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Dear Carmel,

Carers NSW welcomes the opportunity to provide feedback on the Mental Health and Drug & Alcohol Office's Discussion Paper, 'Framework for Consumer, Carer and Community Participation in Mental Health'. Carers NSW has long advocated for greater carer participation and representation and is pleased that carers have been considered in this Discussion Paper. It is gratifying to see recognition of the rights of carers to participation and representation in mental health services, and of the value of carers' expertise and perspective.

### **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.

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.

Carers NSW is also one of the non government organisations delivering the Family and Carer Mental Health Program in New South Wales.

### **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 estimated to be approximately 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

## **Key statistics about caring in NSW**

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

- Approximately one-third of all carers in Australia live in NSW
- 40 per cent of primary<sup>1</sup> 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 income.<sup>2</sup>

Research conducted by the Mental Health Council of Australia and Carers Australia found that individual carers spend, on average, 104 hours per week caring for a person with a mental illness.<sup>3</sup>

## **About this submission**

This submission will provide some general feedback to the Discussion Paper and then respond to particular sections of the paper, making recommendations for the Framework. We hope that this submission will inform the development of the Framework and assist the Mental Health Program Council to foster greater carer participation throughout mental health services in NSW. Although Carers NSW focus is on carer participation, we also value and support consumer and community participation in mental health services.

## **Carers NSW Feedback to the Discussion Paper Framework for Consumer, Carer and Community Participation in Mental Health**

Carers NSW considers the Discussion Paper to be a promising development for carer participation in mental health. It is gratifying to see acknowledgement of: the independence of carer and consumer interests, the diversity of carers (including Aboriginal carers, Torres Strait Islander carers, carers from diverse cultural and linguistic backgrounds, carers at different stages of their life span), the different levels and types of participation, and the need for education and training for carers, management and staff to support carer participation.

### **Background and Context: Policy context (pp 3 – 4)**

The NSW Carers Action Plan 2007-2012 needs to be recognised as part of the policy context that the framework will be making reference to. The Framework should reference and be consistent with the NSW Carers Action Plan 2007-2012, in addition to the other documents and policies listed in the Discussion Paper.<sup>4</sup>

The Framework should also reference and be consistent with the Carer Recognition Bill recently tabled in NSW Parliament and the National Carer Recognition Legislation and Framework that is to be implemented by the Federal Government. The Federal Government is committed to introducing a nationally consistent carer recognition framework in 2010 that will build upon and complement

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<sup>1</sup> 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.

<sup>2</sup> ABS, 2004, Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra, Australia.

<sup>3</sup> Mental Health Council of Australia and Carers Australia 2000, Carers of people with mental illness project report, Canberra.

<sup>4</sup> NSW Department of Health, 2007, NSW Carers Action Plan 2007-2012, Sydney, Australia.

state and territory carer legislation. Queensland, Western Australia, South Australia, the Northern Territory, and the Australian Capital Territory already have Carer Recognition Legislation in place. The proposed state and national legislation will provide legal recognition of carers and award them greater rights. It is important that the Framework is compliant with relevant Carer Recognition Legislation, so that it may effectively support the improvement of carer recognition, participation and representation in mental health.

**Recommendation 1:** That the Framework make reference to, and be consistent with, the NSW Carers Action Plan 2007-2012 and relevant Carer Recognition Legislation.

#### **Purpose of Framework (p 4)**

The Framework needs to identify specific strategies for implementation. For too long mental health carers in NSW have been let down by significant changes in the policy and legislation that affect them as carers not being implemented. Evidence suggests that mental health carers are yet to experience significant improvement in their interaction with mental health services, despite the legislation and policy changes that have occurred to date. For example, more than two years after the introduction of the NSW Mental Health Act 2007, which introduced significant changes to the rights of carers, the NSW Institute of Psychiatry is running Mental Health Legislative Framework Training to combat the lack of knowledge regarding the legislation that they have identified within mental health services. This has occurred despite similar training being conducted when the legislation was first introduced.

Further evidence of the failure to implement policy and legislation affecting mental health carers can be found in the 2009 *Adversity to Advocacy* report, published by the Mental Health Council of Australia. *Adversity to Advocacy* found that despite widespread rhetoric of carers being included as part of the care team, carers still report that they are neither listened to nor respected. Many of the findings of the *Adversity to Advocacy* report indicated that the situation of mental health carers had changed very little, if at all, in the previous ten years.<sup>5</sup>

The Framework must avoid repeating the failure of other policy and legislation changes to result in real change for mental health carers. Implementation by NSW Health via a policy directive is one strategy that should be considered to ensure that real change occurs, but it should not be the only specific strategy the Framework identifies.

**Recommendation 2:** That the Framework identify specific strategies for implementation.

#### **What is participation? (pp 5 – 6)**

The definition of participation given in the Discussion Paper, as participation in "...decision making about their own care (or that of the person they are caring for), service planning, policy development, setting priorities, training and evaluation and addressing quality issues in the delivery of mental health services" (pp 5 – 6) could better take into account what true participation may mean for mental health carers. As well as participation in decision making about the care of the person they are caring for, the definition should acknowledge carers' rights to choice relating to their caring circumstance.

Consideration also needs to be given to differentiating between carer participation on their own behalf, and representative participation which represents a broader carer perspective, rather than a personal perspective. Representative participation has very different practical and ethical implications and this needs to be reflected throughout the Framework.

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<sup>5</sup> Mental Health Council of Australia (MHCA) 2009, *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*, Canberra, Australia.

**Recommendation 3:** That the Framework acknowledge carers' right to choice regarding their caring circumstances.

**Recommendation 4:** That the Framework provide for both individual participation and representative participation.

### **Principles of Consumer, Carer and Community Participation (pp 6 – 7)**

Carers NSW supports the inclusion in the Framework of all the principles set out in this section, with the following points to be taken into consideration.

Carers NSW recommends that the first principle, "Participation is to be valued by the organisation and supported by management at all levels" be amended to include staff. All levels of staff and management in mental health services must value and support participation for true and effective participation, including representative participation to take place.

Carers NSW considers the second principle, "Consumer and carers are considered to have independent, but interrelated interests..." to be of the utmost importance. It must be included in the principles the Framework will set out.

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 confused with, or even given the title of, consumer representative. This undermines their role as representatives of carers and the unique expertise they have as carers. Therefore it is of particular importance that this principle be included in the Framework, and that throughout the Framework it is made very clear that neither the terms "consumer" and "carer" nor the individuals they refer to, are interchangeable.

The seventh principle, "Consumers and carers and service providers are to receive ongoing education to assist in their participation" is fundamental. Consumers, carers and service providers (including both management and staff) all require education to enable true participation, including representative participation. The inclusion of management and staff in this principle will help to avoid situations in which representative participation by carers is rendered tokenistic by the attitudes of management and staff.

**Recommendation 5:** That the Framework articulate Principles for Consumer, Carer and Community Participation.

### **Levels of participation (p 8)**

Carers NSW is pleased to see the consideration being given to the different levels of participation, and the awareness evident in the discussion paper of the importance of participation by carers at all levels of mental health services, through a variety of channels.

Carer participation is important at all levels of decision making in mental health services. At the individual level, it is vital that carers are recognised, respected and valued by mental health services, and considered as partners in care, in accordance with the NSW Carers Action Plan 2007-2012.<sup>6</sup> However, carer participation is no less important at higher levels, whether it be at the Area Health Service (AHS) level, or at a state or national level.

Carers NSW recommends that as outlined in the discussion paper, the Framework addresses participation opportunities at individual, local, AHS and state levels, and includes links to national

<sup>6</sup> NSW Department of Health, 2007, NSW Carers Action Plan 2007-2012, Sydney, Australia.

processes and consultations. The Framework should ensure effective participation of and by carers at each of these levels.

**Recommendation 6:** That the Framework address participation opportunities for carers at all levels and include links to national processes and consultations.

### **Representative Participation (p 9)**

Carers NSW agrees that at times it will be necessary to ensure that carers engaging in representative participation, that is, carer representatives, are representative of a particular group. In these cases it may be appropriate that the carer has links with an appropriate carer organisation such as Carers NSW or ARAFMI NSW Inc. in order to secure links to a larger consultative base and support. Consideration must also be given to the potential of such organisations to be involved in the recruitment, preparation and briefing of carer representatives to ensure that the carer representative's view is representative of the wider body of carers, and that the carer representative has the skills needed to effectively represent this view.

Carers engaging in representative participation in mental health must also be representative of the diversity of mental health carers in NSW. The Framework should provide for and foster participation, including representative participation by carers from specific groups such as young people, Aboriginal people, Torres Strait Islanders, culturally and linguistically diverse communities, rural, regional and remote communities, and gay, lesbian, transsexual and intersex (GLBTI) communities. Carers NSW has a strong Carer Representation Program which represents a diversity of carers.

**Recommendation 7:** That the Framework ensure that carer representatives are able to represent the wider body of carers, and are representative of the diversity of carers.

### **Participation in individual treatment and recovery (p 9)**

The consideration given to the inclusion of families and carers in this section of the discussion paper is positive. However, Carers NSW recommends the Framework be consistent with the NSW Carers Action Plan 2007-2012, particularly Priority for Action 4.4, 'Carers are partners in care'. As stated under this priority "Carers play a crucial role as care partners. They are often experts in the care of the person requiring care and can assist with care planning and delivery, with the agreement of the care recipient..."

The Australian health and community care systems increasingly rely upon the care provided by carers. It has been estimated that the carers provide approximately 74 per cent of the support provided to older people and persons with a disability in Australia.<sup>7</sup> Every year carers provide over 1.2 billion hours of support.<sup>8</sup>

Carers are a vital part of the health care support team. This is a fact which is increasingly acknowledged in international literature:

Family members that care for patients at home can provide valuable information and feedback to health care professionals. Educating and training carers can increase compliance with discharge plans and prevent readmissions. During hospitalisations, carers can act as quality monitors, alerting staff to potential costly problems before they happen.<sup>9</sup>

<sup>7</sup> The Allen Consulting Group, 2007, The Future of Community Care, Report to the Community Care Coalition, Melbourne.

<sup>8</sup> Access Economics, 2005, The Economic Value of Informal Care. Report for Carers Australia, Canberra

<sup>9</sup> Performance Improvement Adviser, 2004, Caregivers can play a vital role in reducing readmissions, 8 (5): 58-60

That carers are a vital part of the health care support team is well acknowledged in hospital settings with regard to carers of children with chronic conditions or disabilities.<sup>10</sup> It is a fact, however, which is less acknowledged within other areas of the health system. International research indicates that carer inclusion in mental health services can have benefits to patient quality of care<sup>11</sup> and can reduce readmission rates.<sup>12,13</sup>

Carers NSW strongly recommends that the Framework be consistent with and make reference to the NSW Carers Action Plan 2007-2012, especially Priority 4.4, 'carers are partners in care'.

**Recommendation 8:** That the sections of the Framework relating to participation in individual treatment and recovery are consistent with and make reference to the NSW Carers Action Plan 2007-2012 Priority 4.4 'Carers are partners in care'.

### **Consumer and Carer Workers (p 9)**

Carers NSW agrees that detailed guidelines for consumer and carer workers are a necessity, and believes that the Framework should ensure the provision of such guidelines, even if the actual detail of the guidelines is not included within the Framework.

Carers NSW notes that the development of such guidelines, including a Code of Professional Standards, is to be undertaken separately by the Consumer Workers Forum. As stated in the Discussion Paper, consumers and carers have independent interests. It should also be made clear that consumers and carers have different expertise and different circumstances, and that a Carer Worker has a different role to a Consumer Worker, and faces different issues in the execution of that role. Any guidelines created, including the Code of Professional Standards, need to take into consideration the different roles and experiences of Consumer and Carer Workers and ensure that these are provided for. Carers NSW would suggest that the Consumer Workers Forum liaise with carers and carer organisations such as Carers NSW and ARAFMI NSW Inc. to ensure that the Code of Professional Standards is appropriate for both Consumer and Carer Workers. Consumer and Carer Workers are not interchangeable and should not be treated as such, especially by the guidelines that are intended to support and define their employment.

**Recommendation 9:** That detailed guidelines are created for Consumer and Carer Workers, in consultation with carers and carers organisations, as well as with the Consumer Workers Forum.

### **Systemic Participation (p 10)**

Carers NSW supports the clarification in the Framework of the roles of the NSW Consumer Advisory Group – Mental Health Inc (NSW CAG) and ARAFMI NSW Inc. in the participation process. Carers NSW believes that these organisations, with Carers NSW, are key stakeholders in consumer and carer participation in mental health services and have a role to play in supporting and enabling consumer and carer participation in mental health.

As the peak body for carers in NSW, Carers NSW is a stakeholder in carer participation in mental health services. Carers NSW has a Carer Representation Program, which provides carers with

<sup>10</sup> Wilson, L and Harnett, E, 2005, Parents as Carers: The Development of a Family Resource Centre at The Children's Hospital at Westmead, Conference Proceedings, Shifting Paradigms in Health Care: Leading Practice in Carer Support, Carers NSW and NSW Health, Sydney

<sup>11</sup> Kelly, M and Newstead, L, 2004, Family Intervention in routine practice: it is possible!, Journal of Psychiatric and Mental Health Nursing, 2004, 11,64-72

<sup>12</sup> Bridge, J, and Barbe, R, 2004, Reducing hospital readmission in depression and schizophrenia: current evidence, Current Opinion in Psychiatry, 17 (6): 505-511

<sup>13</sup> Carers NSW, Response to consultation paper by Australian Commission on Safety and Quality in Health Care on the Draft National Patient Charter of Rights

training, information and support to act as Carer Representatives, and connects health, community and other human services with appropriately prepared and supported Carer Representatives.

While Carers NSW does not solely represent carers of people with a mental illness, our role as the peak body for all carers in NSW and the expertise acquired in this field, especially in regards to carer participation and representation, positions Carers NSW to actively support carer participation, especially representative participation in mental health services.

As a service provider Carers NSW also supports carers and families of people with mental illness, and the largest increase in referrals to the National Carer Counselling Program (which Carers NSW delivers in New South Wales) has been for carers of people with a mental illness. Service provision and systemic advocacy for carers of people with a mental illness is a key component of the work of the organisation.

**Recommendation 10:** That the Framework clarify the role of NSW Consumer Advisory Group – Mental Health Inc. and ARAFMI NSW Inc. in the participation process.  
**Recommendation 11:** That consideration be given to the role of other key stakeholders, including Carers NSW.

## **Procedural Issues**

### **Remuneration (p 11)**

Carers NSW is familiar with the current NSW Health Guidelines which support 'financial assistance' to consumer, carer and community representatives but not the payment of sitting fees. Carers NSW agrees with the financial assistance provided, but believes that consumer, carer and community representatives should also be entitled to remuneration for the contribution they make in the course of their formal representative activities.

Carers NSW policy on Carer Representation and Participation is that Carers NSW Carer Representatives be remunerated for formal representation activities, such as participation on advisory groups, committees and other decision making bodies and reimbursed for certain expenses arising directly from their participation, similar to those for which NSW Health Guidelines provide 'financial assistance'.

Remuneration and reimbursement of carer representatives, (and consumer and community representatives) is vital to avoid the representative being financially disadvantaged by their participation in representation activities. Carer, consumer and community representatives are more likely to use out-of-work hours to prepare for committee participation or to sacrifice time in paid employment (and the corresponding income) in order to participate than the professional members of the decision making body/committee for whom participation is considered part of their role as employees.

Secondly, remuneration is necessary to ensure that carer, consumer and community representatives are on an equal footing with other members of the decision making body, regardless of whether it is a Government Board or Advisory Council, or a departmental or interdepartmental committee.

Finally, Carers NSW believes that the contribution made by carer, consumer and community representatives warrants remuneration. As this Discussion Paper articulates, consumer, carer and community participation has manifold benefits for the quality, responsiveness and effectiveness of mental health services, and is worth remunerating.

**Recommendation 12:** That consumer, carer and community representatives are remunerated for formal representative activities, and reimbursed for expenses.

### **Processes where consumer is ill or person carer is caring for is ill (p 12)**

Carers NSW agrees that the Framework should include guidance on processes for committees to follow when a consumer falls ill or where the person a carer is caring for is ill, and for employed Consumer and Carer Workers to ensure that having a mental illness does not prevent consumers nor carers from participating in representative activities or paid employment as Consumer or Carer Workers.

Carers NSW Carer Representation and Participation Policy recognises that carers and the people they care for may be affected by ill health or other factors and that there needs to be processes in place for this eventuality. The policy recommends that where appropriate, two carer representatives are appointed to a committee to provide peer support and also cover for ill health or other eventualities. This is one possibility for the Framework.

**Recommendation 13:** That the Framework include processes for when the consumer or carer is affected by factors such as ill health.

### **Key recommendations**

Carers NSW recommends the following:

1. That the Framework make reference to, and be consistent with, the NSW Carers Action Plan 2007-2012 and relevant Carer Recognition Legislation.
2. That the Framework identify specific strategies for implementation.
3. That the Framework acknowledge carers' right to choice regarding their caring circumstances.
4. That the Framework provide for both individual participation and representative participation.
5. That the Framework articulate Principles for Consumer, Carer and Community Participation.
6. That the Framework address participation opportunities for carers at all levels and include links to national processes and consultations.
7. That the Framework ensure that carer representatives are able to represent the wider body of carers, and are representative of the diversity of carers.
8. That the sections of the Framework relating to participation in individual treatment and recovery are consistent with and make reference to the NSW Carers Action Plan 2007-2012, Priority 4.4 'Carers are partners in care'.
9. That detailed guidelines are created for Consumer and Carer Workers, in consultation with carers and carers organisations, as well as with the Consumer Workers Forum.
10. That the Framework clarify the role of NSW Consumer Advisory Group – Mental Health Inc. and ARAFMI NSW Inc. in the participation process.
11. That consideration be given to the role of other key stakeholders, including Carers NSW.
12. That consumer, carer and community representatives are remunerated for formal representative activities, and reimbursed for expenses.
13. That the Framework include processes for when the consumer or carer is affected by factors such as ill health.

Carers NSW thanks the Mental Health Program Council for the opportunity to comment on the Discussion Paper.

If you require any further information about Carers NSW response to the Discussion Paper, please contact Alison Parkinson, Carer Representative Project Officer on 02 9280 4744 or email [alisonp@carersnsw.asn.au](mailto:alisonp@carersnsw.asn.au).

Yours sincerely

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

Elena Katrakis  
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Carers NSW