



NMHCCF Advocacy Brief

Issue: Consumer and Carer Participation – Key Issues and Benefits

Definition

Consumer and carer participation sets out to achieve cultural change and systemic reform through the expression of our collective experience and expertise. Participation enhances recovery and well-being and leads to improved service quality and developments..

Consumer and carer participation is defined as:

“participation by consumers and carers in formal or informal planning, delivery, implementation, and evaluation of all activities associated with mental health services (voluntary or paid), as well as in all processes which effect[sic] the lives of consumers and carers, through sharing of information, opinions, and decision making power.”¹

Background

Historically, services and programs that treat, care or assist people with experience of mental health problems (consumers) have been designed by clinicians and administrators. Consumers and their carers have had little opportunity to provide input. Service users have a unique perspective and their ‘customer feedback’ can create more responsive and higher quality services.

Health planners, clinicians and service providers have begun to include consumers and carers in decision-making around services, policies and programs. Increasingly, consumers and carers are actively contributing to decisions that impact on the services they use. This is in line with recent national mental health inquiries and reports, which recommend increased consumer and carer participation across all aspects of mental health planning/evaluation, design/conduct of research, peer support services and representative roles.

Key Points for Consumers and Carers

Key elements of consumer and carer participation are – trust, openness, equal opportunity, advocacy and support, responsiveness, shared ownership, dissemination and evaluation.

Consumers and carers can help improve the quality, responsiveness and variety of service and program delivery through participation in development, implementation, and evaluation.

Benefits

There are many benefits derived by consumers, carers, service providers and bureaucrats from consumer and carer participation.

Research indicates that consumer participation in health services results in higher quality cost effective accountable services and projects and improved health outcomes for consumers. Consumer and carer participation in mental health services can also allow staff

¹ NCCF Consumer and Carer Participation Policy 2004

to gain new insights into service provision and build positive relationships with consumers and carers.

Participation can provide opportunities to have expertise acknowledged, earn an income, increase social contacts and develop new skills. Consumer participation is regarded by many as integral to the recovery process, as it enhances social inclusion through socially valued roles.

The literature on participation also suggests that health service staff experience greater job satisfaction where consumers and carers are actively involved in the service.

Capacity Building

To ensure participation of consumers and carers is genuine, effective and sustainable over time, there needs to be a focus on leadership and policy, workforce development and consumer and carer development.

Reporting back

*“Reporting back to peer groups is an essential element of participation for all consumer (and carer) representatives. There is never an adequate reason to cut a representative off from his/her support structures or peer influence.”*² Services need to ensure that there are appropriate mechanisms for representative feedback.

Principles for consumer and carer participation³

The effectiveness of consumer and carer participation is enhanced if the following principles are acknowledged/ enacted:

- Consumers and carers have unique expertise and separate needs
- Involvement of consumers and carers is promoted at all levels of the organisation
- Varying communication styles and participation needs are recognised and acknowledged and sometimes diversity or uncertainty is accepted
- Consumers and carers are involved from the beginning
- Participation results in cultural and organisational change
- Participation is built from the bottom up and is supported from the top down
- Consumers and carers are selected using transparent processes
- Consumers, carers and staff are supported appropriately to enable effective and sustainable participation
- Multiple strategies for participation to ensure a range of people are able to participate
- Independence of consumer and carer representatives to increase autonomy and reduce conflict of interest
- Consumers and carers are encouraged to advocate for themselves and structures exist which support self advocacy
- Advocacy from individuals and organisations who are independent of the health system (or other entity) is an essential component of quality improvement activity.

Consumer participation in health is about change. It is a reallocation of power between experts and users. It makes individuals and communities take responsibility for the

² Reference: Meagher J. 2002 Partnership or Pretence

³ Reference: NCCF 2004 “Consumer and Carer Participation Policy”
Consumer focussed Collaboration 2000 “Improving Health Services Through Collaboration”

protection of their wellbeing, and the promotion of healthier communities. It will change how organisations are structured, and their culture. It reduces professional boundaries, improves collaboration and establishes partnerships.

Recommendations for Change and Key Issues for the Future

The NMHCCF believes that change has to occur to enable valid and responsible consumer and carer participation in Australia. This change needs more than high level agreement.

There must also be a commitment and belief within the mental health sector in the value of consumer and carer participation. Work needs to be done to improve and clarify policies, procedures and structures in order to ensure participation is genuine, supported, effective and sustainable.

To enhance and guarantee quality consumer and carer participation, consideration should be given to:

1. Building the capacity and the structures to support participation. This could be on multiple levels- personal, organisational, financial or structural.
2. Adopting strategies for involving consumers and carers in policy development, service and program planning, implementation and evaluation, staff and professional development, education and research.
3. Determining how to ensure consumers and carers are active participants, not just sources of endorsement or information. This may require changing the culture in order to properly support consumers and carers.
4. Creating structures to provide necessary background briefing, training and support for consumers and carers
5. Identifying how and where to access genuine and appropriate representatives.
6. Creating opportunities for suitably experienced consumers and carers at every level; particularly to have consumer / carer participation opportunities identified, enable participation in, and show leadership through, training, education, development and employment.
7. Building in accountability and feedback mechanisms to align and enable two-way feedback between the participant consumer or carer and their wider constituency.

The NMHCCF supports:

- The development of an overarching national mental health consumer and carer participation policy and strategy.
- Participation that values the participant and their expertise by adequate remuneration for all consumer and carer participants and nationally standardised minimum sitting/ participation fee rates.

Other Resources

The NMHCCF Consumer and Carer Participation Policy is available at www.nmhccf.org.au

Name of Nominated NMHCCF contact on this issue

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