



**Carers ACT's response to the ACT Health
Mental Health and Wellbeing Framework**

February 2015

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We offer our respects to their Elders past and present, and celebrate the Ngunnawal people's living culture and valuable contribution to the ACT community.

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Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 carers living in the Australian Capital Territory.

These carers provide ongoing unpaid care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to around 8000 families through our counselling, information, respite support, education, social support and case coordination services. We continue to meet national accreditation standards for delivery of our services to carers at a high level.

Carers ACT has a constitutional mandate to represent the voices of carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.

Introduction

Carers ACT welcomes the opportunity to comment on the ACT Mental Health and Wellbeing Framework 2015-2025 (the 'Framework').

Carers ACT is the key organisation in the ACT providing specialist carer support services to the 43,000 carers in the ACT. We support carers through referral to services, provision of advocacy, counselling, information, respite, support, education, social support, and case coordination services. Our engagement with the many carers who have accessed our services over a period spanning more than 21 years and our membership of the national network of carers associations, have provided us with an evidence-based understanding of, and insights into, the interests and concerns of Australian carers.

We note that each of the ACT Government Directorates will be responsible for developing strategies to address the Framework's ten Objectives and, related to this, identify activities for the community organisations they fund. Carers ACT understand that there will be further consultation on the development of measures associated with the Objectives. As they currently stand, it is not appropriate for us to provide input on the measures given that they are not linked to any actions. However, Carers ACT believes that further consultation on the measures should ensure they are congruent with the new service access and delivery arrangements introduced by the roll out of the National Disability Insurance Scheme (NDIS).

This submission draws on feedback from mental health carers and Carers ACT's Counselling and Young Carers program teams. The key areas that this submission focuses on are the relationship between trauma and mental health issues, and the identification of carers as an 'at risk' group. In addition to these topics, carers have commented that the Framework does not recognise the role and contribution of private health service providers, in particular general practitioners, in mental health promotion, prevention, early intervention, and suicide prevention. Carers ACT understands that the Framework will apply to public government agencies and the community organisations they fund. However, as one carer noted:

Most people first use their GP, sometimes only use their GP. When you can't get into public services you go private. ... Some strategy here seems necessary to me and as I understand this exercise it will result in a two stream approach to care. I think this is critical, as carers have to find their way between this, and manage perceptions - there is no charter document you can take with you.

We have also received input from one carer that the term 'psychosocial disability' be included in the Framework.¹ Carers ACT supports this feedback, and believes this terminology fits in well with the Framework's consideration of the broad range of factors informing the social determinants of health.

¹ National Mental Health Consumer & Carer Forum (2011). *Unravelling Psychosocial Disability, A Position Statement by the National Mental Health Consumer & Carer Forum on Psychosocial Disability Associated with Mental Health Conditions*. Canberra: NMHCCF. According to the National Mental Health Consumer and Carer Forum, psychosocial disability refers to 'the disability associated with a person's psychosocial experience' (p. 7).

Trauma and Mental Health Issues

The elephant in the room is still trauma (Carers ACT counsellor)

The Framework identifies women, asylum seekers and refugees as the most likely group of people with trauma histories. We suggest that many of the 16 groups identified in the Framework as ‘at risk’ populations may also have been impacted by trauma. For example, Aboriginal and Torres Strait Islander peoples, CALD minority groups, and people who are lesbian, gay, bisexual, transgender, intersex and/or queer are more likely to have experienced community violence.² Aboriginal and Torres Strait Islander peoples have also been and continue to be impacted by the policies of forcible removal of children.

Carers may also have trauma histories. The counselling team at Carers ACT have found that many of the carers who access their services have experienced trauma (see Table 1 below).

Table 1 - *We're the circuit breakers in so many cases*

Prior to her employment with Carers ACT one of the counsellors spent her career working in trauma services, including domestic violence, sexual assault, and torture and trauma services. Based on everyday individual counselling together with the issues raised in group sessions for mental health carers, she has found that many carers have symptoms that are akin to Post-Traumatic Stress Disorder, for example, hyper-vigilance - the perception they 'can never relax'; sleep disturbances including insomnia and/or nightmares; feeling under threat; flashbacks; angry outbursts; appetite problems - eating too much or not at all; depression; anxiety; suicidality. She has found that for the long term carers, these symptoms are chronic. The counsellor has called for assistance from the police and the crisis team on a number of occasions.

Carers may also describe the ‘mental health system’ as traumatising; as one carer explained: *failure to communicate with families and carers on the part of the mental health treatment team is a major source of ongoing trauma for families and carers, enforcing isolation, lack of skills in managing the illness, and a culture of blame and stagnation rather than a culture of wellbeing, co-operation and recovery.*

Of those people who develop Post-Traumatic Stress Disorder, many develop other mental health conditions and substance use problems. In one study, it was found that about 80 percent of people with PTSD will have at least one comorbid psychiatric disorder.³ It is not surprising, then, that a number of studies have found the majority of people who access mental health services have a

² Jenna Bateman, Corinne Henderson, and Cathy Kezelman. 2013. *Trauma-informed Care and Practice: towards a cultural shift in policy reform in mental health and human services in Australia*. Mental Health Coordinating Council: Rozelle, page 4.

³ Bradley D Grinage. 2003. *Diagnosis and Management of Post-traumatic Stress Disorder*. American Family Physician. Dec 15;68(12):2401-2409.

trauma history of child abuse, violence, substance abuse, and/or poverty. This highlights the need for trauma sensitive service systems as integral to mental health promotion, prevention and early intervention and suicide prevention:

Being trauma informed means realising that the vast majority of people we come in contact have trauma histories. Trauma must be seen as the expectation, not the exception in mental health service systems. (Linda Rosenberg, in Bateman et al, p. 24)

A trauma informed response is a holistic approach for responding to people who access human services. In addition, trauma informed care identifies and responds appropriately to complex and intergenerational trauma; improves consumer outcomes; and reduces re-traumatisation.⁴ There are also budgetary savings for local, state and federal governments when service systems adopt trauma informed practice.⁵

Despite the evidence of the relationship between trauma and mental health conditions,

Australia's mental health and human service systems have, generally speaking, a poor record in recognising the relationship between trauma and the development of mental health conditions, co-existing difficulties and complex psychosocial problems, and responding appropriately to them. The lack of policy focus is reflected by a lack of awareness around trauma-informed approaches within practice and service settings. (p. 4)

Carers ACT believes that the Framework provides an opportunity for the ACT to consider service system awareness of and responses to trauma. Moreover, a trauma informed approach is congruent with the 'person in environment perspective' proposed by the Framework that acknowledges the social and environmental factors contributing to 'mental ill-health' (page 10). Therefore, we recommend that the Framework would be further strengthened by:

- a greater recognition of trauma, and the relationship between trauma and the development of mental health issues, including suicidality; and
- the inclusion of trauma informed care measures in the Objectives.

⁴ Bateman et al, pages 31-32.

⁵ See, for example, Cathy Kezelman, Nick Hossack, Pam Stavropoulos, and Pip Burley. 2015. *The cost of unresolved trauma and abuse in Australia*. Adults Surviving Child Abuse and Pegasus Economics, Sydney.

Table 2 - *all the stress that we have to suffer at home*

In a meeting with female Aboriginal Elders in 2015, participants disclosed how traumatised their family members are by mental illness, drug and alcohol misuse, and deaths by suicide or drug overdose. Women talked about how helpless they feel in getting help for relatives experiencing mental health and drug and alcohol issues. They described lives of worry, of walking on egg shells, and of being too scared to go to sleep at night. The Elders are concerned that there are not adequate services to look after their children and grandchildren. They described the stresses associated with calling police or the crisis team to their homes, the accusations from family members who feel betrayed and the disharmony this creates for them. They also expressed their concern that the people they care for are not being kept in psychiatric facilities long enough to stabilise the symptoms of their mental illness. One woman recalled how her son was discharged after only three days of inpatient care. He took his life several days later.

Families are reluctant to evict people experiencing comorbidity from their homes. They want to keep their children and grandchildren safe. This admirable trait occurs at the cost of their own health and wellbeing. Elders spoke of their fears for their own safety. These women feel helpless and powerless, and that they have nowhere to turn to (apart from each other). Their experiences are that the service system is mostly not interested in listening to them. They believe they have no alternative but to put up with volatile family dynamics. Not surprisingly, these Elders are worn out and traumatised by the complex, social and environmental situation in which they find themselves.

The Elders also raised the issue of community members detained in Alexander Maconochie Centre who are not being permitted to attend interstate funerals. For cultural, spiritual and social reasons, it is very important for Aboriginal and Torres Strait Islander peoples to participate in funeral ceremonies and take part in the mourning process.

The meeting with Aboriginal mental health carers reveals some of their trauma experiences. It highlights the importance of promoting cultural safety in all aspects of service delivery, and the importance of a trauma informed response by the human service system to the signs of mental distress, drug and alcohol misuse, and family violence.

Carers ACT believes the Framework would be strengthened by referencing Closing The Gap measures and secondly, including measures that address cultural safety and cultural competence in the workforce.⁶

⁶ See, for example, the paper prepared by the National Aboriginal Community Controlled Health Organisation – *Creating the NACCHO Cultural Safety Training and Standards Assessment Process* (2011) - http://www.naccho.org.au/download/cultural_safety/CSTStandardsBackgroundPaper.pdf

The recognition of carers as an ‘at risk’ group

Under Objective 9 - Enhance services to groups within the community at increased risk of developing mental ill-health - it is acknowledged that:

There is strong evidence that some population groups are at higher risk of developing mental ill-health because they experience additional stresses, discrimination and stigma. These include: ... children of parents who have a mental illness.

Carers ACT applauds the recognition of young people who may be in an informal caring role of a parent with mental illness, and welcomes their inclusion in mental health promotion, prevention and early intervention programs. We are aware that young carers are more likely to experience difficulties in attaining good educational outcomes; social isolation; stigmatisation; and issues with bullying, directly relating to their carer role.⁷ Children of parents with mental illness may also be at risk of experiencing trauma and developing a mental health condition.⁸ Many of these young carers may grow up to become adult carers, still dealing with the issues that they were presented with as children or adolescents: *I see many adult carers who now in their 50's plus, are still managing the effects of caring for a parent with a mental illness and the long term effects on their own mental health* (Carers ACT counsellor). Therefore, it is vital that these young people receive timely and appropriate supports in their schools, and through other community groups, including the development and maintenance of programs targeted at young carers.

Carers ACT is disappointed that while the Framework identifies carers as an at risk group (page 8), carers are not included – alongside children of parents with mental illness - under Objective 9. In addition to the voices of our counselling team and what carers are telling us, a number of local, national and international research studies have found that carers and their families are more likely to experience mental health problems, including depression, and a general lack of wellbeing. These symptoms may be directly attributed to the caring role. While many carers describe their roles as rewarding, caring does come at personal cost. A study found that one in three carers had separated from their partner after taking on the caring role.⁹ This finding is significant when one considers the findings of the Carer Health and Wellbeing Survey, administered to 10,939 carers (37.6% response rate), that ‘in terms of household composition, the most disadvantaged group is sole parents’.¹⁰ Key findings of the Carer Health and Wellbeing Survey are outlined in Table 3 below:

⁷Fatmata Johns. *Young Carers and Mental Health Predictors*, paper presentation. National Carers Conference, Gold Coast, 2014; Tim Moore, 2005. *Stop to Listen: Findings from the ACT Young Carers Research Project*. Youth Coalition of the ACT: Lyneham.

⁸ Andrea E Reupert, Darryl J Maybery and Nicholas M Kowalenko. 2012. *Children whose parents have a mental illness: prevalence, need and treatment*, MJA, Open Issue 1 Supplement 1: 7-9. ; Royal College of Australian and New Zealand College of Psychiatrists. October 2009. Position Statement 56: Children of Parents with a Mental Illness, https://www.ranzcp.org/Files/Resources/College_Statements/Position_Statements/ps56-pdf.aspx; Leone Huntsman. 2008. *Parents with mental health issues: Consequences for children and effectiveness of interventions designed to assist children and their families. Literature Review*. NSW Department of Community Services: Ashfield.

⁹ In 2006, the Australian Institute of Family Studies administered a survey to 1,002 carers. The results are described by the authors Ben Edwards, Daryl J Higgins, Matthew Gray, Norbert Zmijewski, and Marcia Kingston (2008) *The Nature and Impact of Caring for Family Members with a Disability in Australia*. Australian Institute of Family Studies: Canberra.

¹⁰ Robert A Cummins, Joan Hughes, Adrian Tomyn, Adele Gibson, Jacqueline Woerner, and Lufanna Lai. 2007. *The Wellbeing of Australians - Carer Health and Wellbeing*, Australian Unity Wellbeing Index, Survey 17.1, Report 17.1, October 2007. Geelong: Deakin University.

Table 3 - Key findings of the Carer Health and Wellbeing Survey

- Carers have the lowest collective wellbeing of any group we have yet discovered.
- Carers have an average rating that is classified as moderate depression.
- In terms of household composition, the most disadvantaged group is sole parents.
- A total of 20.6% of the carer sample are unemployed.
- For those carers who are employed, over one third has a degree of worry about losing their job that depresses their wellbeing even further.
- The wellbeing of carers is more vulnerable to pain than is normal.
- Carers are more likely than is normal to be experiencing chronic pain. Therefore, pain for carers is a double jeopardy.
- Having a significant medical or psychological condition is associated with lower wellbeing for carers than found within a normal population sample.
- Not receiving treatment for a significant medical or psychological condition is extremely damaging to wellbeing.
- The major reasons carers are not receiving treatment for themselves is that they have no time or cannot afford the treatment.
- Household income is a double jeopardy for carers. Their average household income is lower than is normal within the general population, and their wellbeing is more vulnerable to low income than the general population.
- The wellbeing of the 3,049 people (83% of the sample) who live with the person requiring care is 58.4 points. This is the lowest value we have ever recorded for a large group.

NB: Australian Unity note that the Personal Wellbeing Index ranges from 55-90 points; and the average wellbeing for an individual is 75 points.

Eight years have passed since the publication of the Carer Health and Wellbeing survey findings. There has been little or no improvement for carers. Some key findings outlined in the Ninth Statistical Report (HILDA survey) published in 2014 reveal that main carers have the lowest mean household income and the lowest employment rates. They have the highest rates of severe and moderate disability, poor general health and poor mental health. And they have the lowest average levels of overall life satisfaction, satisfaction with their financial situation, health satisfaction and satisfaction with the amount of free time they have (p. 83).¹¹

Based on the evidence, Carers ACT strongly recommends that activities addressing carer wellbeing be developed for the Mental Health and Wellbeing Framework.

¹¹Roger Wilkins (editor). 2014. *Families, Incomes and Jobs, Volume 9: A Statistical Report on Waves 1 to 11 of the Household, Income and Labour Dynamics in Australia Survey*. Melbourne Institute of Applied Economic and Social Research, University of Melbourne: Melbourne.

Recommendations

Carers ACT recommends that ACT Health, as lead agency for the Mental Health and Wellbeing Framework consider:

1. Developing measures that are congruent with the new service access and delivery arrangements of the National Disability Insurance Scheme
2. Including the term 'psychosocial disability' in the Framework, and elaborating on the relationship between mental illness and disability
3. Elaborating on the prevalence of trauma across community populations and the relationship between trauma and the development of mental health issues, including suicidality
4. Recognising trauma informed care as a valuable strategy in mental health promotion, prevention, early intervention and suicide prevention and developing appropriate measures in the Objectives
5. Referencing Closing The Gap measures and related to this, developing measures that address cultural safety for Aboriginal and Torres Strait Islander peoples, and that promote a culturally competent workforce
6. Developing measures under Objective 9 - *Enhance services to groups within the community at increased risk of developing mental ill-health* - that address carer wellbeing