CONSUMER PARTICIPATION IN THE EDUCATION AND TRAINING OF MENTAL HEALTH NURSES

Queensland Mental Health Commission

Issues paper

Context

This paper has been prepared by Dr Brenda Happell for the Queensland Mental Health Commission as background reading for a roundtable to be convened in May 2015. The aim of the roundtable is to identify strategies to increase the effective participation of consumers in educating nurses for mental health practice.

Participation in the roundtable will be by invitation and will include consumer academics and educators, mental health nurse academics, senior nurse academics with influence over resource allocation, nursing directors (mental health), government representatives, academics and clinicians from other health disciplines with a demonstrable track record of implementing consumer involvement in the education of health professionals.

Background

Contemporary mental health policy espouses a recovery approach. Recovery is a contemporary and innovative approach to mental health care that emphasises the long-term health and wellbeing of mental health consumers (DoHA, 2012a). This approach encourages clinicians to support consumers as they set and attain personal goals, make decisions, and connect with the community in ways that build meaning and life satisfaction.

The principle is that this mutual relationship will lead to improved health and wellbeing, be empowering, preventative and restorative, rather than the reactive treatment of symptoms (McCloughen, Gillies, & O'Brien, 2011). Recovery is now a clear objective of Australian mental health policy and an expectation for the future standard of care that consumers will receive (DoHA, 2009, 2012a).

Transitioning to a recovery approach in Australia will contribute significantly to addressing the Australian National Research Priority: *Promoting and Maintaining* *Good Health*. However, it will require a radical change in the mental health care system from the traditional culture of clinician authority, to a new culture of consumer participation (COAG, 2012; DoHA, 2009).

Just as policy recognises the need for consumers to take more responsibility for their mental health and recovery, it also recognises the need for mental health care providers to value and include consumers' views and participation in care and encourage them to lead their own recovery (Goodwin & Happell, 2008; Happell, Moxham, & Platania-Phung, 2011). Unfortunately, in many areas the traditional culture of clinician authority still prevails.

Consumer involvement in all aspects of their care and recovery (referred to as 'consumer participation') benefits mental health consumers and the mental health care system as a whole because it encourages services to become more responsive to the needs of consumers based on their own 'lived experience' of service use and first-hand knowledge of what best facilitates their individual and collective recovery (Happell et al., 2014; Happell & Roper, 2009).

Consumer participation at the individual level means including consumers in all aspects of their own care and treatment, while at the systemic level, it implies consumers should collectively become active participants in the strategic design, development, implementation and evaluation of mental health services.

Consumer participation in mental health services

Consumer participation in all aspects of mental health service delivery is now clearly embedded in Australian national and jurisdictional mental health policies, including *Standards for Mental Health Services* (Commonwealth of Australia, 2010) and *National Standards for the Mental Health Workforce* (Commonwealth of Australia, 2002). The need for a highly skilled professional workforce is crucial for



achieving "Better Services", the first of four pillars of reform articulated in the *Queensland Mental Health*, *Drug and Alcohol Strategic Plan 2014-2019*. The strategic plan's Shared Commitment to Action "engagement and leadership priorities for individuals, families and carers" clearly demonstrates this commitment through the statement:

We will improve inclusion, meaningful participation and outcomes by drawing on the diversity of the experience and wisdom of people with a lived experience of mental health difficulties and substance use problems, their families and carers (p.18).

The increased focus on consumer participation has given rise to new roles for consumers within mental health services, non-government organisations and educational institutions. Roles include consumer consultants, peer support workers, educators and researchers.

These roles have provided opportunity for consumers to influence the mental health policy agenda and profile the importance of consumer inclusion in the provision of mental health policy. While the implementation of these roles is promising, it has tended to be ad hoc, without uniformity in understanding and clear position descriptions to guide the roles.

Other factors limiting the benefits include limited availability of training and education; adequate resources and infrastructure; attitudes of health professionals including their perceived value of these roles. These issues present major barriers to the effectiveness, development and sustainability of consumer roles within the mental health sector (Bennetts, 2009; Happell & Roper, 2009; National Mental Health Consumer and Carer Forum, 2010; Sierakowski, 2010).

As stated above, attitudes of mental health professionals have been identified as a major barrier to consumer participation within mental health services. This reflects difficulties in relating to consumers without traditional power differentials. Acceptance of consumers as colleagues requires the capacity to value their contribution as at least equal to the contribution of health professionals, and an appreciation of lived experience as legitimate knowledge which sits alongside the scientific paradigm rather than below it in a hierarchical, evidence-based approach. There is substantial research evidence to suggest these negative attitudes are long-standing despite the proliferation of consumer roles, and stigma remains strong (Bennetts, Cross, & Bloomer, 2011; Borg, Karlsson, & Kim, 2009; McCann, Baird, Clark, & Lu, 2008).

This resistance to change is likely to severely limit the effectiveness of the transition to recovery oriented services.

Nurses are the largest professional group working in the mental health area, and have the closest professional relationship with consumers (Australian Institute of Health and Welfare, 2013; Miller, Siggins, Ferguson, & Fowler, 2011). Nurses also have a significant capacity to adopt new attitudes and behaviours and bring them into clinical environments to effect culture change (Woolen & Crane, 2003).

Therefore mental health nurses have significant potential to transition to a new clinical culture focused on consumer participation and recovery (COAG, 2012). It is likely that consumer participation in academic and clinical educational roles has significant potential to influence the transition to a Recovery approach (Byrne, Happell, Welch, & Moxham, 2013b; DoHA, 2009; Happell et al., 2014).

Consumer participation in education

The involvement of consumers in the education of health professionals has been identified as a potentially effective strategy in influencing more positive attitudes towards consumer involvement in mental health services.

Both the importance of, and lack of, consumer involvement in the education of health professionals was the central issue in the Deakin University Learning Together Project conducted in the late 1990s (Deakin University Human Services, 1999). The level of consumer involvement was found to be minimal in Australia across all five health disciplines.

A survey of Australian Schools of Nursing conducted in 2006 suggested that while most universities had some consumer involvement in undergraduate programs this was generally limited to guest lectures, membership on advisory committees and course review (McCann, Moxham, Usher, Crookes, & Farrell, 2009).

A survey conducted in 2013 showed that approximately three quarters of undergraduate and postgraduate nursing programs involve consumers in mental health nursing programs in some capacity (Happell, Platania-Phung, et al., In press). The findings suggested some areas of best practice with two universities with substantive academic positions for consumers of mental health services while the majority still have minimal consumer input still primarily focused on guest lectures and course committees, with about 15% involved in curriculum development.

Qualitative research undertaken as a follow up to the survey suggests the mental health nurse academic participants recognise the benefits of consumer involvement in nurse education, conveying lived experience through story-telling was particularly emphasised. Most participants expressed the need for increased involvement and some specifically referred to the desirability of a consumer academic position.

Funding and attitudes of non-mental health nurse colleagues to mental illness were seen as major barriers to implementation or increasing consumer involvement. Many worked in an environment where mental health nursing was undervalued and under resourced and therefore considered support for a consumer academic highly unlikely (Happell, Wynaden, et al., In press).

The nurse and consumer participants in this research identified numerous barriers to the implementation and sustainability of consumer involvement in nurse education including:

- the absence of a clear conception of the role often leading to tokenism, labelling and inequity
- disjuncture between the consumer component and the more traditional components of the curriculum
- limited opportunities for collegiality and information sharing between consumers undertaking educator roles
- safety issues including minimal debriefing
- lack of measures to promote the growth and sustainability of these roles
- inadequate investment in research and evaluation to demonstrate the impact of these roles.

Research and evaluation

Research findings (albeit very limited) suggest the involvement of consumers in the education process has positive benefits as identified by students, consumers and academics.

Students

Evaluations of student perspectives have suggested a generally favourable reception to consumer involvement in education. The experience was perceived as positive, valuable, and interesting, and the sharing of expertise somewhat redressed the power imbalance between nurses and consumers/carers) (McGarry & Thom, 2004).

Other research suggests consumer involvement positively influences understanding of the human impact of mental illness and enhances a more holistic approach to practice (for example: Babu, Law-Win, Adlam, & Banks, 2008; Byrne, Happell, Welch, & Moxham, 2013a; Repper & Breeze, 2007).

Academics/educators

Consumer involvement in the education of health professionals has generally been viewed positively, particularly in enhancing students' understanding of the experience of mental illness and mental health service use (Anghel & Ramon, 2009; Felton & Stickley, 2004; Holttum & Hayward, 2010; McGarry & Thom, 2004; Simons et al., 2007).

However, not all were convinced this added more to student education than that obtained through clinical experience. Concerns were also raised about the consumers' mental state and how that might create anxiety for students; unpredictability of input including expressing unresolved issues; the degree to which their views are representative of consumer views more broadly; tokenism; and limited understanding of how consumers could be involved.

Organisational barriers to employment including funding constraints and the logistics of payment for consumers were also identified, as was the inadequate provision of support, and the potential harm this kind of activity might create for consumers.

The power differentials between traditional academics and consumers, have been particularly noted (Happell, Wynaden, et al., In press), with academic staff from the health professions tending to remain the gatekeepers to consumer involvement in education.

Consumers

Interestingly, the views and opinions of consumers have been under researched in comparison to other stakeholders (Forrest, Risk, Masters, & Brown, 2000; McGarry & Thom, 2004; Meehan & Glover, 2007).

Benefits were identified including being a worthwhile experience which boosted confidence; enhancing students' knowledge and understanding (McGarry & Thom, 2004).

Less positive responses included:

- insufficient structure to guide consumers' input (McGarry & Thom, 2004; Meehan & Glover, 2007)
- vulnerability and exposure through giving of self
- lack of perceived value of lived experience
- voyeurism, particularly in relation to diagnosis and symptoms (Meehan & Glover, 2007).

In one study a disconnect was evident between the focus of education on diagnosis, symptomatology and medication, and the interpersonal communication skills students valued much more highly. Education was seen to impact negatively on the humanistic and caring qualities generally innately characteristic of students (Forrest et al., 2000).

Impact on attitudes

While finding the experience positive might be advantageous, ongoing commitment to consumer involvement in education is likely to be stronger if its impact can be measured in some tangible way.

Positive changes in attitudes to people with mental illness would be one constructive change. Nursing students' attitudes and beliefs about mental health consumers tend to reflect societal attitudes, and even after traditional mental health nursing education attitudes reflect common negative stereotypes towards consumers (Happell et al., 2011; Stevens, Browne, & Graham, 2013). Mental health nurses have demonstrated a reluctance to work with consumers in a more collaborative way (Bertram & Stickley, 2005; Middleton et al., 2004; Moxham, McCann, Usher, Farrell, & Crookes, 2011).

These negative attitudes and fear of working with mental health consumers negatively influence student preference for mental health nursing as a career or mean those who do choose this path do not have the requisite skills, knowledge and attitudes to promote recoveryfocused mental health services (Happell, 2008; Happell, Byrne, et al., In Press; Hoekstra, Meijel, & Hooft-Leemans, 2010).

The most conclusive evidence currently available demonstrates a stronger improvement in attitudes towards people with a mental illness in students taught a consumer-led recovery course in comparison to students from the same university who were taught a traditional nurse led mental health nursing course (Happell, Byrne, et al., In Press). The consumer-led cohort showed a significant reduction in negative stereotypes towards people diagnosed with mental illness and a significant increase in intention to pursue a career in mental health nursing, neither change was observed in the nurse-led cohort. Furthermore, while both groups showed more positive attitudes towards consumer participation in mental health services and education at the post-test stage, the consumer-led group showed a higher level of positive change in the more systemic levels, as opposed to more individually focused responses from the nurseled cohort (Byrne, Happell, & Platania-Phung, In press).

Proposed issues for roundtable discussion

This issues paper suggests consumer involvement in the education of health professionals is likely to realise clear benefits. Major barriers have also been identified and need to be addressed if consumer academic positions are to grow and be sustained. These issues outlined briefly below would form the basis of discussion for the roundtable discussion of key stakeholders to be held in May 2015:

- The need for consumer academic positions to be valued and supported within Schools of Nursing. Consumer involvement in the education of nurses must be valued if limited financial resources are to be allocated to these positions.
- 2. A commitment to co-production and co-design of curricula to ensure resultant course content and delivery reflects genuine partnership between nurse and consumer academics.
- A more structured process for the implementation of consumer academic positions, based on the expertise already developed by pioneers of these positions
- A clear set of principles to ensure the positions provide meaningful consumer-led input and avoid tokenism
- Commitment from Schools of Nursing to the growth and sustainability of positions, ensuring the appropriate supports and opportunities for consumer academics
- 6. Acknowledgement of the necessity of research and evaluation to demonstrate the impact of these roles and facilitate quality improvement.

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