



NMHCCF
Workforce Project Steering Committee
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To whom it may concern,

Carers NSW welcomes the opportunity to comment on Supporting and developing the consumer and carer identified workforce – a strategic approach to recovery, a position statement from the National Mental Health Consumer and Carer Forum.

This submission will provide some feedback on the position statement.

About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful. Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of aged through to the very elderly.

Key statistics about caring in NSW

According to statistics on carers from the Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers (SDAC):

- Approximately one third of all carers in Australia live in NSW
- 40 per cent of primary¹ carers cared for a partner, 29 per cent for a child, 32 per cent for other (eg sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income²

Carers NSW response to ‘Supporting and developing the consumer and carer identified workforce – a strategic approach to recovery’

Carers NSW welcomes the release of this position statement from the National Mental Health Consumer and Carer Forum. We strongly support the focus this strategy brings to the support and development needs of the consumer and carer identified workforce. The strategy comprehensively identifies the many issues faced by this workforce and makes practical and informed recommendations. Carers NSW supports the implementation of these recommendations.

Carers NSW Carer Representatives

Carers NSW’s Carer Representation Program provides training, information and support to carers to enable them to act as carer representatives, and facilitates their involvement in a variety of activities and roles. Carers NSW Carer Representatives sit on a variety of advisory groups and committees, and participate in forums, media interviews and public speaking. The program aims to ensure the systemic introduction of the carer perspective across all relevant health, community and other human services in NSW, including mental health services. There are currently 50 carers involved in the program, approximately one fifth of whom are carers of people with mental illness.

Carers NSW feels that the strategy comprehensively addresses the issues commonly experienced by carer representatives, particularly those faced by carer representatives in the mental health sector. Our experience is that carers working in the carer identified workforce repeatedly express many of the frustrations reflected in this strategy. However, we would like to emphasise the following issues, which we feel could have received greater consideration in the strategy.

Unpaid carer identified workers

The majority of the mental health carers on our Carer Representation program also work independently of Carers NSW representing and advocating for mental health carers. In several cases, their contribution to local mental health and related services is considerable, and at times is made at the explicit request of staff of these services.

¹ A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care.

² ABS (2004) Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra

However, they are rarely paid for the work they do or reimbursed for the expenses they incur, which, particularly in rural and regional areas, can be considerable.

Although in section 5.2.3 the strategy does acknowledge the varying remuneration practices that exist, including payments in kind, those carer identified workers who are not paid at all are not mentioned. This would suggest that they are excluded from the strategy, as with the volunteers referred to on p 18 of the strategy.

Carers NSW is disappointed that the strategy does not better address the needs of unpaid carer identified workers who are not volunteers. This includes carers who are acting as carer advocates, facilitating and organising carer support groups, advising service providers and Government Departments, and those who are members of advisory and decision-making bodies. The great and pressing need for the services they provide, often at the request of service providers, means that the work of these carers is not an activity they choose freely or complete at their leisure – it is necessary not voluntary, and it comes at a cost to them personally and financially.

Carers NSW would like to see the strategy better address the issues faced by carer identified workers who receive no payment at all, and the necessity of services creating remunerated positions instead of asking time-poor and often financially disadvantaged carers to devote even more unpaid hours to the provision of mental health care. As it is carers who provide the majority of mental health care, the unpaid work demanded of them needs to be lessened, not increased. The strategy needs to ensure that services do not rely on unpaid consumer and carer workers and that they instead create appropriate, formal and remunerated positions. We support the call made in the strategy for employers to stop the exploitation of this workforce, but feel that it needs to be made clear that this includes unpaid workers.

Provision of funded respite options

In addition to remuneration, Carers NSW Carer Representation Program also reimburses carers for the cost of respite services required for them to be able to participate so that they are not financial disadvantaged through their participation, or forced to use up the limited respite they may be entitled to. Without this reimbursement, many carers' respite costs would equal or exceed the amount they receive in remuneration.

Carers NSW position is that in addition to remuneration, carer representatives should be provided with funded respite, where possible. This is an issue that could also be addressed in the Strategy.

Distinction between consumer and carer roles

It was pleasing to see that the strategy and its recommendations address the need to clarify the positions and duties of consumer and carer identified workers. However, Carers NSW would like to emphasise the importance of there being a clear and well understood distinction between consumer and carer roles. Too often carer representatives are given the title of or considered interchangeable with consumer representatives. In some cases, carer representatives are expected to also act as consumer representatives and vice versa. This is not acceptable, and perhaps it could be made clearer in the Strategy that carer representatives and consumer representatives have responsibilities to different groups, with distinct experiences and needs.

Another issue facing carer representatives in particular is a lack of understanding and awareness of their role and its importance. While there are increasing levels of consumer representation throughout the mental health and health sectors and greater

awareness of its role, it is our opinion that carer representation is not yet as prevalent, or as well understood as consumer representation. This is evident in policies, position statements and other work generated on the subject which either exclusively address consumer representation, or include carer representation as an afterthought. This too could be addressed in the strategy.

Carers NSW is pleased to see that the strategy addresses the need for clarity in terms of the roles of consumer and carer workers, however we would like to emphasise the importance of this issue to carer representatives in particular, whose role is often less understood than that of the consumer representative.

Importance of training and mentoring

Carers NSW is pleased to see the inclusion of training needs of the consumer and carer identified workforce in the Strategy. The feedback we receive from many carer representatives is that training and support is required so that they can develop the skills necessary to their work.

In 2007-2008 the Australian Government Department of Health and Ageing funded the Mental Health Council of Australia's (MHCA) Mental Health Consumer and Carer Mentoring Project. This project aimed to strengthen the ability of mental health consumer and carer representatives to promote the issues and concerns of consumers and carers through the provision of training in leadership, advocacy, policy development, and communication. The MHCA continues to deliver similar training, and has developed a National Register of Mental Health Consumers and Carers.

Carers NSW mentions this initiative as an example of the importance of funding for the provision of training and mentoring for the consumer and carer identified workforce. Carers NSW supports the recommendations regarding the responsibilities of employers to identify and meet training needs, and the responsibility of Government to implement the 4th National Mental Health Plan. It is vital that responsibility is also taken for the provision of adequate and appropriate training for this workforce. Carers NSW believes that the strategy should include a recommendation that funding be provided to consumer and carer organisations to facilitate the development and delivery of training and mentoring for this workforce.

Conclusion

Carers NSW thanks the National Mental Health Consumer and Carer Forum for the opportunity to comment on this position statement. If you require any further information please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely,



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