain with HACC despite being eligible for packaged care need to be considered. While the difference in cost is one factor, the comments from the survey and anecdotal evidence also reveal that the risk of receiving less support through packaged care, lack of flexibility around service providers (especially the potential to have to leave a service with which they have developed a strong relationship) and restrictions around access to valued community based respite care programs are also significant.

Another issue in the transition to CHSP is that many HACC and NRCP funded services are providing additional support which does not reflect the funding received. This is particularly the case for programs funded under HACC Service Group Two, such as case management. See comments in response to Question 12 for further detail.

Carers Australia is also concerned about transitional arrangements for carers of people under the age of 65 (or carers of Aboriginal and Torres Strait Islander people under 50) who are currently accessing support through the NRCP. In some cases they will be eligible for support provided through the NDIS when it is rolled out nationally. However there are many other cases where the person has a disability, a chronic illness or a palliative care need who will not be eligible for the NDIS but the carer has previously been assessed as eligible for respite and wishes to continue to receive this support. In some regions this would be provided through state based programs, but in some states it is unclear where carers of people who are ineligible for the NDIS will access respite care. The fact that the NDIS will not be operational in all areas until after the CHSP is introduced also poses challenges.

In transitioning to the new CHSP it is important that this program be integrated as much as possible with other funded aged care services, the NDIS and other programs which support carers and older people, including the primary and acute health systems and state based programs.

The interplay between client and carer need and multiple service use across differently funded programs is highlighted by the Australian Institute of Health and Welfare (AIHW) finding that about 60% of users accessing both disability services and HACC programs had a carer in 2010–11, and that their carers relied on respite services from both disability services and HACC programs:

> *"Users accessing both programs were much more likely to receive disability respite services than Disability Services only users and to receive HACC respite care and centre day care services than HACC only users.*
>
> *Informal carers provide most of the assistance needed by people with severe or profound core activity limitation living in the community (AIHW 2011). This highlights the importance of providing a range of flexible services to support informal carers, and to help maintain the stability of community living and caring arrangements.*
>
> *Ageing of informal carers, especially ageing of parents caring for their child with early onset disability, is likely to continue as a main issue. Around half of informal carers of users accessing both programs were aged 45 or over, including 15% who were aged 65 or older."*

(Australian Institute of Health and Welfare 2014. People using both Disability Services and Home and Community Care 2010–11. Disability series. Cat. no. DIS 64. Canberra)

A final point to consider is the uncertainty for carers and older people who are clients of existing programs. Many carers have built strong relationships with services and staff that may lose funding with the introduction of the CHSP. In order that the transition can be as smooth as possible with minimal disruption to carers and older people supported by these programs, it is vital that clear information is provided in a timely manner to allay fears and

explain the new system, including any new service providers which might be taking over from those which they have grown accustomed to working with.

**10. How are supports for carers (other than respite services) best offered? For example, should these be separate to or part of the Commonwealth Home Support Programme?**

## 9.1 Recommendations of the Productivity Commission

The Productivity Commission Inquiry into Caring for Older Australians, 2011 made the following points:

- The Commission supports the development of a National Carer Strategy but also considers there is an *immediate need* to develop additional supports for carers from the existing base of programs in the aged care system

- Carers should be better supported in their caring role through a variety of measures: – The proposed Australian Seniors Gateway Agency would assess the capacity of informal carers to provide ongoing support when assessing an older person's needs – The proposed Carer Support Centres should be developed to undertake assessments of carers needs. Where appropriate, these centres would also deliver specialist carer support services including carer education and training; emergency respite; carer counselling and peer group support; and carer advocacy

- Action in other areas can also improve support for carers, including trials and evaluations of various respite options

Additionally the Productivity Commission Inquiry into Disability Care and Support recommended that in order to sustain informal care and support, the NDIS should:

- assess carer needs as well as those of people with disabilities and, where needed, use the assessment results to:
  - refer people to specialist carer support services including Carer Support Centres and to the National Carer Counselling Program
  - include the capacity for accessing counselling and support services for carers as part of the individual support packages provided to people with a disability

Whilst the two reports differ slightly regarding carer assessment, they are in agreement on the need for carers to have access to a range of carer support services other than respite care in order to sustain their caring role and that these services should be available separately to direct services for older and younger people with care and support needs.

The Productivity Commission recognised that carers form a key, if unpaid part of the aged care and disability support workforce and that sustaining informal care is crucial to the sustainability of these formal systems. Of course carers are not only part of the workforce, they are also co-clients and people with needs separate from their caring roles.

CHSP is clearly being re-oriented to a lower intensity support service, with people with higher and more complex needs being diverted into Home Care Packages and Residential Aged Care. The program is also clearly constraining eligibility towards those over 65 years of age only (or 50+ for Aboriginal and Torres Strait Islander people). It is important that in

the division of responsibility for services to clients aged over and under 65 years of age between different levels of government, there is no net loss in access to support services for carers.

**Recommendation 13:**
Carers Australia recommends that carer support services other than respite care should not be part of the CHSP, just as they are not part of the NDIS. Whilst direct service delivery offered under NDIS and CHSP should always take account of the needs of people in care relationships, carers are usually not able to access these independently of the person they care for.

Independent access is an important principle in the design and delivery of specialist carer support services. Currently carers do not require the knowledge, permission or cooperation of the person they care for in order to access services such as peer support or counselling.

Currently carers cannot access the suite of direct service delivery such as domestic assistance under the Commonwealth HACC Program in their own right without the older person they care for having been assessed as eligible. In some situations where a client does not wish to be assessed, this means carers do not receive these services. This includes the proposed service outcomes under Care Relationships in CHSP, specifically respite care. Respite care or any other services cannot be provided to a client who is unknown to the 'system' except in an emergency. However carers are currently able to access the NRCP as they are considered the clients of this program, hence the provision of 'indirect respite' services under NRCP to carers.

In order to provide maximum support for carers, eligibility in their own right must be part of the future design of the remaining elements of carer support services. The future design of the carer support services must also continue to enable brokerage of some of the specific services available under the CHSP where this is required to support the care relationship.

**Recommendation 14:**
Carers Australia recommends that in line with the previous aged care reform commitment to the development of Carer Support Centres, these will be established as the 'place to go' for carers. They will provide carer specific information, education and training, counselling, access to emergency respite and referral to other services. Carer Support Centres will focus on preventative assistance to sustain carers in their caring role and reduce reliance on emergency respite.

**Recommendation 15:**
Carers Australia further recommends that carer advocacy, whilst not a support service identified in the government's response to the Productivity Commission, is an essential support to assist caring families to transition to new programs and to navigate the changing landscape of aged care and disability services as the reforms continue to roll out.

The discussion paper prepared for the then Department of Health and Ageing by Urbis on developing a model for new carer support centres emphasised the importance of carer support services:

- integrating with other functions and services of the Aged Care Gateway
- complementing other aged care, disability, health and community care systems

The vision outlined in the Urbis paper of carer support services being for “all carers” regardless of the age of the person receiving care, their condition or their eligibility for formal care and support services is now more important than ever. Transfer of funding responsibility between different levels of government for clients aged over and under 65 years of age must not result in unintended consequences for carer access to the support services they need.

**Recommendation 16:**
Carers Australia recommends that DSS expedites internal discussions between the former FAHCSIA and DOHA divisions about how to approach caring needs and issues across the lifespan.

**Recommendation 17:**
Carers Australia further recommends that DSS convenes a cross-sector advisory group to provide expert advice on nationally consistent design and delivery of carer support services.

## 9.2 Connections between CHSP and carer support services

As the examples of carer support services currently in existence across Australia demonstrate, carer needs for support are multi-faceted and vary according to characteristics of the carer and the person receiving care, and the nature of their care relationship. Reviews of national and international research reported in the Urbis discussion paper support multi-component intervention with carers. Provision of respite care alone does not have demonstrated health and wellbeing impacts for carers. For carers to be supported as well as possible in their caring role, services provided under CHSP and carer support services must not result in additional difficulties in navigating the service system and must be provided in an integrated and coordinated way.

**10 What capacity building resources are needed to assist with the sector’s transition to the Commonwealth Home Support Programme?**

Carers Australia supports Alzheimer's Australia’s position on activities that would need to be in place for both consumers and providers in the transition to the Home Support Program:

- Clients and carers should be supported to understand the changes, particularly around the approaches to restorative care and reablement.
- Clients and carers need information on the changes and assistance to navigate the new system and be supported and empowered to make choices about their care. Without support consumers are unlikely to know what options to consider beyond traditional services.
- Training service providers and staff on how to work with consumers to develop genuinely goal directed care plans in the context of their emotional, social and physical needs.
- A focus on workforce development which aids the development of the attitudes, approaches and skills involved in a wellness and reablement approach to service provision.

**Recommendation 18:**
Carers Australia recommends that any strategies to build the capacity of the aged care workforce should also consider the education and training needs of informal carers, especially in relation to embedding a wellness and reablement approach.

**Recommendation 19:**
Carers Australia recommends the allocation of resources aimed at empowering clients and carers and enabling them to advocate for themselves.

**11 How should the current Assistance with Care and Housing for the Aged Program be positioned into the future?**

Given the specialist nature of this program Carers Australia supports the ACHA program being retained as a specialist program as part of the vulnerable persons linking service attached to My Aged Care. Given limited coverage, limited resources and projected growth in need, this program will need growth funding to meet future demand.

**12 Are there any other issues that need to be considered in transitioning functions from the current HACC Service Group Two to My Aged Care?**

There are risks that the proposed changes to Service Group 2 will mean that non-output based support services needed by clients and carers will not be met by My Aged Care or the National Aged Care Advocacy Program and will leave clients and carers without access to the services they need to address their particular needs and circumstances.

Some of these provide specialist support to culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people and those living in rural and remote areas. Carers Australia supports NACA's position that in some cases, such as for CALD and ATSI clients and carers, ongoing support to register with My Aged Care will be needed beyond the transition period. This may include interpreting services and funded support positions with CALD/ATSI organisations to support clients and carers to communicate with My Aged Care as there is a risk that agencies with no specialised cultural knowledge may not accurately assess the needs of CALD/ATSI clients and carers.

Some of these specialist services are also currently provided through Carers Associations and Alzheimer's Australia in each state and territory. The funding provides for specialist information and education to individual clients, carers and families as well as building the capacity of providers to work effectively with carers and people with dementia respectively.

**Recommendation 20:**
Carers Australia recommends the continued funding of these state based activities in the CHSP as they provide a more local and more specialist service than will be provided through the national My Aged Care. These types of services are not provided incidentally through direct service provision.

## 12.1 Information and referral

There is a need to retain the specialist information advice and referral function within carer support services to ensure good connections between CHSP and the range of other services that carers access.

## 12.2 Assessment

The National Assessment Framework and Tool used by My Aged Care assessors must be designed in such a way that identifies carer needs and enables referral for specialist carer assessment in carer support services where required.

## 12.3 Care Coordination and Case Management

Currently many service providers are providing case management for carers and older people which they are not necessarily funded to do. The survey of Victorian NRCP providers revealed that over three quarters of respondents are providing care coordination or case management (not respite related) because there is no one else to undertake this, although most were not funded to do so. Comments from providers revealed that the key reasons for this were that:

- the carer did not receive care coordination or case management elsewhere
- the client and carer were waiting lengthy periods of time to access case management through home care packages
- the case management which they were meant to be receiving through other programs was inadequate
- the case manager overlooked the needs of the carer

> *"Significant amount of time goes to case management. Most clients do not have anyone other than the respite coordinator to call on. All referrals, trouble shooting, care planning, forward planning and day to day care coordination is managed by the respite coordinator... It is impossible not to do that for them. Carers are elderly, frail, confused, exhausted and need a lot of information and service coordination and someone to do things for them*."

> *"It is amazing how many carers attend our service without having had any other services in place or having any knowledge of what support is available. Short term case management and care coordination is provided until we have been able to refer them to receive that extra support through the appropriate services and this can take some time, so in the mean time we have no other options. This impacts the program resources greatly, however our duty of care is to ensure that our carers and consumers have the appropriate care and support in place."*

Anecdotal evidence indicates that this is also the case for other HACC funded programs. This means that the full extent to which case management is provided throughout the HACC and NRCP programs is not reflected in the current funding or data regarding the

program, despite the fact it can represent a significant proportion of their workload, and also contributes to improved outcomes for the older person and their carer.

## 12.4 Counselling

Carers Australia supports the direction of professional counselling being made available under the allied health outcome area.

## 12.5 Advocacy

There is a need for specialist carer advocacy support especially with carers in complex care relationships or where the person they care for is reluctant to engage with the formal care system. Carers need support to be able to advocate for themselves, access to independent individual advocacy not only within the aged care system and systemic advocacy by groups representing their needs and issues. Due to the specialist nature of this advocacy, it is unlikely that it will be able to be provided within the expanded National Aged Care Advocacy Program.

**13. Is there anything else you want to raise to help with the development of the Commonwealth Home Support Programme**?

## 13.1 Fees

Carers Australia is concerned that when developing the nationally consistent fees policy for the CHSP additional costs faced by carers are considered. Carers may be assessed as having the ability to pay more for their services than they are actually able to, due to high costs related to their caring role. These include medications, medical appointments, therapies, transport (especially costly for those living in rural areas) and aids and equipment. Assessments of a client's ability to pay for services must consider their total out of pocket costs so that they are not forced to make difficult decisions about which services to receive, when they have been assessed as requiring it. It is the experience of all providers of carer support services that carers often put the needs of the people they care for first and will go without support for themselves, even at great personal cost. This jeopardises the sustainability of the caring relationship and risks the older person requiring greater support in the future.

## 13.2 Aids and Equipment

As noted on p. 56 the current Commonwealth HACC program funds only a very small proportion of older people's aids and equipment requirements compared to state and territory programs. Although there is much evidence that timely and appropriate provision of aids and equipment can reduce the ongoing need for other support services, the paper proposes a subsidy of only $500 per person per year.

As the Commonwealth will take over aids and equipment for people aged under 65 years as part of the NDIS, we suggest that the Commonwealth should also take on the funding for aids and equipment for people aged over 65.

## 13.3 Evaluation

As WA HACC services will not be included in the CHSP until the implementation of a transition period from 2016-2017, we believe it will be beneficial to the evaluation of the new program to compare the CHSP to provision of HACC in WA during the transition period.