

# Adversity to Advocacy report card

Welcome to Australia's first ever national survey of mental health carers.

**This survey reveals the 15 key issues which affect mental health carers and provides the first ever national report card on how well Australia is managing these issues.**

The survey results highlight the gulf between mental health policy and practice. There is now a plethora of government reports, policies and strategies which aim to address the needs of mental health carers and carers more broadly.

This first national survey shows how these federal, state and territory mental health policies are yet to positively impact on the experience of mental health carers.

More than 1,500 mental health carers from across the nation came together in small groups from Broome to Bega, Cairns to Carnarvon. The carers attended a full day workshop delivered by the Mental Health Council of Australia (MHCA) in partnership with local organisations and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). In these workshops, carers talked about the issues and concerns they faced as carers of someone with a mental illness. The MHCA visited 116 locations throughout Australia with two thirds being rural, remote or regional.

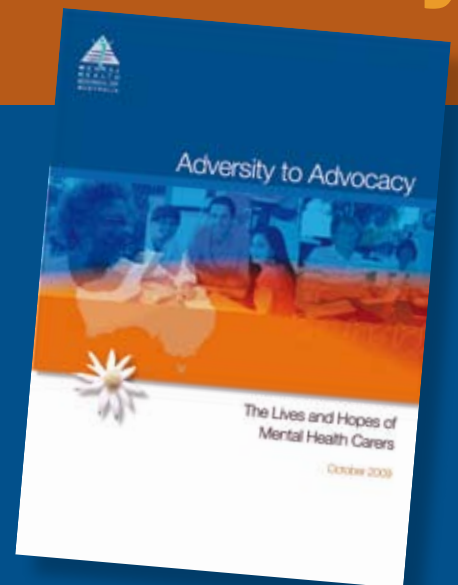
Many mental health carers are over 40 years old but the workshops also specifically engaged with young carers, some as young as nine.

The result of this work is a unique insight into the difficulties and concerns of Australians caring for someone with a mental illness. Collecting this information has been a privilege. Responding to it is a responsibility shared by funders and decision-makers. Ignoring it is not an option.

The MHCA has built a national network of mental health carers and will be striving to ensure this survey is just the first in an ongoing series designed to ensure the voice of mental health carers is loudly and clearly heard.

*Adversity to Advocacy* continues the saga initiated by the *Not for Service* Report 2005 and the report of the Senate Inquiry into Mental Health of 2006, *From Crisis to Community*. It extends the same national listening ear to mental health carers, hearing of their lives and, very sadly, it tells much the same stories. Little seems to have changed in the level of access to services when things start to deteriorate, the anguish at being excluded from information to help them care better, and the desperation and desolation at the thought:

*"what will happen to my son when I am gone?"*



# The 15 Key Issues Affecting Australia's Mental Health Carers

The table below highlights the gulf that exists between the existing policy approaches and the reality of the experience of care in each of the 15 key areas identified in this first national survey of Australia's mental health carers.

Key Issue Identified by Mental Health Carers in the Survey	How the issue is currently being addressed	What the Survey tells us about the real experience of mental health carers
<b>Issue 1</b> <b>Listen to and respect carers</b>	<p>The need to increase respect for carers is part of the new House of Representatives Inquiry announced on 1 May 2009, but has been a consistent theme in both national and state mental health strategies for more than a decade.</p>	<p>The common view among carers is that they are neither listened to nor respected. The rhetoric of including carers as part of the care 'team' for the consumer is not borne out in reality. Often this leaves carers trapped, excluded, feeling unable to provide adequate care, but also unable to find the services needed for the person they are caring for.</p>
<b>Issue 2</b> <b>Integrated recovery-based care for the consumer</b>	<p>The term 'recovery' now features in key government documents in relation to mental health, such as the 4<sup>th</sup> National Mental Health Plan and the new National Mental Health Service Standards. These documents clearly refer to the need to provide holistic care, involving clinical and non-clinical care, and services beyond health care in order to meet consumer needs towards recovery.</p>	<p>The intolerable stress faced by carers reflects the inadequacy of the care available to consumers. Of particular note here is the common experience faced by carers of lack of integration between different health services, and between health services and other community services such as housing or employment services, and lack of services such as Personal Helpers and Mentors. Recovery is very much an individual matter, assessed in the eye of the beholder. The system is not currently able to provide individualised or tailored approaches to care.</p>
<b>Issue 3</b> <b>More and better trained staff at all levels</b>	<p>This is the central role of the Mental Health Workforce Advisory Committee, which works as part of the Australian Health Ministers' Advisory Council structure. It has been highlighted in key national reports as a major issue for the future of mental health in Australia. The Better Access Program has enabled Medicare-funded access to psychology services for hundreds of thousands of Australians, although this access still relies on GPs providing a mental health care plan.</p>	<p>Carers identify inadequate staffing as a key part of current service failure. Access to psychiatry remains extremely limited. Increased access to registered psychology services was not seen as a significant benefit when inadequate workforce numbers impact on availability. Carers report that access to other forms of care, in particular sub acute care, remains a significant issue, particularly in non-metro areas.</p>
<b>Issue 4</b> <b>Knowledge and information for carers</b>	<p>The workshops to inform this survey were initiated by FaHCSIA partially out of concern to provide more information to mental health carers about available programs and services. Increasing mental health literacy has been identified as an important target in the National Health and Hospitals Reform Commission recommendations, and is implied in most Australian mental health strategies.</p>	<p>One of the most debilitating aspects of being a mental health carer is the sense of isolation and helplessness. Knowledge of services such as Commonwealth Carelink is minimal at best. Carelink's understanding of mental health also varies greatly from office to office. Knowledge of peer support options also seems very patchy, with many carers meeting for the first time at the local workshops. Carers reported that the knowledge of how to care for someone with a mental illness was rarely available at first onset of illness.</p>
<b>Issue 5</b> <b>Carer and consumer education for all professional groups and agencies</b>	<p>In areas such as policing and medicine, there are a number of jurisdictions now incorporating carer / consumer education and awareness components into required training.</p>	<p>Many carers feel ignored or patronised by professional groups and agencies. Most carers feel professionals appear to have no understanding of the role of carers, in particular their integral role in the ongoing care of the consumer. There is a real need for increased carer / consumer informed professional development for mental health and other service providers.</p>



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<b>Issue 6</b> <b>Support systems, services and processes established for carers</b>	This is a recommendation made by the National Health and Hospitals Reform Commission, and echoes the sentiment in previous national mental health plans about engaging more directly with carers.	The need for more carer led support programs for carers was raised in many workshops. The infrastructure to support carers is generally very weak, with some exceptions. Overall, mental health carer organisations are very poorly resourced. Health services have also generally failed to invest in robust systems to enable engagement with the carer sector. Carers often use their own resources and pay their own way in order to participate in policy and service development activities.
<b>Issue 7</b> <b>Acute care to be therapeutic and accessible</b>	Improving access to care has been a consistent theme of all four national mental health plans and was a key matter assessed by the 2007 Survey of Mental Health and Wellbeing. The second progress report on the COAG Action Plan 2006-11 reports on the therapeutic value of mental health care nationally for the first time.	The 2007 Survey of Mental Health and Wellbeing confirmed Australia's inability to lift access to care over the past decade. While the reasons for this are not clear, the impact on carers is very clear. Carers indicate they are commonly faced with providing care to consumers who are acutely unwell, leaving them and the people they care for more vulnerable to the effects of ill health. Carers also considered that acute care (when accessible), was rarely of a therapeutic or recovery oriented nature and often increased the trauma of an acute illness.
<b>Issue 8</b> <b>Stigma, discrimination and isolation for carers and consumers</b>	The reports recently prepared by both the National Health and Hospitals Reform Commission and the Prevention Taskforce articulated the need for a national campaign to address the issue of community stigma towards mental illness. This follows repeated acknowledgement of the issue in national mental health plans and strategies. There is currently no major national mental health awareness or promotion campaign.	Carers and consumers face daily discrimination and stigma. This manifests itself in the realms of employment, housing, health services, schools, in fact all professional agencies. Sometimes even extended family members can look down on people with a mental illness and their carer. This stigma leads to increased isolation with many carers feeling silence is better than reactions from admitting they care for someone with a mental illness.
<b>Issue 9</b> <b>Accommodation options for consumers at all levels of care</b>	An appreciation of the intimate link between mental health and housing is clear both in mental health policies and strategies, and also in the Australian Government's recent housing policy, <i>The Road Home</i> . There has been some investment by states in mental health housing through programs such as the Housing and Accommodation Support Initiative (HASI).	Carers report that access to safe, supported housing is a critical problem particularly for consumers with chronic and complex mental health problems. Failure to provide access to housing, or only to unsustainable housing options, leaves consumers very vulnerable to dangers, including worsening health and experiencing violence.
<b>Issue 10</b> <b>Financial costs to carers</b>	The Australian Government has moved to make carer payments a fixture in the welfare system. Annual payments plus other allowances paid by Centrelink recognise the financial impost on carers. Eligibility criteria are still primarily focused on physical care needs – able to shower, toilet or feed themselves.	In the absence of consumer access to regular mental health care, carers often take on complex and time consuming caring roles including meeting increased costs of transportation or private treatment. The carer role often precludes participation in paid employment leading to significant current and future financial disadvantage for both consumer and carer. Mental health carers are often refused entitlements from Centrelink which, in any case, only partially defray costs incurred, and rarely allow for the level of support and monitoring involved in caring for someone with a mental illness.

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<b>Issue 11</b> <b>Physical and mental health of carers</b>	A range of government reports have acknowledged that mental health carers have a much higher rate of mental health disorders themselves.	Carers do not feel as though their needs are addressed by anyone. Financially they are not in a strong position leaving them isolated and often facing their own deteriorating health without adequate access to the support they need.
<b>Issue 12</b> <b>Flexible respite options for carers</b>	The Australian Government has attempted to come to grips with the respite needs of mental health carers under the FaHCSIA portfolio. New FaHCSIA programs are operating well below capacity, with some of this activity catering for people with intellectual disability rather than mental illness.	The new respite care program implemented by FaHCSIA has only partially met the needs of mental health carers. Service providers have commonly not understood mental health carers' needs and carers have concerns about respite workers with little or no knowledge of mental illness. As a result, carers do not feel as though respite is a realistic or safe option, and those who try to use the respite services often report problems in finding appropriate options. A possible option suggested by some carers is the co-location of the Personal Helpers and Mentors service for consumers and the respite service for carers within the same organisation (sharing services).
<b>Issue 13</b> <b>Privacy and confidentiality issues</b>	The Australian Law Reform Commission undertook a review of privacy law in 2008 and recognised that disclosure of information to 'a person responsible for an individual' can occur within privacy law. The need for legislative reform in this area was also recognised by the 2009 House of Representatives Inquiry into Better Support for Carers.	Carers' rights to be part of the care team are frequently trammelled as they are excluded on the erroneous grounds of privacy and confidentiality. Carers who were aware of Advance Directives for consumers endorsed their implementation to help navigate the privacy and confidentiality minefield.
<b>Issue 14</b> <b>Early intervention at each episode of care</b>	Early intervention has been a key feature of successive national mental health plans and also features in the recommendations made by the National Health and Hospitals Reform Commission.	The vast majority of mental health funding remains targeted at acute mental health care. There is only one comprehensive early intervention service for psychosis operating in Australia. Carers are forced to watch consumers wait until their conditions become sufficiently florid to demand the attention of the largely hospital-based acute care system currently in place. This is often despite repeated calls from carers for help and assistance prior to the issues escalating into more dangerous, unhealthy and long lasting situations.
<b>Issue 15</b> <b>Employment options for carers</b>	The recent National Mental Health and Disability Employment Strategy mentions the significance of employment for carers, as part of the Australian Government's Social Inclusion agenda. The needs of carers are to be addressed as part of the commitment to develop a National Disability Strategy.	The poor rates of employment or meaningful occupation for consumers means that many carers are also unable to work or unable to work as many hours as they would like. This leaves many carers vulnerable to the negative effects on physical and mental health associated with financial disadvantage.



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