



## ***Working with Carers, Families, and Support People***

### **Position Statement**

***Recovery-oriented practice and service delivery recognises the unique role of personal and family relationships in promoting wellbeing, providing care, and fostering recovery across the life span, and recognises the needs of families and support givers themselves.<sup>1</sup>***

Carers, family members and support people make a significant contribution to the recovery process of people experiencing mental illness. Further, the economic value of the informal, unpaid caring role is substantial: the annual replacement value of informal care in Australia is estimated to exceed \$60.3 billion per annum.<sup>2</sup> As the major service provider for ACT carers, Carers ACT is aware that many families are impacted by their caring responsibilities. Acts of caring for a loved one occur within the dynamics of family relations and friends, and in interactions with service providers and other agencies. While many carers describe their roles as rewarding, caring does come at personal cost. Family relationships may break down under the pressures and demands of caring for someone experiencing severe and persistent mental illness.<sup>3</sup> Parents, siblings, children and other family members may be directly or indirectly impacted. Research findings suggest that people in a caring role of someone with a mental illness are at risk of developing depression and anxiety. Children of parents with mental illness may also be at risk of experiencing trauma and developing a mental health condition.<sup>4</sup> It is not unusual for mental health carers to become hyper-vigilant as a result of their fears for the wellbeing of their family

<sup>1</sup> Australian Health Ministers' Advisory Council. 2013. *National Framework for Recovery-Oriented Mental Health Services. Guide for Practitioners and Providers*. Commonwealth of Australia: Canberra.

<sup>2</sup> Deloitte Access Economics. 2015. *The Economic Value of Informal Care in 2015*, Report for Carers Australia.

<sup>3</sup> A study found that one in three carers had separated from their partner after taking on the caring role. 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.

<sup>4</sup> 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](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*

member. Carers may also self-isolate as a result of experiences of stigma, feelings of shame, grief and guilt, alongside the demands of the caring role.

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.<sup>5</sup>

In addition to the personal costs of caring, carers continue to be frustrated in their interactions with mental health services. The National Mental Health Commission observes that a significant percentage of support people (across a range from 20 per cent to 60 per cent) consider that they were rarely or never made to feel part of the caring team.<sup>6</sup> Bland and Foster note that 'despite the good intentions of policy makers in Australia, many families continue to experience difficulties in relationships with service providers and in accessing services'.<sup>7</sup> The reluctance of some health providers to involve carers may be related to the norms governing the traditional doctor-patient relationship; and to a risk-averse and simplistic application of privacy and confidentiality legislative guidelines. This occurs in situations where an inflexible focus to protection of privacy means that carers are excluded from treatment planning, discharge and transfer information, but are still expected to manage the day-to-day care when the person returns to the home environment or the care situation.

While Carers ACT agrees that the rights of all individuals to privacy and agency is a fundamental human right, principles can sometimes lead to poor outcomes for carers and the people they care for. As peak body for ACT's mental health carers, we believe there are practical ways in which privacy and confidentiality rights can be upheld while at the same time supporting information sharing that is vital to the caring role, as set out in the National Mental Health Consumer and Carer Forum's Position Statement on Confidentiality, Privacy and Information Sharing. This Position Statement articulates a tripartite approach of information sharing between the consumer, carer and clinician and adopts the following principles:

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*effectiveness of interventions designed to assist children and their families. Literature Review.* NSW Department of Community Services: Ashfield.

<sup>5</sup> Roger 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, p. 83.

<sup>6</sup> National Mental Health Commission. *A Contributing Life: the 2012 National Report Card on Mental Health and Suicide Prevention*, p. 36. <http://www.mentalhealthcommission.gov.au/our-2013-report-card/2012-report-card.aspx>.

<sup>7</sup> Robert Bland and Michele Foster. 2012. Families and Mental Illness. Contested perspectives and implications for practice and policy. *Australian Social Work*, 65:4, 517-534

- *The privacy of consumers is a basic human right*
- *Each consumer's right to privacy should be balanced with their carers' need to give and receive information relating to their carer role*
- *Nominated carers should be identified, supported and incorporated into service provision*
- *Nominated carers play a vital support role in a consumer's recovery and should be included in information exchanges, where appropriate and with the consumer's consent*
- *Nominated carers' involvement should be regularly reviewed*
- *Consumer and carer participation is essential in developing best practice guidelines for information sharing.*<sup>8</sup>

Carers ACT notes that a tripartite approach of information sharing, recommended by the National Mental Health Consumer and Carer Forum, is assumed in the principles of the *Carer Recognition Act 2010* (Cth) which provide (at Principles 6 and 7 of Schedule 1) that:

*The relationship between carers and the persons for whom they care should be recognised and respected.*

*Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.*<sup>9</sup>

The object of the *Carer Recognition Act* is 'to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society.' The intent of the Act symbolises that which is at heart of many carers' struggles with the service system. Carers ACT believes that carer recognition and respect is broadened and enhanced by service providers' awareness of the impact of mental illness on families and support people and, related to this, that carers and families have their own support needs.<sup>10</sup>

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<sup>8</sup> [http://nmhccf.org.au/sites/default/files/docs/nmhccf\\_pc\\_ps\\_brochure.pdf](http://nmhccf.org.au/sites/default/files/docs/nmhccf_pc_ps_brochure.pdf)

<sup>9</sup> <https://www.comlaw.gov.au/Details/C2010A00123>

<sup>10</sup> As articulated in the *National Framework for Recovery-Oriented Mental Health Services: Guide for Practitioners and Providers*, Domain 2F: Responsive to Families, Carers and Support People, whose Core Principles recognise carer contributions and their support needs as well as the role of significant relationships to a person's recovery process; the importance of a partnership approach; and that 'choices about the involvement in personal recovery of family and significant others rests with the person living with mental health issues, with due consideration for what is age appropriate,' p. 57.

## **Carers ACT's principles for working with carers, families and support people**

Carers ACT recommends the following principles for working with carers, families and support people be adopted as part of best practice, recovery-focused service provision:

1. Care relationships are recognised and respected by service providers through the development of collaborative approaches to service planning and delivery, and set out in organisational business plans, policies and procedures.
2. A tripartite approach of information sharing between the consumer, carer and clinician is adopted by service providers, in line with the National Mental Health Consumer and Carer Forum Position Statement on Confidentiality, Privacy and Information Sharing.
3. Carers are made aware of their rights and responsibilities by service providers, and are encouraged to provide feedback on the services received in support of themselves, their family member or friend.
4. Service providers acknowledge the support needs of families, carers and support people including their own need for recovery and healing, and provide referrals as appropriate.<sup>11</sup>
5. Service providers are aware of culturally sensitive practices that consider specific support needs that the family, carer or support person deem appropriate. Cultural sensitive practice includes an awareness of religious/spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age and socio-economic status.<sup>12</sup>
6. Carers and families are provided with information and opportunities to identify their own support needs and to formulate their own plan in developing and sustaining strong and positive family relationships.<sup>13</sup>

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<sup>11</sup> In line with the *National Framework for Recovery-Oriented Mental Health Services. Guide for Practitioners and Providers*.

<sup>12</sup> *Ibid.*

<sup>13</sup> *Ibid.*