

Consumers—the critical reference group for mental health reform

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Introduction

In 1993 the Human Rights and Equal Opportunity Commission published a damning report following an inquiry into mental health services in Australia. Known as the Burdekin Report,¹ it was very influential in mental health reform. From a consumer perspective it did three important things:

1. It raised the profile and acceptability of the first person account as a genuine and important contribution to what constitutes knowledge.
2. It focused on issues to do with human rights which is a vital part of the consumer agenda and which brought consumers together.
3. It exposed the mental health sector to a substantial critique. Page after page of analysis condemned the state of services for people with mental illness. In this way consumers saw their own experiences represented in the report. This gave them hope for change.

Shortly before the Burdekin Report was published the *First National Mental Health Strategy (First Strategy)* was endorsed in April 1992. It was a five-year framework with a new vision for people with mental illness to start playing vital roles in 'the system' as peer supporters, mental health workforce educators, consultants to the system, advocates and other paid roles in service delivery, consumer evaluators, decision makers, service auditors, researchers, orators and visionaries. The *First Strategy* was reaffirmed in 1998 with the *Second National Mental Health Plan* and again in 2003 with the *National Mental Health Plan 2003–2008*.

National Community Advisory Group on Mental Health

An important aspect of the *First Strategy* from a consumer perspective was the appointment of an influential committee of consumers and carers that became known as the National Community Advisory Group in mental health or NCAG. It reported straight to the Australian Government Minister for Health and had its own secretariat. NCAG's greatest achievement was the official recognition that people with mental illness and carers were significantly important players in mental health reform.

I sat on NCAG for five years through the mid-1990s. Every committee, planning group, or project funded by the Australian Government had to pass through a selection process and oversight by a committee that involved NCAG representatives during this period.

Many mental health professionals had never been asked to sit on committees where they had no more power (on paper anyway) than the person sitting next to them who might happen to be a NCAG consumer member. During the years of the *First Strategy*, consumers and carers slowly progressed on all decision-making fronts. I experienced first hand the resistance and reluctance of some powerful medical groups to take us seriously and then this slowly changing with the realisation that NCAG was here to stay and something with which mental health decision makers must learn to live.

During the life of the *First Strategy* significant funds were channelled into initiatives to involve consumers and carers nationally, and we all gained skills and confidence. At this time I pencilled what was to become my consumer participation motto:

Beware the groups with the most charming voices; tea and scones; nodding heads and general agreement with everything you say. This is the sign of institutionalised 'yesness'. It will not lead to change. Respect the groups that put their hands up in horror and say, "How can this possibly be? It seems too hard!" They are honest. This is a good place to start. Trust those who admit consumer participation is a bit scary as it must be because it seeks to change the

very foundations on which health institutions have traditionally been built.

NCAG positions were ministerial appointments, which bred disquiet at consumer grass roots level. People living on pensions and disempowered often saw us as a privileged consumer class and were resentful. This was reinforced by the lack of resources for us to consult adequately or feed back sufficiently to other mental health consumers. These essential parts of 'representing' a constituency were limitations in an NCAG-like model. Nonetheless, the promotion of 14 consumers and carers (representing each state and territory) to positions of prominence and authority was one of the most important achievements of the *First Strategy*.



The Mental Health Council of Australia and 'critical mass'²

In the late 1990s Health Minister Wooldridge promised us that NCAG would be replaced by a new national council that would competently represent us. This became known as the Mental Health Council of Australia (MHCA). I sat for a few months on its provisional board. In drafting the constitution we tried to build in clauses to ensure that the consumer voice would not get swamped by professional and other voices, which would now demand to be part of this new and, potentially, influential body.

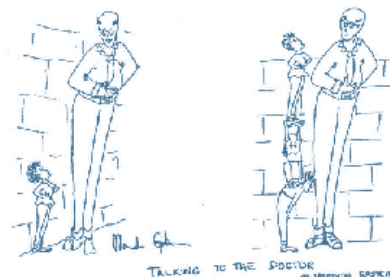
It was obvious from the beginning that MHCA could not be the strong articulate consumer voice that NCAG had been. We would never have the numbers. A critical mass is essential for any process that attempts to include consumers as equal players. Having the numbers is essential because we don't have power derived from professional or institutional authority. Demanding critical mass has become a salient aspect of consumer politics.

NCAG was successful because it only had to juggle two different perspectives—those of consumers and carers. MHCA, on the other hand, was charged with representing everyone. It was always going to have

trouble. Left to its own momentum the power gauge would automatically swing back to those groups most established in the health sector. The only way for the 'small' voice of consumers to be heard was to invite more and more consumer organisations onto the MHCA Board until a point of critical mass was reached. There were only four national consumer organisations as potential voting members of MHCA so this would be impossible. Their voice would always be diluted as new professional organisations joined the MHCA Board.

The MHCA is now the first port of call for mental health sector input at a national level for consumers and carers. Structurally, this may present a challenge for consumer organisations involved in MHCA as they struggle to keep themselves funded and afloat while some other members of MHCA are much better supported and resourced and may seem to have a stronger voice. Experience has shown that this may lead to a tension between "getting up the players who can give the more powerful professional groups a run for their money" and the needs of mental health consumers to have the voices that best represent their experiences to be heard.

It worries me that MHCA and other powerful groups seem to be pulling the strings as consumers and consumer organisations jockey for places at the political table. It worries me that we have 'representative' consumers working in Australia today who choose never to speak from a consumer perspective and are disinterested in and apathetic about the rich history of consumer participation within Australia and around the world. It worries me when we have no time or resources to have our own internal debates or educate the next generation of consumer activists. It worries me when class and gender become dominating factors or hierarchies appear between different diagnostic groups within the consumer community. It worries me when consumers start to talk about 'real' and 'not real' mental illness or when people using private psychiatric services pit themselves against people using public services or vice versa. And, it worries me when we try to annihilate each other.



Consumer participation in 2005

The *Second National Mental Health Plan* and the *National Mental Health Plan 2003-2008* have let consumers down. Suspect and reactive processes drove the development of both plans where, amongst other things, powerful groups and individuals tried to claw back power they thought they had lost on the wave of the *First Strategy*. The term 'expert' reasserted itself in the rhetoric, and new funding priorities have led to the position that we have today typified by:

1. National, state and territory governments using the rhetoric of consumer participation without adequate funding and without enough support for ongoing consumer articulated change in service culture and practice.
2. Many local services also using the rhetoric of consumer participation without doing it.

This is essentially dishonest. In order to "do it" the funding needs to increase ten-fold. Even then it would still only be a small impost into national, state and service level mental health budgets.



Conclusion

Wadsworth defines consumers as the critical reference group.³ Services are designed to provide mental health services for us. Arguments about stakeholders having a necessarily shared stake, equal political power, and equal interest only in the wellbeing of the consumers they serve is obviously nonsense. My life and death, connected intimately with my mental illness, is of greater importance to me than to my psychiatrist or my case manager. We do not (on paper) have mental health services in order to find jobs for aspiring clinicians and researchers, or so people can become famous or earn a living. The *First Strategy* recognised us as the critical reference group and this upset some individuals and organisations which were used to wielding power in the sector.

It gave consumers and carers an unassailable role in the 'new order' with responsibility to supervise the transition towards better and more-accountable mental

health services. Unfortunately, despite its reputation as a leader in consumer participation the mental health sector is now under extreme pressure both from inside and, in terms of, public debate. Since the end of the *First Strategy* participation initiatives have slowed down and funding for innovative projects has dried up.

The awful problems in the mental health system have roots much deeper than the last 12 years of unprecedented change including that in consumers' roles. To abandon the reform agenda now or somehow blame consumer participation—holding it responsible for diverting attention and resources away from the main game (direct service provision)—would be a misguided, unhelpful but possible final scenario. As a chronically under-funded underclass active consumers must vigorously resist this.

References

1. Human Rights and Equal Opportunity Commission. National Inquiry on the Human Rights of People with a Mental Illness. Australia, 1993.
2. Definition: The size or amount of something that is required before something can take place, in Encarta Dictionary. United Kingdom.
3. Wadsworth Y. Do It Yourself Social Research, Allen and Unwin. Sydney, 1999. page 11.

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