

Chris Williams
Senior Policy Officer
Community and Government Relations Branch
NSW Department of Health
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20 October 2010

Dear Mr Williams,

Carers NSW welcomes the opportunity to provide feedback to the *Community Engagement Framework Policy*. Carers NSW is pleased to see the development of this policy, particularly given the current context of health reform. We hope that the *Community Engagement Framework Policy* will ensure a real commitment to community and carer engagement in the reformed NSW health system.

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's 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.

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 age through to the very elderly.

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. The program aims to ensure the systemic introduction of the carer perspective across all relevant health, community and human services in NSW. There are currently 50 carers involved in the program.

Carers NSW comments on the *Community Engagement Framework Policy*

1. Importance of carer participation and representation

Carers NSW believes that consistent and effective community engagement is vital, and that community input into the operation and governance of the health system is critical to ensure the provision of appropriate services which are responsive to local needs. It is important that broad and effective community engagement is achieved, which is inclusive of all members of the community.

In particular, Carers NSW looks forward to seeing carer participation and representation at all levels of the health system. We believe that this is of fundamental importance, as carers have significant needs which are different to those of consumers. The perspective of carers needs to be included in policy development, service planning and service delivery. Carers are the major providers of care for people in the community so it is important that services are appropriate to their circumstances and responsive to their needs. Carers have a right to have their voices heard by the people who make decisions which impact upon them. Carers NSW believes that better participation, representation and engagement of carers in the reformed health system will result in better services and support for both carers and the people that they support.

2. Key Principles (Section 1.2)

Carers NSW supports the Key Principles outlined in the draft policy. However, Carers NSW recommends that a principle regarding the importance of transparency be added to the Service Charter. Community engagement processes need to be transparent, particularly in terms of the reporting of issues raised by the community and the response made to these issues. Work plans, outcomes and the details of committees, including member contact details, should be publicly reported and easily accessible.

Recommendation 1: Carers NSW recommends that a principle regarding the transparency of community engagement processes be added to the *Service Charter of Healthcare Participation*.

3. Education and Training (Section 3.1)

Carers NSW believes that the provision of education and training to Department, Network and health service staff is critical. Carers NSW supports the requirement of each to Network to have a full time, skilled community engagement position, and believes that training in engagement and consultation techniques will enable effective community engagement.

Education and training for community representatives is equally important. The Framework states that community groups should have access to Department and/or Network training opportunities, and that the Department and Networks should provide appropriate information and training to meet the needs of community representatives. Community representatives, including consumer and carer representatives, must be able to access training to enable them to participate effectively and confidently. The Carers NSW Carer Representation Program involves a two day workshop on joining the program which focuses on carer issues, practical representation and advocacy skills, and the ethical and legal elements of representation work. Carers NSW recommends that the Department and/or Networks create training specifically for community representatives. The Department and/or Networks should also look to involve organisations, including peak organisations with expertise in this area, and who have

already developed training and other resources, such as Carers NSW, the Mental Health Council of Australia and others.

4. Strategies for the inclusion of carers (Section 3.2)

Carers NSW was pleased to see the 'Strategies for Inclusion' for specific groups of people who "continue to remain marginalised in our society". However, it was both surprising and disappointing to see that carers were not included in this section. As acknowledged by NSW Health in the *NSW Carers Action Plan 2007 – 2012*, it is well established that caring can have a negative impact on carers' physical health, emotional wellbeing and financial security.¹ Carers have lower income levels than the general population, and often experience high levels of financial stress and social isolation. Considering both their marginalised position in our society, and their unique and highly significant role in the health system as the 'invisible health workforce'², Carers NSW recommends that specific strategies for the inclusion of carers be included in section 3.2 of the Framework.

Carers NSW has experience of supporting carers to take on representative roles and to participate in the community engagement activities of various organisations through the Carer Representation Program. Carers NSW suggests that the following points be considered for section 3.2 of the Framework.

- Consultation with consumers is not the same as consultation with carers (and vice versa). 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. Carers have their own experience of the health system, and their own needs for services and support.
- Carers often have considerable demands on their time and may be limited in the amount of time that they can be away from the care recipient. To ensure that care responsibilities do not exclude them from participating, events should be kept short. Advance notice should be given of the time and date of any events to maximise the carer's chances of being able to organise alternate care arrangements. At times it may also be necessary for the care recipient to travel with the carer. In these instances, transport and accommodation costs should be covered for both parties.
- Many carers have unpredictable caring responsibilities, and at times may need to withdraw from a commitment at short notice, particularly due to changes in the health of the care recipient, or the availability of alternative care arrangements. Proxy carer representatives should be appointed to minimise the pressure of participation on individual carers and to ensure that the carer perspective is represented at all times.
- Carers may require assistance to organise assistance with their caring role in order to participate. Some carers may require reimbursement for child or respite care, as acknowledged in section 3.3 *Resources for participation*. Consideration should be given to the need for help with transport or other support.

¹ NSW Department of Health 2007 *Carers Action Plan 2007 – 2012*, Sydney, p 4.

² National Health and Hospital Reform Commission 2009 *A Healthier Future For All Australians: Final Report of the National Health and Hospitals Reform Commission*, Canberra.

- Carers come from all walks of life, cultural backgrounds and age groups and have diverse experiences of caring. Any attempt to engage with carers or to understand the carer perspective must be informed by an awareness of the different carer situations and populations that exist. Anyone can be a carer, including people from the marginalised groups discussed in section 3.2.

Recommendation 2: Carers NSW recommends that strategies for the inclusion of carers be included in the Framework.

5. Resources for participation (Section 3.3)

Carers NSW was pleased to see recognition in the Framework that resources are required to enable members of the community to engage with the health system. In particular, Carers NSW was very pleased to note the recognition of the need to reimburse carers for the respite care expenses associated with attending meetings. The cost of respite care and its limited availability contributes to the exclusion of carers from society.

It is also pleasing to note that the need for carers or attendant care for people with a disability has been recognised (p 20). Carers NSW recommends that this paragraph be amended to acknowledge that some carers may need to bring the care recipient with them, particularly when an overnight stay is required. In these instances, reasonable travel, accommodation and meal costs should be reimbursed for both the carer and the care recipient.

Recommendation 3: Carers NSW recommends that the Section 3.3 be amended to acknowledge the need of some carers to bring the care recipient with them.

6. Remuneration

Carers NSW was disappointed that the remuneration of community representatives was not included in the Framework. Carers NSW policy, under the Carer Representation Program, is that carers engaged in formal representation activities as carer representatives should be reimbursed for their expenses and remunerated for their time, in recognition of the value of their contribution and of their time, which is often very limited by their caring responsibilities. Remuneration also compensates for earnings that may be sacrificed in order for them to attend, and creates equity. It is unreasonable and unfair to expect community representatives to provide their expertise *pro bono* on a committee or advisory group when the other participants are there as part of their paid work. Carer NSW recommends that the Framework support remuneration for community representatives, particularly for formal representation activities.

Recommendation 4: Carer NSW recommends that the Framework support remuneration for community representatives, particularly for formal representation activities.

Recommendations

1. Carers NSW recommends that a principle regarding the transparency of community engagement processes be added to the Service Charter of Healthcare Participation.
2. Carers NSW recommends that strategies for the inclusion of carers be included in the Framework

3. Carers NSW recommends that the Section 3.3 be amended to acknowledge the need of some carers to bring the care recipient with them.

4. Carer NSW recommends that the Framework support remuneration for community representatives, particularly for formal representation activities.

Conclusion

Carers NSW appreciates the opportunity to provide feedback to the NSW Department of Health on the *Community Engagement Policy Directive & Framework*. If you require any further information about Carers NSW comments on this Framework, please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Elena Katrakis', written in a cursive style.

Elena Katrakis
CEO
Carers NSW