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## **CARER SUPPORT and RESPITE CENTRE INC.**

### **Response to 'Draft' Productivity Commission Report:**

#### ***Caring for Older Australians.***

**February 2011**

# **Carer Support and Respite Centre Inc.**

*(Trading as Carer Support).*

**Response to Draft Productivity Commission report,**

**Caring for Older Australians:**

## **Introduction:**

It is our understanding that the primary focus of the report is on 'reforming' the current Aged Care Sector to provide a more streamlined, flexible, responsive and affordable Aged Care system.

This encompasses both Residential and Community aged care services.

The responses below address the probable impact of the reform on unpaid 'informal' Carers and the currently funded specialist services for these Carers. Further, it raises points of consideration when developing the final extent of recommendations for the final report in respect to these key stakeholders.

## **Background:**

Carer Support is in its 21<sup>st</sup> year of operation and is a specialist organisation supporting Carers living in the South and East Metropolitan regions of Adelaide. We are a not-for-profit, community based organisation with Charity status. We receive funding for specialist Carer Services from the Federal Government through the National Respite for Carers Program (NRCP), the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), as well as the South Australian Government through the Home and Community Care Program (HACC), the State Mental Health Unit and the Office for Youth.

## ***Specific Funded Programs include;***

- South and East Metropolitan Adelaide Commonwealth Respite and Carelink Centre. (NRCP). *Since its inception in 1997.*
- In-Home Emergency Respite Program. (NRCP).
- Respite Choices Program. (NRCP).
- Saturday Club Respite Program. (NRCP).
- NRCP Disability - Planning in Partnership Program. (NRCP).
- Employed Carers Program. (NRCP).
- Older Carers of People with Dementia and Challenging Behaviours Respite Program. (NRCP).

- Mental Health Respite Program. (FaHCSIA).
- Older Carers of Younger people with Disabilities Program. (FaHCSIA).
- Young Carers Program. (FaHCSIA).
- Targeted Carer Support Program. (HACC).
- Southern Collaborative Program (HACC).
- 'Raw Energy' – Young Carer Program. (HACC).
- Flexible Respite Options Program. (HACC)
- Carer Retreats Program. (HACC).
- Regional Respite Program. (HACC).
- Support Program for Carers of people with Mental Illness. - State Mental Health Unit.
- S.A. Office for Youth Grant for providing 1:1 tutoring to Young Carers.

This collective range of programs provided over the 21 years of operation has enabled Carer Support to provide a range of flexible, yet targeted support options to Carers of all ages and cultural backgrounds and has extensive grass roots experience in working with these Carers in supporting them and the person they care for.

### **Key areas of consideration:**

#### **1. Respite:**

Carers' lives and the needs of the person they care for do not only revolve around the Monday to Friday 9am to 5pm time periods. Therefore the support they require and their ability to access meaningful respite of both the planned and emergency nature outside of these time frames is essential. Quality Respite options must be available 24 hours a day 7 days per week and are critical in emergency situations. The current operations of the Commonwealth Respite and Carelink Centre (CRCC's) have been an outstanding resource in meeting the needs of significant numbers of Carers and the care recipient throughout the 24/7 time frame.

#### **Key operational aspects of existing Respite and Carelink Centres include;**

- a. A national 1800 number available 24/7 which allows the transferring of calls across all Centres using the Centel Network. Therefore anyone contacting the Centre on this number where they require to be transferred to another Centre can be immediately and directly linked with the appropriate Centre for that specific and individual caller. This transfer of calls is at no cost to the person contacting the Centre. This is a significant resource for people accessing services inclusive of the outside of normal office hour's circumstances.
- b. The ability of CRCC's to underwrite empty bed days in Residential facilities ensures for Carers and the person entering the facility for planned Respite that any fees associated with the Respite beyond their ability to pay can be met. This increases the accessibility of these Respite beds. This is of specific note in Emergency Situations. This underwriting of bed days is also a significant benefit to any residential respite provider as it ensures economic viability of the beds and

therefore these providers are then more willing to offer Respite within their facility.

- c. CRCC's have access to a significant 'Pool' of Brokerage funds which can be used in a range of flexible but targeted ways to ensure that Carers and the care recipient can access support regardless of their placement on 'waiting lists' for Packages or other in home supports; IE Personal care, Respite. This ability to 'Broker' skilled and often known and trusted workers is a proven cost effective, flexible and timely response to Carer/care recipient need. It provides reassurance and peace of mind for all concerned that the support provided is meaningful and of a quality nature. This outcome for families cannot be overlooked and must be ongoing.
- d. The ability of CRCC's to support people in a palliative care situation is exceptional and must be continued. It is our experience that this support, that is available 24/7, is very well received and considered to be a key component in the entire palliative care system operating in S.A. today. These fundamental and critical links between hospitals and the general health system with CRCC's should not be overlooked or removed.
- e. Carers from a myriad of cultural backgrounds currently access information, respite and support from Carer Support through the various programs funded to us. The ability of CALD and Aboriginal Carers to access support in culturally appropriate ways is essential and fundamental to the role we undertake. The established and trusted relationship these communities and individuals have with Carer Support services must be maintained.
- f. The relationships and continuity of services that CRCC's and the Seniors Information Service in South Australia have established via the CRCC Consortium is unique. Equally, but on a broader level, the successful relationships each of the Consortium members have with locally based providers has been and continues to be outstanding. These relationships and outcome driven links must be maintained.
- g. The relationship between CRCC's with broader Carer Support organisations is a must. The S.A. **CRCC Consortium** and the S.A. **Carer Support Network** already exist and the links between these organisations/Networks should be strengthened.
- h. It must be noted and accepted that being assessed for eligibility for a service is only one aspect of people accessing appropriate support which meets their needs. To be assessed and deemed eligible for services and then subsequently be placed on a waiting list for those services is often a worst case scenario for many Carers and the person they care for. Current Carer services in South Australia (as outlined above) do provide choice for people. It does offer interim support, it is cost efficient and effective and it does respond on an individual basis. These services can be provided on an interim basis while people 'wait' for more routine and packaged care. In any system supporting people, these fundamental elements of being able to access services when they are needed is essential and therefore must be available at that point in time.

## **RECOMMENDATIONS (FOR CONSIDERATION):**

- *The primary functions of Commonwealth Respite and Carelink Centres be maintained with an enhanced level of available resources to ensure the increasing demands for Carer Support can be met into the future. The Specialist Carer Organisations concept as outlined in the draft report reinforces this role for CRCC's.*
- *The links between Commonwealth Respite and Carelink Centres and broader Carer Support organisations such as the Carer Support Network in S.A. are recognised and strengthened.*
- *The links between Residential Respite Providers and Commonwealth Respite and Carelink Centres are strengthened to ensure of more viable and comprehensive range of both in and out of home Respite options are available, inclusive of emergency situations.*

### **2. Information:**

- a. Currently the provision of information can come from a range of sources. Including; Local Councils, Commonwealth Respite and Carelink Centres, Seniors Information Service, Local Community Centres and a range of locally based providers to name but a few. Additionally, many older people 'look' to their G.P. or local council or a perceived Government service such as CRCCs to provide them with **initial** information about where to go to find out not only what services they can access, but how to access them, how much will it cost and how soon can I get them? From our experience gathered over the 20+ years of operating, it is highly doubtful that this 'process' or link or expectation will alter significantly into the future. For many people entering the 'system' for the first time they have already had some level of assessment and contact with their G.P. before they are even aware of their needs into the future. For many Carers they don't even recognise themselves formally as being a 'Carer' so they are highly unlikely to seek information about Carer Support Services when first entering the system. Further, at this point, these family members are more likely to be focussed on the 'care' needs of the person they are caring for above anything else. This traditionally has been the approach most families and specifically Carers undertake. 'Their' support needs are often not even considered or when they are it will be at some considerable time 'down the track'. These broader and less tangible aspects around information provision must be tackled first. G.P. education is a must.
- b. It is noted that a criticism of CRCC's has been focussed on the ability of such Centres to provide timely and accurate information. Since their inception the role of CRCC's has been to provide information predominately targeting HACC funded services. This has limited the comprehensive nature of the information that

could be made available. Further, as it is with any information service, there is reliance on other providers and a range of external organisations and individuals to update the accuracy of the information being accessed. Accepting this, the current day to day operations of existing information services or any future information service is unlikely to alter in respect to the extent of accurate and up to date information available, due predominately to these external factors. Given this, the criticism of CRCC's in this regard, in isolation, remains largely unfounded.

- c. Carer Support has been operating a one-stop-shop identical to the concept outlined in Chapter 8 of the draft Commission Report, for Carers, their families, other service providers and the general public for decades. Organisations such as these should be strengthened and their resources enhanced to enable them to increase the scope and depth of what can be provided.

### **RECOMMENDATIONS (FOR CONSIDERATION):**

- *Existing Information services should be resourced to greater levels to enable these services to update the available data more regularly. Enhancing current on-line technology to improve and streamline the updating of data to existing databases should be explored as a cost effective way to increase the availability of real time comprehensive information.*
- *Broaden the scope of what information CRCC's can provide and resource them accordingly to provide this greater level of information.*
- *Build on the Network of existing Carer Support services to streamline the range of options for people to access targeted information.*
- *Undertake a significant and sustained education program for G.P.'s to streamline how their clients can be linked into appropriate information services.*

### **3. Assessments:**

- a. The directions outlined in the report are supported by this organisation. The who does what of assessment processes can be systematically streamlined and made far more efficient and effective. This is particularly appropriate for the more complex and specialised assessments. The broad and shallow (screening) assessments can also be streamlined to some degree however it must be accepted that the 'no wrong door' approach must be maintained. People will go to known providers, or their G.P. or their local council and therefore the 'system' must be able to support these people regardless of their entry point, without adding to their frustrations or time wasted with further referral processes. The report is unclear as to the

outcome/process for the Carer or the care recipient should they enter the system through another regional agency other than the gateway agency. This needs to be clarified.

- b. CRCC's undertake this shallow and broad assessment processes for both Carers and the person being cared for. The CENA-R Assessment tool which has already been trialled has assisted this outcome and could be introduced nationally within the CRCC network with minimal problems.
- c. The comprehensive and specialist assessments will continue to be done by the appropriate agency/individual. Guided referral processes will ensure this occurs in the most effective manner possible. Electronic client records will aid this process.
- d. It has been stated that the base assessment process is to include an asset test to determine the ability of the Carer/care recipient/family to contribute to the costs of their services. This will have significant impact upon a large proportion of families in accessing support. This impact may be in several ways.
  1. Families may not access services simply because they cannot afford to pay and therefore won't even look for support.
  2. Families may be reluctant to undergo such a test as they consider their entitlement to service is already there.
  3. It may create increased levels of guilt and conflict due to the extent of 'care' the Carer and/or the family provide or is provided based around how much can be afforded or they are willing to pay. This will have a negative impact and may lead to serious issues of conflict between family members and the person in need of care.
  4. Many Community based services in the past have not been subject to a formal fees structure. This would have to change under the reform directions. Fees for HACC services will have to be determined alongside of all other funded Respite, information and general support services. In the 'Who Cares Report' the financial burden of caring was clearly identified and recognised for Carers. This direction of a fee for all services would clearly add extra financial pressures on Carers and their families. This must be explored further before any final decisions are reached or recommendations made.

#### **RECOMMENDATIONS (FOR CONSIDERATION):**

- *The streamlining of shallow and broad assessment processes is further refined to fully encompass the 'no wrong door' outcome.*
- *The role of CRCC's in these initial screening processes be recognised and enhanced. Specific to this role is the introduction nationally of the CENA-R Assessment tool.*
- *The concept of an asset test to determine the ability of families to pay for services needs significant more work to explore the 'real' impact on people's willingness and ability to pay for these services. Alleviating, not increasing the financial burden*

*on Carers and their families to care must be a fundamental direction and outcome of the reform.*

**4. Care Coordination:**

- a. Several of the directions outlined in the report are supported by this organisation. It is clear that the coordination process must be provided at a number of points within a region. Once again the 'no wrong door' approach must be recognised and accepted. Therefore the outcome of this is that more than one agency will have to have a primary coordination and referral role.
- b. In line with the 'no wrong door' approach entry points for the system can be streamlined by being linked via technology. Specifically, if they have access to electronic client records, have the ability to transfer calls across agencies and then have the available resources to meet the demands on a daily basis. These entry points must also have the ability to respond outside of the normal office hours. As mentioned previously in this paper, people's lives do not start or stop Monday Friday 9.00am to 5.00pm. Therefore access to services outside of these hours is essential.

**RECOMMENDATIONS (FOR CONSIDERATION):**

- *Entry points into the system can be more than one but are linked via a range of technologies to streamline their abilities to improve and enhance access options for people needing information and support.*
- *CRCC's be maintained as an entry point for the reform directions.*
- *Emergency support options for people outside of the normal office hour's timeframe are addressed and the current emergency support service of CRCC's be expanded to broaden the scope of the service.*

**5. Consumer Directed Care:**

- a. Carer Support totally supports the directions for this approach to funding services. There are many issues to be worked through as outlined in the draft report but as a concept this approach is excellent and the opportunities for families to access the 'packages' should be increased.

**RECOMMENDATIONS (FOR CONSIDERATION):**

- *Increase the number of CDC Packages available.*
- *Increase the extent of flexibility that Carers and the care recipient have in determining how the allocated funds can be expended.*



## SUMMARY:

Carer Support recognises and endorses the broad directions contained within the draft report. It is clear however, that many of the recommendations relative to Carers and the nature of their caring role, as well as the agencies currently funded to support these Carers and the care recipient, do not address the full impact that the reform would have on these key stakeholders. Asset testing and fee for services is but one very obvious example outlined in the draft report. It is our understanding that several of these recommendations for Carers would be at odds with the key issues and findings identified in the Parliamentary Enquiry into Better Support for Carers, '*The Who Cares Report.*' around improved financial support for Carers recognising the burden already being suffered by Carers associated directly with their caring role.

The National Carers Strategy directions must also be considered in regard to the recommendations contained within the Final Report. Further, while streamlining of many services must occur, the existing Carer targeted services have been effective over the past decade or more and with additional resources will continue to lead the way in ensuring Carers and their families can access the supports needed in a flexible, timely and meaningful way in to the future. Many of the functions of CRCC's have been proven to be effective and acknowledged as being essential to be maintained. Therefore these functions and this proven history must not be overlooked but considered fundamental components in the design of any new aged care system.

Carer Support is about Carers and the person being cared for. Our experience has shown us the ways in which Carers can and should be supported. There is no one right approach or method or strategy. What works for one won't work for another. Therefore any system must have genuine in built flexibility to respond on a case by case basis regardless of where people enter the system. Design the aged care sector by outcome for the Carer and the care recipient;

Signed

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Peter Sparrow

Chief Executive Officer.