Improvements in rhetoric, but the practice still lags a long way behind: Consumer participation, the most significant change in mental health practice since Burdekin.

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In 1993 the Human Rights and Equal Opportunity Commission published a damning report following an inquiry into mental health services in Australia. This report, The Report of the National Inquiry into the Human Rights of People with Mental Illness, came to be known as the 'Burdekin Report' after the then Human Rights Commissioner, Brian Burdekin. The Burdekin Report was a very influential document in mental health for many reasons. However, from a consumer perspective the Burdekin Report did three important things.

Firstly, it raised the profile and acceptability of the first person account as a genuine and important contribution to what constitutes knowledge. The Burdekin Report is powerful in part because people's lived experience of mental illness and 'the mental health system' are treated as important as so-called 'scientific fact'. When they came with the imprimateur of a public figure as well known as Brian Burdekin and an office as well respected (at that time) as the Human Rights and Equal Opportunities Commission this was a major, if not commonly articulated, challenge to the mental health sector.

Secondly, it focused on issues to do with human rights, a vital part of the consumer agenda and an issue which brought consumers together.

Thirdly, the report was not scared of exposing the mental health sector to a substantial critique. This gave consumers hope for change.

The First National Mental Health Plan

The First National Mental Health Plan was endorsed by the Australian Health Ministers in 1993, at about the same time that the Burdekin Report was published.

In the pages of this strategy and its accompanying action plan, history was made as consumers were perceived, for the first time in this country, outside the sick role. Oh! What a shock this was for many professionals. There was a new vision for people with mental illness to start playing vital roles in 'the system'; as peer supporters, educators of the mental health workforce; as consultants to the system, advocates and other paid roles in service delivery; as consumer evaluators and decision makers and service auditors; as researchers; orators and visionaries.

Since then there have been two further National Mental Health Plans as the Commonwealth has tried to guide mental health systems around Australia through this period of post-institutionalisation.

Innovative Funding - the Lemon Tree Experience[1]

In 1995 the Commonwealth Mental Health Branch made a series of innovative funding grants available to groups and organisations around Australia. All groups applying for this Commonwealth money were expected to include consumers in their projects and their application needed to reflect this. Despite the fact that far too many groups rang up consumer organisations placing orders for 'take-away-consumer-participation' on the eve of the submission date they were, at least, forced to think about it.

More importantly, several large and influential consumer projects were funded as part of this round. Two of the most important of these were projects of the Victorian Mental Illness Awareness Council (VMIAC). The VMIAC[2] is the peak mental health consumer organisation in Victoria. It is the only

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[1] For more information about the Lemon Tree Learning Project see Epstein M, Shaw J 1997, Developing Effective consumer participation in mental health services: the report of the Lemon Tree Learning Project, VMIAC, Brunswick, Vic.

[2] http://www.vmiac.com.au

peak of its kind at this stage in Australia. These grants marked a significant point in National Mental Health Strategy history as 'Vincent's', the first totally consumer-run peer support service in Australia was funded. However this grant money was meant to encourage innovation and not to fund ongoing services. It was never meant to be anything but short term. 'Vincent's' life was tragically cut as the Commonwealth pulled out and the VMIAC failed to attract ongoing financial support from the State, charitable trusts or other funding sources. Also funded was the Lemon Tree Learning Project which was a precursor to the growing idea of consumer perspective education and training of the mental health workforce. Indeed even though the actual Lemon Tree Project was funded for only 18 months it left an indelible imprint in the sector as the lemon tree came to represent the organic connectedness between the roots of consumer empowerment and a healthy tree of service structures and policies.*

National Community Advisory Group on Mental Health (NCAG)

One of the most important aspects of the First National Mental Health Strategy from a consumer perspective was the appointment of an influential committee of consumers and carers that was to become known as the National Community Advisory Group in mental health or NCAG. The appointment of NCAG was significant for many reasons but its greatest contribution was perhaps emblematic in that it was official recognition that people with mental illness and carers were significantly important players in mental health reform. NCAG reported straight to the Commonwealth Minister for Health and had its own secretariat.

I sat on NCAG for a period of five years through the mid-1990s. One of the most important contributions that NCAG was able to make was simply that we hung in there. No matter which committee, or planning group, or project - everything that was funded by the Commonwealth during this period - had to pass through a process of selection and oversight by a committee where NCAG representatives were actively involved. I am sure that this must have made some people in the mental health sector, who were not used to consumers being in positions of authority, frustrated.

I did not always understand the specialised scientific content of every committee on which I sat but this was not the main reason I was there. I quickly developed a repertoire of questions and statements that I would routinely ask knowing that part of my role was to slowly start to 'build-in' automatic consideration of these principles into the everyday thinking of all who would seek funds from the Commonwealth in the future. My favourite questions included:

1. Have you asked consumers what they think?
2. Which consumers have you asked?
3. At what point in your project did you get consumers on board?
4. Have you a budget for paying consumers? How much per hour? Childcare? Parking?
5. Can people be paid in cash?
6. Have you worked out payment so that people don't lose their pensions?
7. Have you checked your language with consumers?
8. What does that acronym mean?
9. Please don't drop people's names when I've got no idea who you are talking about; and so on.

Many mental health professionals had never before 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 consumer member of NCAG. During the years of the First Strategy, consumers and carers slowly moved in on all decision-making fronts. As a member of NCAG I experienced first hand the resistance and reluctance of some powerful medical groups to take us seriously and then this slowly changing as there was a realisation that NCAG was not an aberrant detour from the main agenda but was rather here to stay and was something with which mental health decision makers must learn to live.

During the life of the First National Mental Health Plan significant funds were channelled into initiatives to involve consumers and carers at the National level. This was brilliant. We all gained skills and confidence. It was at this time that I pencilled what was to become my motto of consumer participation:

> 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. Beware also the groups who, with false authority shake their heads saying, “no! no! no! This can’t be done!” This is a sign of institutionalised ‘noness’. Respect instead the groups that put their hands up in horror and say, “How can we do this? It seems too hard! Please help!” They are honest. This is a good place to start.

NCAG was not democratically elected. Our positions were Ministerial appointments. This bred some disquiet at the grass roots level from consumers. People living on pensions and disempowered in nearly all aspects of their lives often saw us as a privileged class of consumer and they resented it. I think they were right to do so and I understood this disquiet. It was made worse by the lack of resources to enable us to consult adequately or to feed back sufficiently to other mental health consumers. These essential parts of ‘representing’ a constituency were real limitations of an NCAG like model but nonetheless, starting from a history of absolutely no consumer involvement I think 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 National Mental Health Strategy.

The Mental Health Council of Australia and the concept of ‘critical mass’

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

It was obvious right from the beginning that the MHCA could not be for the consumer voice the strong articulation that NCAG had been. Put simply, we would never have the numbers. Having 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 and the politics of all relatively disempowered groups in society. One of the reasons why NCAG was so successful was that it only had to juggle two different perspectives - those of consumers and carers. The Mental Health Council, 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 industry. The only way for the ‘small’ voice of consumers to continue being heard given these conditions was to invite more and more consumer organisations on to the Board of the MHCA until a point of critical mass is reached. Of course, everyone knew that this would be impossible. There are only four national consumer organisations that could even potentially become voting members of the Council. No matter how loud these groups might try to be their voice will always be diluted as each new service organisation joins the Board of the MHCA.

Since the time of its inception the Mental Health Council of Australia has grown in size and in power. It is now routinely the first port of call for anyone wanting specific mental health sector input at a National level - including consumer and carer input. At the present time the Mental Health Council of Australia has an uneasy relationship with the National Mental Health Consumer Network which is the only national representative organisation for people with mental illness in Australia. My unease about this is not because I hold the Mental Health Council of Australia solely responsible for the problems in its relationship with consumers. Rather, I think that there are some structural problems with a quango such as MHCA.

Firstly, it assumes that different groups of consumers are backed similarly by their sponsor organisations. This is obviously not true in the case of the Mental Health Council as ‘bluevoices’, for example, is solidly backed by beyondblue which is a non-consumer, relatively wealthy, pro medical model organisation. On the other hand, the National Mental Health Consumer Network is funded to fail. There is barely enough money to cover irregular meetings by teleconference, let alone maintain a campaign to get its representative elected on to the Mental Health Council Executive. The network has problems as the consumer movement wrestles with issues of representation versus ‘getting up the players who can give the more powerful professional groups a run for their money’! This is an age old problem not only in mental health but in all sorts of representational politics. Authentic process is desired but does not necessarily deliver people who can ‘do the job’ in the rough and tough political minefield of national decision making.

In an Australian context we have some old campaigners who have been busy in consumer politics in mental health for a long time. We try to promote opportunities for others to come up through the ranks, gain skills and gain an understanding of the ethics of consumer advocacy which behoves us to share power, distribute both jobs and responsibilities, and pull out of things where we have a conflict of interest or simply know there are other consumers who know heaps more about the subject than we do. We also try to share our history with ‘newbies’. However we are so resource impoverished as a movement that we have been unable to provide adequate educational opportunities. Training is insufficient, and inconsistent. It is interesting to me that there are new people coming into the consumer politics industry all the time who seem to believe that those who came before must have been totally disempowered or totally misinformed or, god forbid, ‘mentally ill’. I am laughing at myself when I comment on this because I remember being totally non-plussed when I first became involved in this sector. Somehow I thought I was going to be some sort of ‘super-consumer’- providing guidance and light to all ‘the others’! It was a bit of a let down when I found out everyone was really just like me. This common tendency to believe that we will be god’s gift to the consumer movement fascinates me. It is actually an example of ‘highly developed intra consumeral discrimination’! These issues around legitimacy of course become starker and potentially more divisive when the sector starts to produce paid work opportunities.

Problems of ‘intra-consumeral angst’ will always be with us in some way or other because, just as all consumers are not incapable just because they have mental illness: a mental illness does not protect people from ambition, self-indulgence, lack of self-insight or any one of a bewildering assortment of human frailties that exist in this world. Perhaps equally as importantly, we are starting to see the consumer movement as a social movement on par with the feminist movement or the gay and lesbian movement. Indeed, like the gay and lesbian movement we share a concept of ‘coming out’. All social movements are open to splintering, internal factions and fights and positioning. It would be totally unrealistic to expect the consumer movement to be any different. Indeed, the more it presents as a coherent whole the more I get nervous. Perhaps the best example of this that I have experienced has been the effort by the Mental Health Council of Australia to quash the differences between the consumer perspective and the carer perspective. This is both unrealistic and dangerous because substantial differences pushed under the carpet have a habit of breaking through the warp just when you least want them to.

It does worry me that the Mental Health Council of Australia and other powerful groups seem to be pulling the strings as consumers and consumer organisations jockey for places at the political table. It does worry 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 both within Australia and around the world. It does worry me when we have no time or resources to have our own internal debates or educate the next generation of consumer activists. It does worry me when class and gender become dominating factors or hierarchies appear between different diagnostic groups within the consumer community. It does worry 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. It does worry me when we try to annihilate each other.

Consumer Participation in 2005

The Second and Third National policies have let consumers down. Suspect and reactive processes drove the development of both strategies where, amongst other things, powerful groups and individuals tried to claw back power they thought they had lost on the wave of the First Plan. The term, ‘expert’ reasserted itself in the rhetoric and new funding priorities have led to the position that we have today which is typified by:

1. National and State and Territory governments using the rhetoric of consumer participation without funding it anywhere near adequately and without embracing it with enough energy to support ongoing consumer articulated change in service culture and practice.

2. Many local services also using the rhetoric of consumer participation without actually doing it.

This is essentially dishonest. In order to ‘do it’ the funding needs to increase tenfold. Even then it would still only be a small impost into State, Federal and service level mental health budgets. There are examples at a local level of services who much to our eternal cynicism proudly proclaim they have budget neutral consumer participation policies and practices.

Conclusion

Consumers are not just one of many stakeholders. We are what Wadsworth (1999 p11) defines as the Critical Reference Group. Services are designed to provide mental health services for us. Put crudely, 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 much greater importance to me than it is 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. As nice as these things might be they are secondary. The First National Mental Health Strategy recognised us as the Critical Reference Group and this upset some individuals and organisations who were used to wielding power in the sector.

The First National Mental Health Strategy 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 to a walk and consumers are frustrated as funding for more innovative projects has dried up.

More frightening, however, is the possibility that consumer participation might be used as a scapegoat to justify, at least in part, the lack of progress being made towards creating an acceptable system of ‘care’ for people with mental illness. The awful problems in the mental health system have roots much deeper than the last fifteen years of unprecedented change which includes change in the roles played by consumers. 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, unfortunately, very possible final scenario which, as active consumers we must vigorously resist. It is imperative that consumers continue to rage against human rights abuses, lobby for a new discipline of consumer perspective studies, and demand a further injection of money for innovative consumer projects including consumer run services. It is imperative at this time of growing public critique - the Senate Enquiry, and sensational media coverage - that consumers continue to remind society that what is in the best interest of healthy consumer participation is also in the best interest of healthy mental health consumers. However, we must not let this become the rhetorical chant of a chronically under resourced underclass.

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