



**National Recovery-Oriented Mental Health Practice Framework Project**

**Carers ACT response to the discussion paper**

**24 April 2012**

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 continuation of the Ngunnawal people's living culture.

Carers ACT sincerely thanks all carers who have contributed to the research and consultation activities which inform its policy and representation activities.

***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 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 7,000 families through our counselling, information, respite support, education, social support and case coordination services. Our services were assessed in 2009 to meet Home and Community Care and National Carer Counselling Program accreditation standards at a level of excellence.

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.

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## **Introduction**

Carers ACT appreciates the opportunity to respond to the *National Recovery-Oriented Mental Health Practice Framework Project*<sup>1</sup> Discussion Paper (hereafter the 'Project'). In preparing this response Carers ACT has not addressed all the issues raised in the Discussion Paper, but has focused on the role of family or informal carers who support people with mental illness, particularly in their recovery process, and to maintain their mental health.

We are pleased that the Introduction to the Discussion Paper states that the recovery orientation that has been largely championed and driven by people with experience, their families and friends and the non government mental health sector is now being increasingly supported by clinicians and policy makers.

Carers ACT supports mental health carers through referral to services, provision of respite and counselling. It also coordinates the ACT Mental Health Carers Voice, an ACT Government-funded representation program for carers of people with mental illness. Our engagement with the many carers who access these specialist services and participate in the representation program has been valuable to inform our response to this Discussion Paper.

## **Background Information: Who are carers and what is the impact of caring?**

Throughout Australia it is estimated that there are 2.6 million carers who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or are frail aged.<sup>2</sup> One third of carers are primary carers – meaning that they provide the majority of help and support for the person they care for.<sup>3</sup> Over two-thirds of primary carers are women and most care for a close relative such as their partner, their parents or their child/children.<sup>4</sup>

Caring has a significant emotional and physical toll on carers. In one study it was found that almost twice as many carers were in poor physical health than the general population and that these results were not attributable to age.<sup>5</sup> The Australian Bureau of Statistics found that 36% of carers reported that their physical or emotional wellbeing had changed due to their caring role and that primary carers who cared

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<sup>1</sup> Craze Lateral Solutions. *National Recovery-Oriented Mental Health Practice Framework Project*. Discussion Paper Summary and Consultation Questions, Glen Alpine: Craze Lateral Solutions, 2012.

<sup>2</sup> Australian Bureau of Statistics [ABS]. "Survey of Disability, Ageing and Carers [SDAC]." 2009; Carers ACT, *Annual Report*, 2011.

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

<sup>5</sup> Ben Edwards, Daryl Higgins, Matthew Gray, and Nobert Zmijewski. *The Nature of Impact of Caring for Family Members with a Disability*. Research Report No. 16, Canberra: Australian Institute of Family Studies, 2008, 112.

for more than 40 hours or more per week were more likely to feel more worried or depressed (40%) than those caring for less than 20 hours a week (27%).<sup>6</sup> Caring also had an impact on carers' social contact, with one research project indicating that 18% of carers only had face-to-face social contact either once every three months or less often.<sup>7</sup>

The financial impact of caring is also clear – the Australian Institute of Family Studies found that 30% of families with a carer receiving a Carer Allowance, and 29.2% of families with a carer receiving Carer Payment experienced difficulties paying bills on time.<sup>8</sup> This rate was 14.6% amongst the general population.<sup>9</sup> The finances of caring families are also impacted by the fact that the rate of full-time employment among primary carers is 19.2%.<sup>10</sup> The Australian average is 42.0%.<sup>11</sup> Consequently, Access Economics has calculated that the opportunity cost of time devoted to informal care, measured as reduction in paid employment due to caring is equivalent to \$6.5 billion with carers providing 1.32 billion hours of unpaid care every year.<sup>12</sup>

### **Carers and a Recovery Framework**

To a certain extent, a recovery approach resulting in better outcomes for people with mental illness is also beneficial for families undertaking a caring role. However, it is also important to highlight the difficulties and sometimes conflicting interests that can arise in implementing a recovery framework that does not pay sufficient consideration to the needs and perspectives of mental health carers.

One of the first issues relating to a recovery approach is the need to recognise and value the specific skills and knowledge of mental health carers in supporting people with mental illness. This is a priority outlined in *National Mental Health Standard 7* which states, "The MHS recognises, respects, values and supports the importance of carers to the wellbeing, treatment, and recovery of people with a mental illness."<sup>13</sup>

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<sup>6</sup> Australian Bureau of Statistics [ABS]. "Caring in the Community, Australia." 2009.

<sup>7</sup> Ben Edwards, Daryl J. Higgins and Norbert Zmijewski. "The Families Caring for a Person with a Disability Study." *Family Matters*, no. 76 (2007): 8-17.

<sup>8</sup> Ben Edwards, Daryl Higgins, Matthew Gray, and Norbert Zmijewski. *The Nature of Impact of Caring for Family Members with a Disability*. Research Report No. 16, Canberra: Australian Institute of Family Studies, 2008, 113.

<sup>9</sup> Ibid.

<sup>10</sup> Access Economics. (2010). *The Economic Value of Informal Care in 2010, Report for Carers Australia*.

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

<sup>13</sup> *National Standards for Mental Health Services* (2010), Standard 7.

Research indicates that carers are an extremely important source of information for professionals not just at the assessment phase, but also in developing and implementing care plans.<sup>14</sup> Furthermore, if carers and professionals work together they can provide insights and support services that are often complementary. This extract from a personal experience in the UK context illustrates this point:

Looking back I realise how beneficial it was to have two perspectives on my son's recovery, and for two very different reasons. Firstly, as his 24/7 carer, there were long periods when there seemed little change in his condition from day to day, week to week which was disheartening, even depressing at times. However, his care worker, visiting periodically, was able to see a very slow but sustained improvement. And her letting me know this just gave me enough hope to keep going!<sup>15</sup>

And:

Conversely, being around my son all the time meant that I could detect very subtle changes in my son's appearance, behaviour, and attitude. I could then alert his care worker... so she could arrange an interim visit."<sup>16</sup>

Reflecting these sentiments, the *National Standards for Mental Health Services (2010)* states:

"Consumers and carers are actively involved in the development, planning, delivery and evaluation of services."<sup>17</sup> (Standard 3)

Falling under the 'supporting recovery' bracket, "the MHS provides education that supports consumer and carer participation in goal setting, treatment, care and recovery planning, including the development of advance directives."<sup>18</sup> (Standard 10.1.6)

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<sup>14</sup> Mandy Reed, Sharon Peters and Lizzie Banks. "Sharing care with families." In *Promoting Recovery in Early Psychosis: A Practice Manual*, by Paul French, Jo Smith, David Shiers and Mandy, Rayne, Mark Reed, 226-235. Oxford: Blackwell Publishing, 2010, 230.

<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

<sup>17</sup> *National Standards for Mental Health Services (2010)* Standard 3.

<sup>18</sup> *National Standards for Mental Health Services (2010)* Standard 10.1.6.

Incorporating the perspective of carers and working collaboratively also reflects the reality of caring patterns:

Although professionals provide a range of assessments, deliver treatments and offer support to families, their contact with both the individual themselves (unless hospitalised) and their families will only be for a tiny percentage of the time that families are living with the individual. This means that, in the majority of cases and for the majority of the time, families are providing the majority of care.<sup>19</sup>

Consequently, given the high levels of care provided by some carers and families, it is clear that they have a high degree of knowledge and expertise.<sup>20</sup> This is reflected in Schedule 1(7) of the *Carer Recognition Act 2010* (Cth) which states, “Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.”<sup>21</sup>

The *ACT Mental Health Services Plan* (MHSP) 2009-2014 also identifies the importance of carers within a recovery framework: “the ACT MHSP recognises in particular the important role of carers in psycho social support and consumers’ ongoing recovery journey.”<sup>22</sup>

These policies and legislation go some way towards addressing the experience of carers that they are “not acknowledged or respected as experts in providing care” in their dealings with health and community professionals which can lead to carers being “ignored or dismissed, despite the valuable insight, expertise and information they can provide.”<sup>23</sup> Consequently, the *National Carer Strategy*, which is designed to give effect to the *Carers Recognition Act 2010* (Cth), states that, “in everything from planning to service delivery, carers should be involved where appropriate” with such a system deemed to “have positive results for all.”<sup>24</sup>

Because of the complexity of the rights to privacy and confidentiality for the consumer and the rights to information for the carer and family the National Mental Health Consumer and Carer Forum prepared a position statement – *Privacy, Confidentiality and Information Sharing: Consumers, Carers and Clinicians*. This statement discusses when it is beneficial and appropriate for carers to be informed and involved in

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<sup>19</sup> Mandy Reed, Sharon Peters and Lizzie Banks. "Sharing care with families." In *Promoting Recovery in Early Psychosis: A Practice Manual*, by Paul French, Jo Smith, David Shiers and Mandy, Rayne, Mark Reed, 226-235. Oxford: Blackwell Publishing, 2010, 226.

<sup>20</sup> Grainne Fadden, "Family interventions." In *Enabling recovery: the principles and practice of rehabilitation psychiatry*, by Glen Roberts, Sarah Davenport, Frank Holloway and Theresa Tattan, 158-169. London, 2006, 162-163.

<sup>21</sup> *Carer Recognition Act 2010* (Cth) sch 1 (7).

<sup>22</sup> ACT Health. *ACT Mental Health Services Plan 2009-2014*. Canberra: ACT Health, 2009, 10.

<sup>23</sup> National Carer Strategy, *Priority 1: Recognition and Respect*, 2011.

<sup>24</sup> National Carer Strategy, *Policy Direction 2: Ensure that carers are engaged as partners in care*, 2011.

mental health care plans and recovery. It moves from the traditional professional view of carers as “impediments to service provision” to “allies in the recovery process.”<sup>25</sup>

This approach also better reflects the diversity of caring patterns in the community, and “Anglo-Celtic cultural and philosophical traditions that exclude family from decision making around the health... of an individual family member.”<sup>26</sup> The National Mental Health Consumer and Carer Forum has discussed this issue in relation to the New Zealand context where the family caring traditions of Maori peoples are incorporated at a strategic planning level.<sup>27</sup>

A second issue is the need to work within existing privacy legislation, but realising the impact that this can have on the ability of carers to support their loved ones when they are not involved in assessment and treatment discussions. For example:

A further ethical difficulty that has been identified is how to respect the rights of the individual to confidentiality. A vexed issue is that of communication between services and informal carers when the patient states they do not want the carer involved.<sup>28</sup>

This response recognises the right of the consumer to privacy and their right not to disclose personal information. However, in cases when this does occur, and consent is not given, then this can be extremely difficult for the carer who may not understand what is happening with their loved one.<sup>29</sup> For example, in some cases medication regimes may be altered and carers will not be informed about possible and significant health outcomes.<sup>30</sup> At a recent mental health forum hosted by Carers ACT, several of the mental health carers provided examples of medication regimes being altered while consumers were in a mental health recovery unit or hospital without consultation with the consumer’s regular clinician or carer. Carers stated that if they or the clinician had been consulted adverse medication outcomes may have been minimised or averted.<sup>31</sup>

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<sup>25</sup> National Mental Health Consumer and Carer Forum. *Privacy, Confidentiality and Information Sharing- Consumers, Carers and Clinicians*. Canberra: National Mental Health Consumer and Carer Forum, 2011, 30.

<sup>26</sup> National Mental Health Consumer and Carer Forum. *Privacy, Confidentiality and Information Sharing- Consumers, Carers and Clinicians*. Canberra: National Mental Health Consumer and Carer Forum, 2011, 31.

<sup>27</sup> Ibid.

<sup>28</sup> Frank Holloway, “Pulling it all together: the care programme at its best.” In *Enabling recovery: the principles and practice of rehabilitation psychiatry*, by Glen Roberts, Sarah Davenport, Frank Holloway and Theresa Tattan, 231-243. London, 2006, 241.

<sup>29</sup> Interview with Carers ACT Counsellor, 23 April 2012. (Carers ACT delivers the National Carer Counselling Program in the ACT. 60% of carers using this service care for a person with a mental illness.)

<sup>30</sup> Ibid.

<sup>31</sup> Carers ACT Mental Health Forum, 19 April 2012 (attended by 25 carers of people living with mental illness).

In a recovery-oriented system, families' need for information can also relate to being informed about the recovery process including, "letting families know that recovery is possible."<sup>32</sup> In this way, the concept of 'recovery' can be extremely empowering for carers who often struggle under the "burden of caring".<sup>33</sup> Realising that progress and recovery is possible can be beneficial and bring hope to the carer and family.

Being able to access key information about family members can also go some way to addressing the grief and emotional impact of the caring experience – particularly in high-stress situations when the person being cared for is being compulsorily admitted to hospital.<sup>34</sup>

A third theme regarding this issue is the need for the system to initially identify and then support carers.<sup>35</sup> Identifying carers is a difficult task given the diverse nature of caring and carers, and therefore there is a demonstrated need to develop comprehensive systems that identify correctly and then are responsive to carer needs. For example, this is particularly important given that the contribution of young carers is often overlooked, meaning that young carers, "who often taken on substantial responsibilities that are not age-appropriate, such as monitoring a parent's medication, do not receive help and support."<sup>36</sup>

The fourth issue in Carers ACT's response relates to the importance of including carers or having carer involvement in the development of mental health policies and standard operating procedures. Carers with their lived experience and knowledge, and the desire to achieve effective outcomes for consumers, provide an important voice in their development.

All of these points flow into the final theme – that, unfortunately, too often there can be a tendency amongst service providers to simply consider the needs of carers, "in terms of how far they can support individuals in improving their mental health."<sup>37</sup> This viewpoint fails to recognise the needs and rights of carers in their own right and how a better mental health system must engage, value and support the important work of mental health carers in the community. This acknowledgement of the contribution of

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<sup>32</sup> Christine Heron, *Working with Carers*. London: Jessica Kingsley, 1998, 195.

<sup>33</sup> Interview with Carers ACT Counsellor, 23 April 2012.

<sup>34</sup> Grainne Fadden, "Family interventions." In *Enabling recovery: the principles and practice of rehabilitation psychiatry*, by Glen Roberts, Sarah Davenport, Frank Holloway and Theresa Tattan, 158-169. London, 2006, 164.

<sup>35</sup> Interview with Carers ACT Counsellor, 23 April 2012.

<sup>36</sup> Grainne Fadden, "Family interventions." In *Enabling recovery: the principles and practice of rehabilitation psychiatry*, by Glen Roberts, Sarah Davenport, Frank Holloway and Theresa Tattan, 158-169. London, 2006, 164.

<sup>37</sup> Christine Heron, *Working with Carers*. London: Jessica Kingsley, 1998, 187.

mental health carers in policy development and service delivery is essential to improve outcomes for many people with mental illness, and to improve the health and wellbeing of carers.

## **Conclusion**

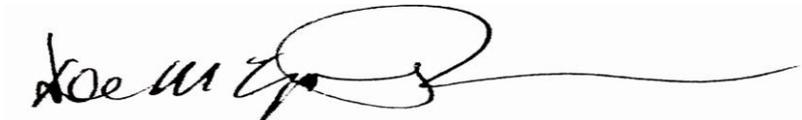
Carers ACT has canvassed five main issues relating to carers and the recovery-oriented approach to mental health. These themes are:

- The need to value the perspectives of carers as ‘experts’ and to work collaboratively to develop care plans for people with mental illness;
- Concerns about how a recovery-focus may have serious implications for carers (and, often consumers) if confidentiality provisions and regulations exclude them from the decision making process;
- Identifying carers, particularly care givers who may traditionally be overlooked such as young carers;
- Informing mental health policies and standard operating procedures by engagement with mental health carers;
- The overarching theme that carers also have their own rights and interests which may sometimes conflict with those of the people they care for; but that these perspectives must also be reflected in any meaningful and productive reforms to the mental health system.

For the project to reach its aim to “provide the opportunity for all mental health sectors to contribute to the development of a shared national framework for recovery orientated mental health services” the input from the carer sector (either individual carers or carer organisations) needs to be duly considered.

For more information or to discuss this response please contact me at Carers ACT by email [dee.mcgrath@carersact.org.au](mailto:dee.mcgrath@carersact.org.au) or phone (02) 9296 9901.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Dee McGrath', with a long horizontal flourish extending to the right.

Dee McGrath

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