

2.6 Consumer and carer participation in mental health care

KEY MESSAGES:

- In 2010-11, about half of Australia's state and territory mental health services had either appointed a person to represent the interests of mental health consumers on their organisational management committees or had a specific Mental Health Consumer/Carer Advisory Group established to advise on all aspects of service delivery. However, one quarter had no structural arrangements in place for consumer and carer participation.
- Significant proportions of state and territory mental health services also had some other arrangements in place for consumer and carer participation, although the extent to which organisations had established particular initiatives varied. Mechanisms for carer participation have been less developed than those for consumer participation, but the gap is closing.
- In 2010-11, there were 4.6 consumer and carer workers employed for every 1,000 full-time equivalent staff in the mental health workforce. This figure has risen by 33% since 2002-03, when it was 3.5 per 1,000.
- In recent times, there have been a number of consumer and carer developments that have had an increased emphasis on social inclusion and recovery. For example, the recently established National Mental Health Commission has produced its first *Report Card*, identifying and reporting on several areas that are important to consumers' ability to lead a contributing life. Moves are also underway to establish a new national mental health consumer organisation, auspiced by the Mental Health Council of Australia, that will ensure that a strong and consolidated consumer voice can contribute to more responsive and accountable mental health reform.

Consumer and carer participation in Australian mental health services underwent rapid maturation over the course of the *First National Mental Health Plan*. Inquiries conducted in the period preceding the National Mental Health Strategy pointed to abuses of the rights of consumers and advocated forcefully on their behalf for action to correct these. Governments responded with a number of proposals for change and, more importantly, consumers began to speak for themselves.

Initial concerns driving the Strategy revolved around concepts of protection from human rights abuses, but these concerns progressively evolved to incorporate more contemporary concepts of consumer empowerment and participation. This required that consumers and carers be given a place in discussions about the planning, delivery and evaluation of services designed to meet their needs.

The Strategy has advocated strongly for this position. Underpinning this is a view that such participation can empower and inform consumers and carers, destigmatise mental illness and ultimately improve mental health outcomes by promoting a recovery orientation in service delivery. Additionally, accountability to consumers at all levels of the mental health system provides an avenue to identify and resolve deficiencies in service quality that, historically, compromised the rights of people with a mental illness.

The early steps taken to promote consumer and carer participation are regarded as one of the hallmarks of the National Mental Health Strategy. Under the *First* and *Second National Mental Health Plans*, states and territories were required to establish advisory groups to provide direct consumer and carer input to mental health policy and service development. The *Third National*

Mental Health Plan promoted further development of opportunities for consumers and carers to take meaningful roles in building a better service system. The *Fourth National Mental Health Plan* has continued this direction.

At the national level, consumers and carers were included in all planning and advisory groups established under the Strategy. Considerable funds were allocated to strengthening their voice in mental health planning, policy and evaluation through representation on bodies such as the Mental Health Council of Australia.

Many other groups play important roles throughout Australia in representing consumers and carers in mental health. They have undertaken a substantial amount of work to increase participation by, and awareness of, the roles of consumers and carers in the mental health reform agenda.

The current report does not detail the contributions of all the individual parties, but focuses on updating previously published data on the extent to which mechanisms for consumer and carer participation have been established at the local service delivery level.

Consumer committee representation at the local service delivery level

The extent to which consumers are involved at the 'coalface' level of service delivery, where they have opportunities to influence the services they receive, is an important indicator of whether the National Mental Health Strategy has made a difference for consumers.

The principle of consumer participation in local services is reflected in the National Standards for Mental Health Services (National Standards). The National Standards set expectations that each service will involve consumers in the planning, implementation and evaluation of services, and that consumers will be active participants in the assessment and treatment planning that directly affects them. All states and territories are committed to full implementation of the Standards within the services under their control.

The annual data collection reported by states and territories has provided the means to monitor trends in the type of local arrangements in place for consumers to contribute to service planning and delivery. As in previous years, the 2010-11 collection required each organisation to describe its structural arrangements for involving consumers. Analysis of the survey data assigns each organisation into one of four levels, ranging from Level 1 (agencies where consumers were given a formal place in the local executive decision making structures or where a specific consumer group had been established to advise on all aspects of service delivery) to Level 4 (agencies with no specific arrangements for consumer participation).

Figure 40
Consumer committee representation within mental health service organisations, 1993-94 to 2010-11^a



(a) Level 1: Formal position(s) for consumers exist on the organisation's management committee for the appointment of person(s) to represent the interests of consumers. Alternatively, specific consumer advisory committee(s) exists to advise on all relevant mental health services managed by the organisation.
 Level 2: Specific consumer advisory committee(s) exists to advise on some but not all relevant mental health services managed by the organisation.
 Level 3: Consumers participate on a broadly based advisory committee that includes a mixture of organisations and groups representing a wide range of interests.
 Level 4: Consumers are not represented on any advisory committee but are encouraged to meet with senior representatives of the organisation as required. Alternatively, no specific arrangements exist for consumer participation in planning and evaluation of services.

The results for 2010-11 are shown in Figure 40 and compared with the situations at the beginning of the National Mental Health Strategy, and at the end of the *Second* and *Third National Mental Health Plans*. They illustrate the considerable progress made over the first 10-year period. Between 1993-94 and 2002-03, the proportion of organisations with some formal mechanism in place for consumer participation (Levels 1 to 3) increased from

53% to 82%. However, the data also reveal that, at the national summary level, little advance has been made since then.

Eighteen years into national mental health reform, about half of Australia's mental health service organisations have consumer representation at the higher level (Level 1). One quarter remain without any basic structural arrangements for consumer participation.

Other local arrangements for consumer and carer participation

States and territories have expressed concern in previous years that exclusive reliance on the 'formal committees' approach to the assessment of consumer participation – the basis of Figure 40 – does not adequately describe the range of initiatives that can be taken to enable participation within mental health service structures and processes. Consumers and carers themselves have articulated similar views.

Commencing in 1998-99, the annual state and territory data collection was modified to explore a fuller range of options being pursued by local services, and requested that each mental health service organisation indicate whether such

arrangements were in place. The options assessed in the survey are summarised in Table 7.

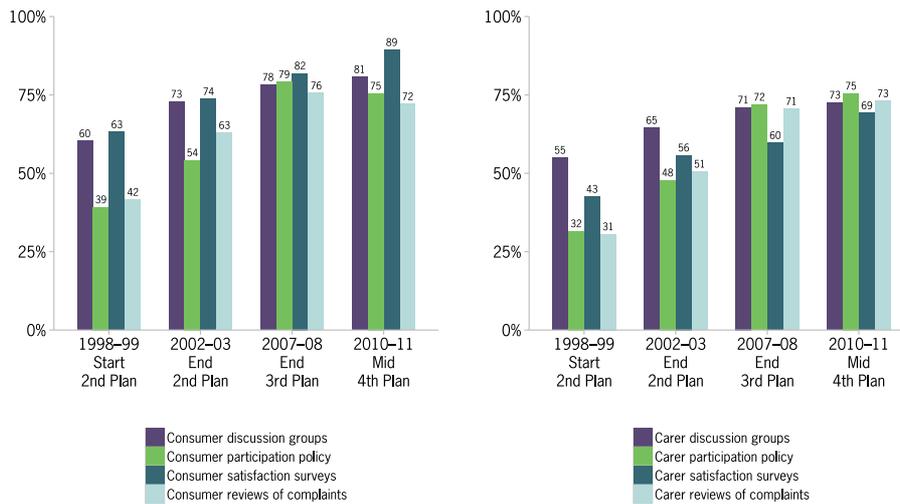
Figure 41 considers the extent to which mental health service organisations have implemented the last four of these strategies (the first strategy is considered separately below). Taken at face value, the data suggest considerable innovation by service providers in the approaches to building a consumer and carer oriented culture, although the extent to which organisations have established particular initiatives varies. As noted in previous reports, mechanisms for carer participation have been less developed than those for consumer participation, but the gap is closing.

Table 7
Additional consumer and carer participation strategies assessed in annual state and territory reporting

Additional consumer and carer participation strategies	
1.	Consumer/carers consultants are employed on a paid basis to represent the interests of primary consumers/carers and advocate for their needs.
2.	The organisation holds regular discussion groups to seek the views of primary consumers/carers about the mental health services.
3.	The organisation has developed a formal (documented policy) on participation by primary consumers/carers.
4.	The organisation periodically conducts consumer/carers satisfaction surveys.
5.	The organisation has a formal internal complaints mechanism in which complaints made by primary consumers/carers are regularly reviewed by a committee that includes primary consumers/carers.

Figure 41

Other participation arrangements for consumers and carers, 1998-99 to 2010-11



Employment of consumer and carer workers

Arguably, a stronger indicator of services' investment in consumer and carer participation is employing them in a paid role. In the early stages of the National Mental Health Strategy, consumer and carer consultants were employed as consultants to represent the interests of consumers and carers respectively, and to advocate for their needs. These consumer and carer consultants took on a variety of roles, including: investigating areas for improvement to local services, policy and procedures and advocating for change; participating in the selection of staff employed in local services; presenting consumer and carer perspectives in the evaluation of local services; and contributing to training programs for service delivery staff.

Consumers and carers valued this strategy as a means to promote services that are responsive to their needs, but argued that they had more to offer. As time went by, new roles for consumers and carers emerged. Some consumer and carer consultants had played a role in developing relationships with individual consumers and carers and communicating their needs to professional staff, and the new consumer and carer workers took this further. 'Recovery workers' and 'peer support workers' emerged, and the people who took on these

roles began to work directly with consumers and carers, offering them support and guidance based on their own lived experience of mental illness. Today, the consumer and carer workforce includes both consumer and carer consultants and the newer type of consumer and carer workers.

Since 2002-03, mental health service organisations have been required to quantify the investments they have made in employing consumers and carers. To do this, organisations reporting that consumer and/or carer workers were employed in their organisations were required to provide substantiation, by reporting supplementary information on salary expenditure and numbers of full-time equivalent staff employed. This was designed to avert the situation where mental health service organisations might, for example, report they had employed a paid consumer consultant if a consumer was given a one-off payment for attending a meeting.

Figure 42 shows the national full-time equivalent tally for consumer and carer workers employed in state and territory mental health services from the end of the *Second National Mental Health Plan* to the middle of the *Fourth National Mental Health Plan* (i.e., between 2002-03 and 2010-11). The number of full-time equivalent consumer workers has fluctuated over time, but was at its lowest at 54 in 2002-03 and reached a peak at 69 in 2010-11. The number of carer workers began at a lower base rate but has risen steadily and, in 2010-11, reached about two thirds of the number of consumer workers. In absolute terms, the numbers of consumer and carer workers is still very low.

Another way of thinking about this is to consider the proportion of the total direct care workforce (clinical staff and consumer and carer workers) in state and territory mental health services that is accounted for by consumer and carer workers. Figure 43 shows that the number of consumer and carer workers employed in 2002-03 was 3.5 per 1,000 full-time equivalent direct care staff. By 2010-11, this had risen to 4.6 per 1,000. Although this represents a 33% increase, the penetration of consumer and carer workers into the overall workforce remains small.

The *Fourth National Mental Health Plan* advocates for substantial growth in the consumer and carer workforce and includes a specific indicator to monitor the extent to which this is occurring (Indicator 21). More detail about this indicator is provided in Part 3 of the current report.

Figure 42
Number of full-time equivalent consumer and carer workers employed in state and territory mental health services, 2002-03 to 2010-11

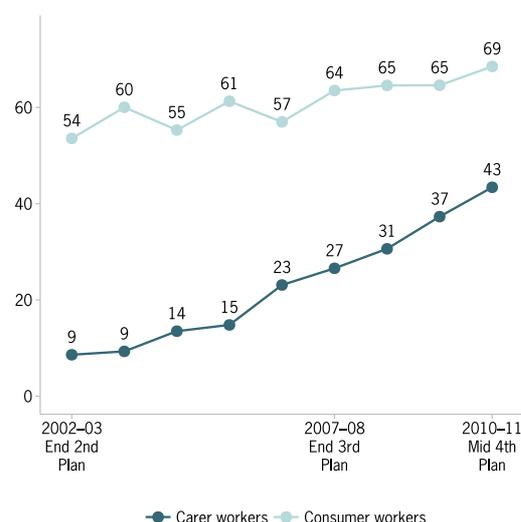
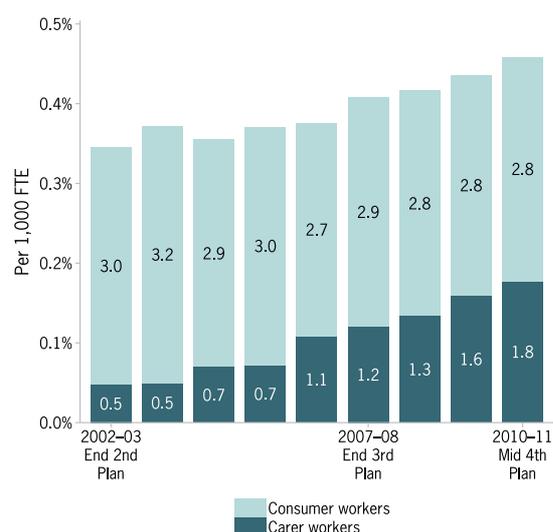


Figure 43
Consumer and carer workers employed per 1,000 full-time equivalent direct care staff, 2002-03 to 2010-11



Ongoing consumer and carer developments

The above indicators suggest that while some progress has been made in providing formal mechanisms for consumer and carer participation, a great deal remains to be done. The *Fourth National Mental Health Plan* reiterates the importance of continuing initiatives to build mental health service systems that are truly consumer and carer responsive.

Over and above this, there is a question about whether the kind of indicators described above are focusing on the issues that are of concern to consumers and carers. In its first *Report Card*,²⁸ the recently established National Mental Health Commission has identified and reported on six areas that stakeholders have indicated are important to consumers' ability to lead a contributing life. These are: the physical health of people with mental illness; approaches to care which are inclusive of carers; access to timely, appropriate, high quality care; participation in employment and community activities; having a safe, stable and secure home; and preventing suicide.

These concerns extend the newer emphases that distinguish the *Fourth National Mental Health Plan* from its predecessors, particularly the focus on social inclusion and recovery themes. A number of the *Fourth Plan* indicators described in Part 2 of this report address these areas and aim to measure progress. The Australian National Mental Health Outcomes and Classification Network is also developing a new measure of social inclusion known as the Living in the Community Questionnaire (LCQ). Funded by the Australian Government, this measure focuses on the consumer's participation in various life domains (for example, employment, education, housing and social activities) and is being designed for use by state and territory mental health services as part of the current arrangements in place for the regular collection of standardised data on consumer outcomes. Routine collection of data from this measure will allow changes in consumers' levels of social inclusion to be systematically tracked.

There are also other broader developments designed to ensure that the participation of people with lived experience of mental illness is central to mental health reform. At the national level, Australian Government funding (\$4 million over the period 2011 to 2016) was provided to establish a new mental health consumer-led peak body. The national mental health consumer organisation will involve diverse mental health consumer groups, organisations and individuals, and represent a wide cross-section of experiences and views, in particular those views which are often under-represented. The new organisation will work towards a shared vision so that a strong and consolidated consumer voice can contribute to more responsive and accountable mental health reform. This will include the work of the National Mental Health Commission that is assessing system performance, described above.

The new organisation is being auspiced by the Mental Health Council of Australia to ensure it has the best possible chance of long term success and sustainability. A Mental Health Consumer Reference Group is advising the Council on planning and implementation of the new organisation, to ensure the voices and views of consumers are front and centre in informing this project. The Council and the Consumer Reference Group are working together to establish a diverse and inclusive membership base and are arranging mechanisms to ensure mental health consumers are involved fully throughout the process. The ultimate aim is to have an independent organisation built upon strong organisational governance and sustainable structures.

