

29 July 2011

Committee Secretary  
Senate Standing Committee on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

### **Re: Inquiry into Commonwealth Funding and Administration of Mental Health Services**

Carers NSW welcomes the opportunity to provide comment on the experiences of carers in the mental health system as part of the Senate Community Affairs Committee's Inquiry into Commonwealth Funding and Administration of Mental Health Services.

This submission will discuss the importance of carers and their role in the coordination of mental health care and the potential impact of changes in funding for GP mental health consultations and the Better Access program. This submission will also provide comment on the delivery of online mental health services, the proposed national mental health commission and mental health workforce issues.

### **About Carers NSW**

Carers NSW is the peak organisation for carers in New South Wales. A carer is defined as an individual who provides unpaid care and support to a family member or friend with a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail. Carers NSW is a member of Carers Australia and works as part of the national Network of Carers Associations. Carers NSW has an exclusive focus on supporting and advocating for all carers in New South Wales.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in New South Wales are recognised, valued and supported by their communities and by governments. Carers NSW aims to increase access to services that meet the needs of carers regardless of their age, gender, circumstances, location or cultural or linguistic background.

### **About Carers**

According to the ABS there are 771, 400 primary carers in Australia, of which 264,300 reside in New South Wales.<sup>1</sup>

Carers are among the most disadvantaged Australians; with lower incomes and increased levels of social isolation than non-carers. Many carers, due to the intensive nature of their caring role, are unable to work and rely on government assistance and payments.<sup>2</sup> Carers are more likely than the general population to have little face-to-face contact with friends or relatives outside the household, especially when caring for someone with high level care needs.<sup>3</sup>

Carers have poorer mental health than other at risk groups, including the unemployed, and have a rating on the depression scale that is classified as moderate depression.<sup>4</sup> Carers are at risk of developing mental illness because of the demands of their caring role and the negative impacts of caring may be ongoing, cumulative and spread over many years. Research has found that carers who have experienced a disruption in their daily schedule and have a low perception of their ability to provide care are highly susceptible to symptoms of depression and anxiety.<sup>5</sup> A recent study of people aged between 64 and 69 in the ACT and Queanbeyan found that carers were 50 per cent more likely than non-carers to experience clinically significant anxiety and depression.<sup>6</sup> Carers are also more likely to report severe stress from life commitments and high psychological distress compared to non-carers.<sup>7</sup>

Carers themselves are likely to be users of mental health services to cope with anxiety and depression that has resulted from difficulties experienced while caring. Anecdotal evidence also points to high rates of suicide ideation among carers, although thorough research is yet to be conducted.<sup>8</sup>

### **The experience of carers of people with a mental illness**

Carers of people with mental illness, in addition to the problems faced by carers generally, experience stigma and higher levels of family conflict and division as a result of their caring role. Caring for a person with a mental illness can be more difficult due to the unique features of the social context which influence the carer role in mental health, such as the stigma, guilt and isolation of mental illness and the intermittent periods of illness with fluctuating symptoms.

Families and carers are the first to act when someone they know begins to show signs of mental illness.<sup>9</sup> Carers, as parents, spouses or close friends are often more attuned to the changes in behaviour that are the warning signs of a developing mental illness. Over three quarters of carers surveyed by the Mental Health Council of Australia (MHCA) were responsible for coordinating care.<sup>10</sup> Carers provide an estimated 104 hours of care per week for family members and friends with a mental illness.<sup>11</sup> For many carers, this time includes periods when they are on alert for early warning signs of a mental health crisis. Carers are the primary coordinators of mental health care for the person they care for, organising appointments and identifying services, and thousands of carers fulfil this role.<sup>12</sup> 40.9 per cent of carers of people with a mental illness had no support from family and friends in their caring role.<sup>13</sup>

Carers of people with mental illness may undertake the following activities in their caring role:

- providing emotional support, sometimes for protracted periods each day
- encouraging the use of medication, checking compliance and observing for side effects
- assistance with personal affairs, such as bill paying and Medicare claims
- reminding the care recipient of appointments and ensuring they get to them
- helping with understanding of medical decisions about treatment
- checking to see there is food in the fridge, and sometimes making meals
- helping with household chores such as cleaning, shopping, lawn care, etc
- making regular phone calls to the consumer to “check in” on them
- assisting with the maintenance of social activities.<sup>14</sup>

During acute episodes, carers provide additional assistance including:

- management of unpredictable and sometimes paranoid and/or aggressive behaviours
- notifying treating staff and negotiating appointments in situations where the consumer has an ongoing relationship with a private psychiatrist or community team
- transportation to services which in some cases may require negotiations with the police
- visiting the consumer if they are hospitalised
- assistance to other family members to enable them to understand what is happening.<sup>15</sup>

The deinstitutionalisation of mental health services over the last 20 years has led to carers becoming increasingly responsible for coordinating care. Any gaps in formal services are filled by carers, which places pressure on the carer to provide a higher level of support in the home.

The health and wellbeing of carers of people with a mental illness is linked to the health of the person in their care, with carers reporting that improved health outcomes for their care recipient decreased their own stress levels and interpersonal tension in the family.<sup>16</sup>

### **Rationalisation of GP mental health services**

A general practitioner (GP) is the first point of contact for any concerns carers may have for their own mental health or for the person in their care. The MHCA's 2010 Carers Report revealed that GPs are the main source of information for carers caring for people with a mental illness (45.5%), followed by carer services (44.8%) and psychiatrists (35.7%).<sup>17</sup> 80 per cent of carers of people with mental illness surveyed by Carers NSW in 2010 also indicated that they would prefer to receive information from their GP.<sup>18</sup>

Carers rely on GPs for the majority of their care, often due to increased costs of seeing other health professionals. A recent study of carers with a chronic condition found that carers were significantly more likely than non-carers to stop seeing health professionals (other than their GP) due to expense.<sup>19</sup>

People diagnosed with depression generally prefer to visit their GP over specialised mental health services not only because they are also more familiar with their GP and they are more accessible but also due to the perceived stigma attached to mental health specific services.<sup>20</sup> Carers have also reported that they are more likely to consult with their GP because psychiatric services are difficult to find and more expensive than a GP consultation. For mental health patients in regional and remote areas, finding adequate mental health care is difficult with some carers reporting that GPs and community nurses are the only accessible mental health professionals in their area.<sup>21</sup>

GP assessments and the development of GP mental health treatment plans and GP mental health consultations are important front line services that have improved access to mental health care for many Australians. The 2010 MHCA Carers Report identified that carers are just as likely to attribute improvements in their care recipients' mental health to GPs as they are to psychiatrists.<sup>22</sup> Carers NSW is concerned that the introduction of the two tiered GP rebate may restrict access to GP services for consumers and carers, considering the important role GPs have in providing mental health services in the community.

## **Rationalisation of allied health treatments through Better Access**

Carers NSW has concerns over the decision to limit psychological consultations to ten sessions annually through the Better Access program. Carers of people with mental illness have experienced difficulties finding affordable psychiatrists and psychologists that bulk bill or that have lower co-payments.

Co-payments typically accompany services accessed through the Better Access program whereas the Access to Allied Psychological Services (ATAPS) scheme does not attract extra fees. ATAPS services can be accessed by people who do not have the capacity to pay for private mental health services, namely health care card holders, low income earners, culturally and linguistically diverse (CALD) communities, young people and patients experiencing financial difficulties. Many people with mental health needs may not meet the criteria for ATAPS but need more than the 10 rebated Better Access sessions. Limiting the number of private psychological sessions that are able to be claimed through the Better Access scheme has the potential to disadvantage consumers and their carers who cannot afford the full cost of their treatment.

Many carers do not have the capacity to pay for increased mental health care costs, whether higher fees are caused by increased gap payments or the need to pay for additional counselling not covered by Medicare. 38.5 per cent of carers of people with mental illness have an income of less than \$350 per week and 42.5 per cent of carers have a household income of less than \$700.<sup>23</sup> Any additional increase in treatment will cause carers financial stress as 41.5 per cent of carers already have difficulty paying for basic everyday items.<sup>24</sup>

Carers have identified continuity of treatment as an important part of recovery for the person in their care. Carers NSW has concerns that with only 10 rebated sessions available through Better Access per year, psychological consultations for consumers may become less frequent. It is important that patients with ongoing and complex mental health needs are able to access a high level of care. Carers NSW welcomes the increase in funding to ATAPS although this increase has been made at the expense of the Better Access program and reduced access for others.

## **Online services**

The expansion of online mental health services is encouraged as distance creates a barrier to services for many Australians who cannot travel to attend appointments. Carers have identified a severe lack of appropriate psychiatric services in small towns and rural areas and online services have the ability to address this service shortage.

According to the Australian Bureau of Statistics Multipurpose Household Survey 72 per cent of Australian households had home internet access and rates of internet access had quadrupled between 1998 and 2009.<sup>25</sup> Similarly, 76 per cent of carers surveyed in the 2010 Carers NSW Carer Survey had access to the internet and the average age of survey respondents was 58.<sup>26</sup> The internet is an important source of health information for carers with 35.1 per cent of carers receiving health and caring information online.<sup>27</sup>

The online mental health portal is an ideal opportunity to increase the information available for carers of people with mental illness. More information on available mental health services should also be available through the mental health portal. The portal should link carers with

carer-specific services, such as those offered by Carers Associations around the country and resources to help them fulfil their caring role.

## **Mental Health Workforce Issues**

Carers have reported that mental health professionals generally have a poor understanding of carers and often do not include them in the treatment and care of the mental health consumer. Carers NSW continues to advocate for better training to alert health professionals to the needs of carers and to encourage health professionals to be sensitive to their caring role. Carers play an important role in administering medication and ensuring that courses of treatment are followed and consumers benefit when carers are consulted by mental health professionals.

Cultural and policy change is required to ensure carers are recognised in accordance with the *Statement for Australia's Carers*. Importantly that the "relationship between carers and the persons for whom they care should be recognised and respected" and "carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers".<sup>28</sup>

Carers have identified that more and better trained mental health staff are needed across the mental health system. Carers have experienced difficulty accessing psychiatric services especially in rural and regional areas. High levels of staff turnover also mean that continuity of mental health care is compromised.<sup>29</sup>

## **Delivery of a National Mental Health Commission**

Carers NSW welcomes the establishment of a National Mental Health Commission. It is vital that the new Commission hears and understands the views and experiences of carers. People with a lived experience of mental illness should be represented on the Commission's board as is the case in other jurisdictions, for example mental health consumers and carers are on the board of the Mental Health Commission of Canada as non-government directors.

It is important that both carer and consumer experiences with the mental health system are considered by the Mental Health Commission. Carers and consumers have independent perspectives and represent different interests. The unique nature of their experiences and perspectives needs to be recognised and respected. Although their interests may often interrelate, it is generally inappropriate for a consumer representative to represent the carer perspective, or for a carer representative to represent the consumer perspective. Too often carer representatives are considered interchangeable with consumer representatives.

The needs of consumers and their carers should drive the National Mental Health Commission with the goal of improving access to mental health care for all Australians. The Commission should monitor and report on existing gaps in services and identify strategies and methods to improve the standards of mental health care in Australia.

## Conclusion

Carers NSW has appreciated the opportunity to provide comment on the funding and administration of mental health services. Carers, as the main coordinators of care, navigate the health system to ensure their friends and family members with mental illnesses receive the care they require. The mental health online portal will provide a much needed single access point for quality mental health information on the internet.

Carers NSW welcomes the increase in spending on mental health, however, we have concerns over the redistribution of these funds and the potential for some consumers and carers to miss out on appropriate services. Carers also need to be recognised as partners in care by health professionals and it is hoped that the proposed National Mental Health Commission will identify strategies to achieve this.

If you require any further information about this submission, please contact Diana Withnall on 02 9280 4744 or email [dianaw@carersnsw.asn.au](mailto:dianaw@carersnsw.asn.au).

Yours sincerely

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<sup>1</sup> Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) Canberra, 2009

<sup>2</sup> Mental Health Council of Australia, *Mental Health Carers Report 2010*, Canberra, 2010

<sup>3</sup> Australian Institute of Family Studies and FaCSIA *The Families Caring for a Person with a Disability Study and the social lives of carers*, Canberra, 2007

<sup>4</sup> Australian Centre on Quality of Life, *Australian Unity Wellbeing Index, The wellbeing of Australians: Carer health and wellbeing*, October, 2007

<sup>5</sup> Aggar, C, Ronaldson S, Cameron I.D, Reactions to caregiving of frail, older persons predict depression *International Journal of Mental Health Nursing*, 19, 409–415, 2010

<sup>6</sup> Butterworth P, Pymont C, Rodgers B, Windsor T.D, Anstey K.J “Factors that explain the poorer mental health of caregivers: Results from a community survey of older Australian” in *Australian and New Zealand Journal of Psychiatry*, 44 616–624, 2010

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<sup>8</sup> Aged Care Insite “Watershed research on suicide risk among carers” [online] available at <http://www.agedcareinsite.com.au/pages/section/article.php?s=News&idArticle=21630> July/August 2011

<sup>9</sup> Lakeman R. “Practice standards to improve the quality of family and carer participation in adult mental health care: An overview and evaluation” in *International Journal of Mental Health Nursing*. 17, 44–56, 2008

<sup>10</sup> Mental Health Council of Australia, *Mental Health Carers Report 2010*, Canberra, 2010

<sup>11</sup> Mental Health Council of Australia and Carers Australia, *Carers of people with mental illness project report*, Canberra, 2000.

<sup>12</sup> Lakeman R. “Practice standards to improve the quality of family and carer participation in adult mental health care: An overview and evaluation” in *International Journal of Mental Health Nursing*. 17, 44–56 2008

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- <sup>24</sup> Ibid.
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