Key Directions for the Commonwealth Home Support Programme Discussion Paper

Submission

Completed submissions are to be sent by 30 June 2014 to:
CHSP@dss.gov.au (preferred method) OR

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State/Territory: Victoria

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Question 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?

The Brotherhood proposes the following for consideration:

1: Provision of services to people with high care needs (using the HACC High/ Level 3-4 criteria) within the respite and social support context needs to be pursued as a key direction in the development of the CHSP. The NRCP was designed to support family / friends to care for somebody who was unable to care for themselves because of frailty or disability, with an increased likelihood of functional decline. As articulated in the Discussion Paper the CHSP is being designed to provide basic support for older people living at home, encompassing the delivery of services under the Social Participation and Care Relationship. These service groups (as described under the CHSP) are currently supporting people with high care needs as demonstrated by the data provided in the *NRCP Victorian State-wide Online Survey 2014,* which reports that every agency funded under NRCP is supporting care recipients with high care needs. The Brotherhood is able to report that 77% of care recipients accessing their NRCP programs have dementia or dementia with challenging behaviours with, 72% of people accessing programs funded under HACC Planned Activity Groups being people with high needs with 74% receiving support from an informal carer. This data demonstrates that the service groups which deliver social support and respite are not only supporting people with low and basic care needs but a higher level of people with high care needs It is a huge concern to the Brotherhood that failure to recognise the needs of people with high care needs (people with dementia) in the implementation of the service models delivered under the service groups 'Social Participation' and 'Care Relationship' will result in a gap to service provision for some people who are currently supported by the HACC and NRCP programs. *Please refer to Question 3 for further information*.

2: Brotherhood recommends the maintenance of the aims, objectives and the intent of the NRCP in the development of the CHSP to ensure that carers are recognised as 'clients' with needs separate to the care recipient. The Discussion Paper articulates clearly how care recipients with low and basic care needs will be supported within the new programme however, the Discussion Paper does not articulate what 'basic support' is for a carer and limits the 'Care Relationship' service group to only delivering respite, which is not the experience of NRCP providers as reported in the NRCP State-wide Online Victorian Survey 2014 where 77% of respondents said they were providing care coordination or case management to carers because there was no one else to undertake these tasks. *Please refer to Question 9 for further information.*

Currently there are carers who are in receipt of respite in addition to the care recipient receiving HACC or HCP services (*NRCP Victorian State-wide Online Survey 2014).* The premise under the proposed CHSP is that once a person is allocated a HCP, it is expected that the package will meet the needs of both the care recipient and the carer, respite inclusive. The Brotherhood is currently providing 3 carers with in home respite options on a full cost recovery basis, however this is not the norm, as most carers require a range of respite options in order to assist them in their caring role (such as day centre - overnight care).These additional costs cannot be met within the funding of the HCP. Although the CHSP proposes when a carer can access additional CHSP services, these will be time limited, monitored and reviewed. This does not recognise the carer as a 'client' with care needs which will only increase over the span of the caring role, particularly carers of people with dementia. The Brotherhood believes that this gap in the service system will compromise the caring role and see the breakdown of the care relationship.

Question 2: How should restorative care be implemented in the new programme?

CHSP needs to consider that the proposed service group (Social Participation) can have a role in the implementation of restorative care. As a result of the ASM implementation within the Victorian HACC program many planned activity groups have been required to review their service delivery models in order to meet this requirement. The role of planned activity groups (which sit under the service group Social Participation) now deliver a range of activities which not only builds on people's social connections but also assists people to maintain their health and well being using a restorative approach. The days of playing bingo and knitting are no longer the norm and many organisations have responded to this policy direction by delivering a scope of activities which are flexible, diverse and based on identified need and interest.

The Brotherhood delivers a range of activities which are based on a person centred approach, where clients are asked for their input into the development of the program. Some of these activities may include fishing, ten pin bowling, volunteering with other organisations (community connections), exercise programs, gardening, men's specific activities, culturally specific social groups, computer skills and intergenerational activities.

Below are some outcomes which have been achieved:

- clients have started their own vegetable garden as a result of their participation in the gardening group.
- clients have increased their physical strengths by increasing their hand weights from 1kg to 3kg.
- clients are involved in the toy making programme for disadvantaged children.
- carers have re-engaged in past activities, such as golf and indoor bowls.
- carers participate in the exercise program.
- clients with dementia are members of a choir.

The new programme needs to provide scope for the service group (Social Participation) to be able to implement a restorative care approach as part of their service delivery. It is imperative for this service group to have the scope and the autonomy to be able to deliver a range of activities which are developed in response to the identified need and have the desired outcomes as expressed by the person.

It is the Brotherhood's view that there is potential for better referral pathways to be established between the service types 'allied health / therapy services and social participation' as currently HACC PAG programs provide not only social support, but also increased independence and nutrition.

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

As stated in Question 1 Brotherhood data demonstrates that the current HACC and NRCP programs are providing support to people over the age of 65 with high care needs. Therefore the Brotherhood considers that the proposed eligibility criteria are not appropriate and the delivery of the service types Social Participation and Care Relationships should not specify the level of functional limitations.

The Brotherhood would like to present two recent referrals as case studies in order to demonstrate a typical request for respite and the possible outcome for carers and care

recipients under the proposed CHSP.

Referral Information: 1:

- Referral for respite
- Carer reported that she is struggling and is concerned that care recipient may refuse services.
- Care recipient is eligible for a HCP Level 2
- Care recipient is 82 years of age has a diagnosis of dementia
- Carer is required to visit care recipient twice a day (to ensure she is set up for the day and to assist her in the evening)
- Carer is requiring respite as she works 2 days per week and care recipient is making her feel guilty for not spending time with her.
- Care recipient is receiving 2.50 hours per week via HACC.

Issues identified:

Carer and care recipient will be eligible to receive services under the CHSP however as the dementia progresses and care recipients support needs increase care recipient will be ineligible to access either the Social Participation and/or Care Relationship service groups as her needs will exceed basic support. If the carer requires respite the care recipient will need to be transitioned into another program which will not be available under the proposed service system, unless there is funding to support people with high care needs.

Once the care recipient is allocated a HCP Level 2 the package will be able to fund the current service level (2.50 hours of support per week); however in reality there will be no available funding in the package for the purchase of respite on a full cost recovery basis.
Outcome: The carer will be unable to remain in the workforce or will need to place the care recipient into residential care.

Referral Information 2:

- Referral for respite
- Wife has recently become a carer after husband had a stroke in December 2013.
- No other family supports and English is their second language.
- Care recipient is up 10 times per night and is urine incontinent.
- Carer is tired as she is unable to sleep throughout the night.
- Care recipient requires constant supervision and becomes frustrated with carer.
- Carer stated that care recipient was very independent prior to his stroke.
- Carer is requesting a break from her caring role one day per week and also thinks care recipient would benefit from the additional stimulation.
- Care recipient has been assessed for a Level 4 HCP. Care recipient is currently receiving 3.00 hours per week via HACC

Issues identified:

Care recipient not eligible for CHSP (assessed for a HCP Level 4) as current support needs exceed the basic support programme therefore unable to access the Social Participation or Care Relationship service types.

Carer's respite needs cannot be met as care recipient's needs exceed the basic support programme.

continues

Outcome: Care recipient will need to wait for a HCP package (Level 2) where the current

level of support of 3.00 hours per week will be maintained however there will be no available funding in the package for the purchase of respite on a full cost recovery basis. Care recipient will be allocated a HCP (Level 4) however there is a high demand for Level 4 packages therefore it may be 12 months before a package can be allocated. Carer stress will increase and care recipient will enter residential care.

Question 4: Are the circumstances for direct referral from screening to service provision appropriate?

Question 5: Are there particular service types that it would be appropriate to access without face to face assessment?

Question 6: Are there any other specific triggers that would mean an older person would require a face to face assessment?

Person has memory loss / dementia / cognitive impairment

Care recipient who may be reluctant to access services and /or

Carer who may be reluctant to access respite however there appears to be a high level of carer stress

It has been the Brotherhood's experience that some carers need additional support in order to access respite services. At times carers will be referred to the Brotherhood for services however when it comes to accessing the program they may not be ready to relinquish care and therefore decline services. Currently Brotherhood will ask carers whether they would like the Brotherhood to give them a call in 8 weeks to review the situation. This additional support (monitoring carers who have not proceeded with the referral) needs to be considered in the design of the CHSP otherwise there will be carers who will fall through the gap.

The other concern the Brotherhood would like to raise is how consent will be managed where the carer is requesting respite however care recipient as a result of cognitive impairment does not consent to receiving support from the respite agency. This needs to be considered in the design of the CHSP otherwise carers will once again be at risk of falling through the gap. Currently the Brotherhood is able to manage this as a result of Assessment Worker undertaking home visits and having the opportunity to speak to both carer and care recipient.

Question 7: Are there better ways to group outcomes?

Question 8: Are there specific transition issues to consider?

Under the proposed CHSP many of the care recipients accessing Brotherhood NRCP and HACC (assessed for Level 3-4 HCP or HACC High) services will need to be transitioned into other programs as it would appear that their needs exceed the basic support programme. It needs to be noted as per the examples provided in Question 3 many carers being referred to Brotherhood for respite are caring for somebody who is waiting to be allocated a HCP. If the care recipient is assessed for a HCP Level 3-4, in interpreting the design elements of the CHSP the carer will not be referred to any of the CHSP funded services as their care needs will exceed the basic support. This needs to be further clarified.

Question 9: 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?

A more considered approach to the needs of carers is required in the development of the CHSP as the model limits the needs of carers to respite in order to maintain the care relationship. As a provider of both HACC and NRCP services it has been our experience that a carer requires a range of other supports as stated:

Carers not only require respite services to assist them in their caring role but also require emotional support and information which is based on individual needs. It is reported that carers who experience a high level of stress often don't feel competent with regard to the caring task. Offering practical and emotional support can result in increased feeling of competence and an extension of the period the carer is able to take on the task of caring (Droes 2004). This is evident with many carers who access Brotherhood programs requiring additional emotional support which often is provided by ALL staff or through the Banksia Carer Support Group. This support is often in relation to how the carer is feeling, how they are managing at home, their coping limitations and often the need for additional services and strategies. This information is often gathered outside review meetings and informally gathered during respite drop-off and pick-up times and telephone conversations. In order to deliver respite services a carer support model is required. Ideally it should be integrated within the respite model of care. The link between carer support and respite provision is interconnected and cannot be considered in isolation. Providing services to carers of people with dementia requires extra encouragement and emotional support. This is given in many ways and by ALL program staff. Staff require the emotional intelligence to be able to read how a carer is feeling on the day of contact and provide validation and encouragement to the carer.

An example of this is when a staff member picking up a client for a Day Program noticed that the carer who always is dressed and ready for the day was still in her pyjamas. After some discussion it was determined that she had been given some terrible news and was not coping well. The staff member reported this to the Program Coordinator where she was able to make contact and offer support. This carer trusted the Brotherhood but did not want any other supports in place. She agreed to have a worker come into the home for a short period of time. This assisted her getting well, and she was open to further supports being put in place. This carer was known to contact the Program Coordinator every week to let her know

that her husband would need the bus. She would then talk in length about her daughter and how hard it was for her. This carer eventually agreed to support from the Commonwealth Respite and CarerLink Centre via a Carer Support Worker which in the past she was not willing to accept. The carer accepted support when she trusted those advising her enough to allow this to happen. Her husband is now receiving a Home Care Package. This carer has limited family, is receiving treatment for cancer and cares for her husband with dementia who also has complicated health issues with asthma and breathing issues. This level of intervention would not have been provided if the service was not carer focused and that there were no provisions for a Carer Support Worker to assist the carer.

The carer focus service cannot only be limited to the Care Relationship service group but also needs to be considered in the service group of Social Participation as some of these participants will also have carers. These services need to be able to deliver this additional support to carers as respite as a stand alone service is not appropriate for carers.

Question 10: What capacity building resources are needed to assist with the sector's transition to the Commonwealth Home Support Programme?

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

Question 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?

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

The new programme does not consider people with dementia as a special needs group or make reference to how services will be delivered in order to meet the needs of people with dementia. The Brotherhood currently receives NRCP and HACC funding to deliver support to carers and people with dementia or dementia with challenging behaviours. Currently some of the behaviours can be managed within the current service structure as a result of our specialist knowledge in dementia care however this is limited once the person requires more intensive staff support.

It is important to note that dementia is a progressive illness and therefore the needs of the person with dementia and their carers will increase over time. For many people with dementia and their carers, a service such as day care is vital to the continuation of living in the community. Although there is recognition of the significance that day care / respite has on the person with dementia and their carer there is also evidence to demonstrate that the current structure is unable to meet the needs of people with more complex care needs as a

result of behavioural psychological symptoms of dementia (BPSD) or requiring palliative care as a result of their dementia. As a result of this gap in services the Brotherhood developed the Short Break Stay (a 3 day respite model of care for people with complex care needs) for which we received some short term funding to deliver the program. We also introduced a High Care Day Program on a fee for service basis as an adjunct to the current day programs. The uptake of the High Care Day Program has been slow as there is often limited capacity in the package to fund attendance in the program; however there is a demand for the service. In 2007, NRCP funding was allocated to some agencies to deliver high level respite services; however there have been no additional growth funds to meet the increased demand or to provide alternative models of respite for people with more complex care needs. The Brotherhood believes that the CHSP should be responsible for funding community based respite which would include services for people with more complex care needs.

The Brotherhood's view is that services delivered to younger people with dementia should remain under the Aged Care Sector given that aged care providers are knowledgeable and skilled in the provision of dementia specific services. Many providers are currently broadening their scope to cater to the needs of people under 65 years of age. Brotherhood is no exception.