

Submission by the Victorian NRCP Services Network to the Productivity Commission July 2010

Issues for Consideration

The hallmark of National Respite for Carers Programs (NRCP) Services has been their flexibility and capacity to respond to local needs. The breadth and diversity of responses to supporting carers is testimony to this.

(See Addendum¹ for a description of NRCP including history, aims and types of respite programs.)

NRCP funding prioritises the needs of the carer over the person needing assistance. With studies demonstrating the poor health and poverty typical of carers, the NRCP program is an important support to carers.

NRCP Providers value the flexibility of this funding.

There are a number of issues and challenges for NRCP providers which this submission seeks to bring to the Commissions attention.

1. **Mixed funding:** For many providers NRCP is just one funding stream amongst many. Currently each funding stream has different standards & reporting mechanisms. This creates complexity for providers managing different funding streams & unnecessarily wasting time & resources on administrative tasks.

Recommendation: Streamline funding & reporting systems

2. **Complexity of the service system:** For community care service providers, carers and people needing care and support, accessing information about the existence of services is confusing and complex. This is a well documented issue. There are a number of disability specific and region specific websites in Victoria. This has added to the complexity of the system.
The Victorian NRCP Services Network has recently developed a state-wide website www.respiteseeker.com.au (in partnership with the Victorian Carer Services Network) which is in its initial stages of development. This serves as a local (Victorian) response to this complex issue created by multiple funding

¹ Victorian NRCP Services Network

streams and governments. It is an inclusive one-stop-shop response to streamlining the respite care system.

Recommendation; Support services which make the community care system less complex & easier to navigate

3. **Primary Care Partnerships:** PCP's create a further layer of complexity with a narrow focus often inconsistent with the catchments of NRCP providers. The number of these projects across regions (31 PCP's in Victoria) precludes participation by most providers which therefore raises questions about their relevance and or capacity to represent and include local providers

Recommendation: Rationalisation of primary care partnerships in Victoria

4. **E-referral:** The e-referral systems are a good example of the unnecessary complexity and inconsistency in the service system with two e-referral systems operating across Victoria (S2S and Connecting Care) with many providers needing to access both systems.

Recommendation: Streamline service provision by using a single e-referral system across the state

5. **Unit costings:** There are inconsistencies between providers in the amount and types of charges applied to the respite programs.

Recommendation: Development of guidelines on charges for NRCP services to ensure greater consistency and equity between NRCP services and more broadly in the sector.

6. **Funding recognition of time spent on carer support and respite coordination:** It is an issue for NRCP services that funding is provided for hours of direct respite provision but not for time spent providing carer support and coordinating respite services.

Recommendation: Capacity in funding for carer support and respite coordination

7. **Case management.** As the complexities of families receiving community care respite services increases, some degree of case management is being provided by services not funded to provide case management and this is inconsistent across providers.

Recommendation: Consideration should be given to a non-brokerage case management service model

8. **Translation/Interpreter Services** - Unlike HACC funded services, NRCP services do not have access to funded Translation/Interpreting services. Therefore respite clients from a CALD background are severely disadvantaged by core funding being diverted to Translation and Interpreting costs rather

than direct respite provision. This is inconsistent with the National Respite for Carers Standards and the expected Outcomes, in particular, Objective 1 Access to Services, Outcome 4.3 which states, "Consumer's cultural needs are addressed".

Recommendation: That all NRCP services be given access to a credit line with a pin number, through a translation/interpreter service, similar to that set up by Home & Community Services.

9. **63 days of respite issue:** How much respite is enough respite? Income support from Centrelink has been an issue for a small number of carers usually part-time working adult children claiming carer allowance and carer payment. It does beg the broader policy question of levels of 'allowable' service in the community particularly with a shrinking carer population as more people enter the workforce and are unavailable to care.

Below is the Centrelink advice to carers and NRCP providers to calculate allowable levels of respite provision whilst still maintaining eligibility for Carer allowance and Carer Payment.

E.ref describes Respite as temporary cessation of care and these provisions are: The temporary cessation of care provisions do not apply for breaks from caring that are less than a full 24 hour absence, midnight to midnight. Short periods of care (of less than 24 hours) during the day or evening by another person or organisation do not count as temporary cessation of care, even if this occurs regularly.

Example - absence calculation: A carer provides care on Tuesday morning and the care receiver enters respite that same day. They provide care again on the Friday afternoon that the care receiver returns home from respite. This would result in a total of two respite dates being coded. The start date is Wednesday and the end date is Thursday.

This is because the carer is taken to have provided care on the Tuesday and again on the Friday. There are only two full 24 hour periods from midnight to midnight that the care receiver was absent.

The definition of respite under the Social Security Guide is as follows:

A carer (1.1.C.40) remains qualified for CA where they temporarily cease to provide the care receiver (1.1.C.21) with care and attention on a daily basis, for up to 63 days in a calendar year.

Short periods of care (of less than 24 hours) during the day or evening by another person or organisation, will not preclude receipt of CA, even if this occurs regularly. These periods do not count toward temporary cessation provisions.

Example: A neighbour, day care centre or other family member provides care while the carer has a break to attend to their own personal needs.

The temporary cessation of care provisions for CA and CP should not be confused with formal respite funded through DoHA.

Case example: How much respite is enough respite?

A woman was caring for her sister with multiple sclerosis. She also worked part-time & claimed a part benefit from Centrelink. The sister with MS accessed residential respite every 3 months for 2 weeks and once a month accessed overnight respite at an overnight community house. She also attended a day centre program. As a result of a Centrelink audit, this carer was forced to no longer access the overnight respite or lose her eligibility for Centrelink support. This has placed considerable strain on this carer and impacted on the sister's social connectedness.

Recommendation: That the Social Security Act be amended to allow for increased use of respite to support carers to maintain their caring role whilst receiving Centrelink carer's payments.

10. Employed Carers: Currently NRCP fund specific programs to support working carers of people who are frail aged or living with dementia. Many working carers are not eligible for services because the person they care for is not aged or living with an age-related disease. The Aged/Disability barrier at 65 years of age creates a 2 tier system.

Recommendation: Eligibility changes to working carers programs to include people under 65 living with disabilities.

11. Increased complexity of care needs: NRCP services, as with other community services, are required to meet the needs of carers and people requiring care that are much higher and more complex than they were at the inception of the program 12 years ago. Changes to entry level residential care (ACFI) and community expectation of community care service provision (Baby Boomers' Expectation of Dementia Care: A Regional Survey 2007 Report) have created an increased demand for service with greater complexity of care needs. Implementation of the Active Service Model in some local government areas has precluded eligibility to HACC services and further impacted on demand for NRCP and the complexity of the client group.

Recommendation: Consideration of increased funding support to enable high needs support. Increased access to allied health and nursing assistance to participants of NRCP services programs.

12. Statistical Evidence: All providers contribute data to the DoHA about level of service provision and issues encountered. There is currently no feedback loop.

Recommendation: Services would benefit from regional and state-wide information to assist with gap analysis and service planning.

Addendum 1: Description of NRCP

History of the National Respite for Carers Programs (NRCP)

In 1995-1996, the National Respite for Carers Program was established by the Commonwealth Department of Health and Ageing. The original funding was provided to the Commonwealth Carer Respite Centres (CCRC). In the following years, funding was provided to a broad range of organisations for the delivery of further individual NRCP services.

The program provides information, counselling and support for carers, as well as assistance to help carers take a break from caring.

The Australian Government currently provides funding of over \$168 million for the program to assist carers with information, respite care and support.

Funding

Funding is provided to:

- **Commonwealth Respite and Carelink Centres**
- **Carer Counselling and Advisory Services**
- **Carers Australia**
- **Respite Services**

This submission is made on behalf of the Victorian NRCP Services.

NRCP services receive funding to provide respite services that support carers to maintain their caring role.

Community based respite services are funded to provide respite opportunities in a variety of settings such as:

- Day care centres that provide respite for part of a day or a full day.
- One to one, respite services, including in-home overnight care and personal care services.
- Activity programs such as men's sheds, gardening groups, coffee outings and trips to the movies.
- Overnight respite in houses in the community.

- Host homes.
- Direct respite which may assist the carer in having a holiday or break away from their caring role.

Aim of NRCP

The aim of NRCP is:

"To contribute to the support and maintenance of caring relationships between carers and their dependant family members or friends by facilitating access to information, respite care and other support appropriate to their individual needs and circumstances and to those of the persons for whom they care."

Source: Administrative and Program Guidelines for Respite Services funded under the National Respite for Carers Program (NRCP) May 2004

For those of us delivering NRCP services, this means putting the carer in the centre of the service picture.

There is a big difference between services that support carers and services that support people who need care. This difference lies in the *intent* of the service.

The intent of respite services, including NRCP funded services, is to **provide support to carers so that they can maintain their caring role**. Carers who are exhausted, stressed or overwhelmed are less likely to continue in their role as carers.

For this reason it is important that the carer's needs are assessed when providing respite. Of course, the planning must also consider the person who needs care but, for NRCP services, the carer's role is paramount.

Here are some things which are taken into account when planning respite services:

- The level of the carer's stress and the extent of their caring burden.
- The times that the carer would like to be able to take a break. For example, they may have a standing engagement or appointment, they might need to go to work or they may be having trouble sleeping at night.
- The length of time that the carer needs a break for. This may be a few hours, a day, overnight or a weekend.
- The carer's confidence and experience in using a respite service.
- The carer's social and financial situation.
- Other supports available to the carer.

- The carer's need for information or education.
- Issues of separation for the carer and the person who needs care.
- Other demands, roles or responsibilities the carer has.

Taking all of these things into consideration, NRCP service providers then aim for the best service for the person who needs care. In finding the best service for the person, the service provider is also helping the carer. When the person needing care has the best possible care and experience, this gives the carer peace of mind while they take a break from their caring role.

Case example: Putting NRCP into practice

Fernlea House Inc, in Emerald, provides respite in a day care setting. Since becoming an NRCP provider, Fernlea have changed their focus from solely providing care and services to the person requiring care. Now, Fernlea also provide care and services that meet the needs of carers.

Types of respite provided under NRCP

In-home respite

These programs provide one-on-one respite care to people who need care in their own home. This enables a carer to have some time away from their caring role. In-home respite is usually provided in blocks of two to six hours, weekly or fortnightly. In-home respite may also include the respite worker taking the person who needs care out to shop, have a meal, a walk, see a movie or participate in other short outings.

Some services also provide in-home respite overnight, with the worker staying in the person's home for the night and providing care. This allows the carer to have an undisturbed night's sleep, either at home or away from home.

Centre-based respite

These programs provide daytime, group and activity-based respite. These programs are very similar to the HACC-funded planned activity groups. Activities may include bus outings to community venues. Some centre-based programs are based around a specific activity, such as gardening, or are designed to meet the needs of specific cultural groups. Centre-based programs provide carers with part of a day or full day respite from their caring role.

Outings-based respite

These programs are funded to provide small to medium group day outings for people who need care. The outings may include a visit to a community venue, a meal or visit to other places of common interest such as parks, gardens or the movies. These outings are sometimes designed for specific groups, such as:

- groups of men or women
- people of a similar age
- people with similar disabilities or conditions (such as early-onset dementia)
- different cultural groups.

Overnight respite houses

These respite programs provide overnight care for a small number of people who need care – usually about two to six people. The respite may be provided for a single night or up to two weeks. It occurs on either a regular basis or from time-to-time. Most overnight respite programs also provide a full day centre-based program or are linked with such a program so that carers receive a full 24 hour break for each day and night that the person receives care.

Host home respite

A small number of programs provide small group respite for three or four people who need care in the home of a respite worker. These programs provide a social, homely respite day for the person who needs care while giving the carer a day of respite from their caring role.

Day respite in an aged care home

In these demonstration programs, high level aged care facilities are used to provide respite during the day. People who need care may join residents of the facility in their daily activity programs and meals and also have access to other services at the facility such as nursing care, allied health, hairdressing and so on.

Employed carers programs

These respite programs assist carers who are in paid employment (or who are studying to obtain employment or looking for employment). This kind of program allows carers to maintain and balance their caring and employment responsibilities. Employed carers programs may deliver any one of the respite types described above. Carers can access this respite either while they are at work or outside working hours.