Consumers as Partners in Writing Projects: Lessons Learned from Mental Health

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In Australia, there have been national directives to involve consumers in all aspects of delivering a mental health service since the early 1990s as part of a National Mental Health Strategy. Consumer consultants, peer support workers and service-user representatives now play an integral role in the planning, delivery and evaluation of mental health services (Cleary, Horsfall, Hunt, Escott & Happell 2011). The role of the consumer consultant or peer support worker can be summed up by the adage: *Nothing about us without us*. Consumer involvement adds a unique and an important dimension to the mental health discourses. As people who have ‘walked the walk’ of experiencing mental health issues, and then engaged with services in their journey to recovery, their insights remind us of the crucial need to truly hear and authentically engage with consumers and look for the consumer's strengths and potential. Furthermore, our written discourses and the language used reflect and strongly influence our discipline and the practices with it. By authentically engaging with and including consumers as co-authors in our work, we are helping to position the concerns, views, and needs of patients and service users as central to our concerns and to ensure that the service-user perspective remains at the heart of our discourses.

True and genuine engagement among consumers, practitioners, managers, educators, and researchers fosters a spirit of authentic collaboration and allows the parties to draw on one another’s knowledge and perspectives to the betterment of services. Indeed, consumers can (and have) provided quite unique perspectives that have enabled mental health services across the country to improve their responsiveness and their approaches to providing healthcare. It would be no exaggeration to say that the mental health services have led the way when it comes to forming meaningful partnerships with consumers, with ongoing consumer involvement in the delivery of mental health services viewed as an essential and standard practice.

Partnerships between consumers and the health service have also extended to the area of quality improvement projects and research (Horsfall, Cleary, Walter & Malins 2007). This involvement needs to be differentiated from consumer participation as subjects in research studies—rather, such participation includes authentic consumer participation in all phases of the research, including developing the aims and objectives of the research, planning and implementing the research, and active involvement in data collection and analysis and also in the dissemination phase. That includes writing up the results for publication in reports and peer-reviewed journal articles (Horsfall et al 2007; Hungerford & Fox in press). Co-authoring also can include partnerships to develop media articles and other diverse projects such as psycho-education, drug health education, opinions pieces (eg, the role of consumer/carer consultants), and articles related to recovery informed practice (see for example Cleary, Hunt, Malins, Matheson & Escott 2009).

The beneficial outcomes of such writing partnerships can be considerable, as they provide practitioners, managers, educators, and researchers with the ‘real life’ view of mental health and illness. Specifically, benefits can include:
• Critiquing the use of language in the written piece;
• Adding ideas from the unique perspective of the consumer;
• Composing and editing text;
• Affirming the value of consumer feedback to the mental health service;
• Creating stronger and more inclusive collaborations between key stakeholders;
• Affirming the principle of consumer participation and inclusion to the mental health service; and
• Challenging explicit or implied notions of stigma, exclusion and discrimination.

In addition, such writing partnerships can also enrich the lives of consumers by providing new opportunities for participation, avenues for engaging with a wider audience of health professionals and policy-makers, and ultimately a means of directly contributing to improvements in the delivery of mental health services.

The lessons learned from the field of mental health provide fertile ground for other specialty areas in the nursing and wider health and social care contexts. Indeed, it is perhaps common sense to consider the benefits of the partnerships and collaborations experienced by mental health services through strong consumer engagement and how they can be incorporated into other areas of healthcare. Mental health consumers or service users are also consumers of general or mainstream health services, not only mental health services, and they use paediatric, acute, rehabilitation, aged care and other health services.

Increasingly, people are demanding a greater say or more meaningful involvement in the way health services are provided (Cleary et al 2011; Cleary, Walter & Escott 2006). Thus, the consumer movement in healthcare requires involvement from representatives of all those who ‘consume’ or use health services. It is important to recognise that many consumers, including mental health consumers, are highly articulate and well educated, having completed University degrees, and have other qualifications and much to offer various health-related projects. This could include projects located in the bed-based or community health contexts and also the less traditional para-health services, such as homeless shelters, jails, residential aged care facilities, alcohol and drug services, housing providers, and employment services.

When working collaboratively with consumers, it is important consider a number of principles. These principles will support the process of collaboration and enable a more productive and harmonious future together. For example:

• The consumer should be treated as an equal partner. Avoid tokenistic involvement: if there is not meaningful contribution, then it is not a genuine collaboration.
• If seeking the involvement of consumers employed in peer support roles, it is important to recognise that many are employed only part-time, need to juggle with competing priorities, and may not get approval from line managers to be involved in a new or different projects. It may be important, then, to communicate with the person’s manager about the proposed involvement and recognise that research is a valid use of the peer support worker's time.
• Consumers should not be precluded from participation based on a lack of research experience or research background as the crucial advantage is the lived experience as a service user.
• It is important to ensure that due recognition is given for any work undertaken (Cleary, Jackson & Walter 2012). Acknowledge or attribute authorship in accordance with accepted author guidelines (Cleary, Jackson, Walter, Watson & Hunt 2012). Remember, honorary authorship is also tokenistic.
Wherever possible, consumers should be paid for their efforts if the work they are undertaking is not part of their work duties and performed outside of work time.

Do not overstretch the consumer with deadlines; ensure timelines are realistic and provide for some flexibility.

Conclusion

In conclusion, rather than being an alternative to clinical or academic-led research and scholarship, consumers can contribute knowledge and insights that can enhance and complement traditional approaches. While there may be some challenges in locating consumers willing to work in partnership to write, the effort and potential benefits are well worth it.

References


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