

Mental health consumer and carer participation: why we bother

TO THE EDITOR: It is becoming increasingly recognised that consumer and carer participation improves both quality and outcomes of health care.¹ The Children of Parents with Mental Illness (COPMI) national initiative is a health promotion program supporting better mental health outcomes for children whose parents have a mental illness (<http://www.copmi.net.au>). COPMI produces and provides information and resources to support children and families, as well as their carers, health workers and the wider community. It endeavours to involve consumers, family members and other carers in an authentic, respectful manner in all areas, from strategic planning to evaluation.

To improve COPMI's consumer and carer participation strategy and the advice that it offers to organisations wanting to adopt their own systems for consumer and carer participation, we conducted a survey of mental health service consumers, family members and other carers. The survey design, implementation and analysis was led by a mental health service consumer (J C) and carer (T C) in conjunction with a health professional (L T). We used a convenience sample of an accessible, intact group. All 50 members of a group actively involved in COPMI's consumer and carer participation strategy at the time of the study (June–August 2011) were invited to participate. Of the 20 participants who completed the survey, 10 were mental health consumers and 10 were carers (including spouses, adult children, young carers and a grandparent). The categories for the survey were determined by a literature review and feedback from J C and T C. We gathered information on (i) key motivators for consumers, family members and other carers to become participants in health promotion service planning, development, delivery and evaluation; (ii) barriers to involvement; and (iii) key areas that consumers and carers see as requiring the most change.

In our sample, altruism was the major factor motivating consumers and carers to participate in health promotion planning, implementation and evaluation processes (Box). We also identified a number of barriers to participation, such as lack of time, money and access to health services, and the alienating effect of professional jargon. Where possible, these should be actively addressed, to harness the wealth of lived experience, knowledge and empathy of carers and consumers, and to realise better health quality and outcomes. Finally, we found that carers and consumers believe that family members play a vital role in the treatment of a parent's mental illness and that they should be offered supporting services and information.

Consumer and carer participation survey: questions and responses (*n* = 20)

What motivates you to be involved in consumer and carer participation?

To improve services and resources	18
To help others	18
Commitment to inclusion and ensuring consumer and carer voices are heard	18
Being able to give back to services	5
It's part of my recovery process	4

What are the barriers to being involved?

Time	12
Feeling like an outsider (professionals use jargon)	10
Money	9
Location/access	9
Health (mental or physical)	9
Confidence	7
Opportunity	6
Options for participation are not flexible	4
Stigma	3
Anonymity	0

What do you want to see changed?

Family to be seen as vital to treatment of mental illness and offered services	16
More information for children and young people	15
Services and resources that are useful for families	15
More workforce education involving consumers and carers	14
A stronger consumer and carer voice in mental health in general	14
Hope for families	13
Professionals to have more confidence to ask about families and provide services	12
Services/professionals recognising the parent role	11

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1 Fact sheet no. 1: An introduction to consumer participation [internet]. Melbourne: National Resource Centre for Consumer Participation in Health, 2002. <http://pandora.nla.gov.au/pan/37708/20061028-0000/www.participateinhealth.org.au/ClearingHouse/Docs/nrcfactsheetanintroductionmay2002.pdf> (accessed Aug 2011). □