

Building a 'user driven' mental health system

LEI NING

Consumer Research and Evaluation Unit, Victorian Mental Illness Awareness Council, Brunswick East VIC, Australia

ABSTRACT

Australian mental health system reform continues to be guided by an outdated vision to design a 'perfect' mental health system. It is then expected that consumers and carers will fit in to it. From the experiences of the past 15 years it is clear that this approach is ineffective. The new vision of mental health system reform should embrace recovery and wellbeing principles to encourage consumer self-directedness and self-determination, and to support the individual consumer to build their own unique support system which wraps around their personal goals, needs and priorities. In order to advance mental health system reform, it must be responsive to, and driven by, consumer and carer needs.

Keywords: Consumer, carer, participation, consumer research and recovery

To date, Australia's mental health system reform has been largely focused on formulating efficient processes and procedures and trying to achieve a 'perfect' system for users of services rather than co-designing services with consumers and carers based on their needs and lived experiences.

The mental health system reform has been oriented towards improving the existing system. While the Australian mental health system is showing signs of improvement, there are still real concerns regarding the scarcity and quality of services, human rights issues, accommodation shortages, employment options for consumers and the prevailing attitudes within mental health services. What is needed to move the reform process beyond the system focused approach adopted for the past 15 years? We believe that the most effective way to move forward is to revolutionise the traditional thinking and design of mental health services to a dynamic system that is

truly driven by its users' needs, priorities and expectations. We are facing new challenges in the 21st century. We have to engender real changes in mental health service planning process, delivery models and evaluation methodology.

A SYSTEM IS TRULY DRIVEN BY ITS USERS

Being cognisant of today's ever changing world through understanding customers' wants, needs and priorities is vital to success in any service organisation. Without this dynamic information the organisation will not be able to provide quality products and services, or indeed, survive and grow. This is certainly the case in the commercial market environment. However, unlike a commercial company, mental health services are not in competing in a market. Mental health services normally only need to satisfy their government funding requirements, and there is no real pressure for them to make great efforts to improve the service quality or the experiences of their con-

sumers and carers. It is rare that there is an effective structure within a mental health service to systematically gather consumers' and carers' experiences of their service. It is even rarer for the service to use this type of information to redesign and improve quality of service collaboratively with their consumers and carers. This lack of responsiveness at all levels of the mental health system is a fundamental flaw and must be changed.

RECOVERY AND WELLBEING

Recovery has become a buzz word within the mental health sector in the past decade. The concept of recovery is attributed to the consumer movement of the 70s and 80s (Deegan, 1988; Anthony, 2007; Slade, 2009). It has made evident impact on mental health systems around the world. Some mental health services claim that their services are recovery oriented. Nevertheless, those mental health services still struggle to grasp the key recovery concepts. 'The recovery stuff has gone nowhere. I mean it couldn't be implemented because actually it requires a fundamental change in the way things are done, and that's just not happening' (O'Hagan, 2010, p. 3).

Meanwhile, the consumer movement has marched on from recovery to the renewed concept of wellbeing (wellness). The word 'wellbeing' is not pathologising and is much more holistic, in that it does not just focus on mental health. Wellbeing is moving away from a medical model of treatment to a social model of care. Wellbeing is about intrinsic human resilience, eagerness for growth, mindfulness, self-transcendence, social inclusion, participation and having access to full citizenship. Regardless of having a mental health problem or otherwise, wellbeing is everyone's goal. This new and developing concept will impact on the evaluation of how to deliver mental health services in the 21st century.

EMPOWERMENT AND CONSUMER AND CARER PARTICIPATION

In an attempt to acknowledge the notorious past and power imbalances in the mental health system, as a baseline measure, mental health services

should have a comprehensive consumer and carer participation plan that empowers consumers and carers to have a strong voice. Consumer and carer empowerment is central to all reform agendas as it enjoins consumers and carers with mental health services to work in a productive partnership. Empowerment supports effective and meaningful participation. It involves an assumption of capacity instead of stigma and discrimination, which is a shift from 'substituted decision making to supported decision making' (Lawson, 2007, p. 20), and it also instils hope in people who are dealing with life challenges. Empowerment consolidates the determination to eliminate criminal law style psychiatric treatments and promotes widespread awareness and consciousness of human rights and responsibilities.

Consumer and carer participation in mental health service planning, delivery and evaluation has been government policy for about two decades (Australian Health Ministers, 1991; Department of Human Services, 2009.). However, consumers and carers are still battling tokenistic approaches from mental health services and governments. There are policies but no resource commitments or real expectations from mental health services and government in terms of providing adequate training, support and career advancement for consumer and carer representatives (The Senate, 2008). Rather than having an effective structure in place, consumer and carer participation programs rely heavily on the ability of the individual consumer and carer consultants. These programs often lack monitoring, sustainable infrastructure and leadership which raises criticisms that consumer and carer participation may be pretence or an example of tokenism (Meagher, 2002). Furthermore, the proportion of the consumer and carer workers employed within clinical mental health services is only about 0.4% of the mental health workforce (AIHW, 2010). Considering consumer and carer participation is a key to improving the mental health system, the level of consumer and carer involvement is far from convincing and satisfactory.

BEYOND TOKENISM

Consumer and carer participation is about consumer and carer involvement in all facets of the mental health service, thereby providing meaningful impact on service planning, delivery and evaluation. The service's consumer and carer participation plan needs to include a sustainable structure and executive leadership in order to provide adequate training, support, equal remuneration and career path prospects for consumer and carer workers commensurate with other mental health professionals. This will aid in attracting and retaining a competent consumer and carer workforce. Recognising the unique expertise of mental health professionals with a lived experience of mental health issues is a positive step towards mental health system reform. This may influence the existing middle class values, orientation and judgment that predominate within the workforce and bring about more empathy, commitment and cultural change. Development of consumer run services should be encouraged in order to provide peer support alternatives. It needs to be reiterated that consumer peer support workers must have access to adequate training, support, supervision, career development and resources.

Consumer and carer involvement in research and evaluation is a promising advancement in mental health system reform. Consumer and carer research is committed to equality and change. It enables consumers and carers to move beyond their own lived experiences and anecdotal information to gather systemic data to inform their views, opinions, and policies to better represent consumer and carer perspectives. Consumer and carer involvement in evaluating mental health services promotes the accountability and quality of those mental health services. Consumer and carer operated research and evaluation improves our understanding of consumer and carer experiences, and contributes to mental health system reform and improvement.

CONCLUSION

Australian mental health system reform continues to be guided by an outdated vision to design a 'perfect' mental health system. It is then expected that consumers and carers will fit in to it. From the experiences of the past 15 years it is clear that this approach is ineffective. The new vision of mental health system reform should embrace recovery and wellbeing principles to encourage consumer self-directedness and self-determination, and to support the individual consumer to build their own unique support system which wraps around their personal goals, needs and priorities. In order to advance mental health system reform, it must be responsive to, and driven by, consumer and carer needs.

In conclusion, if consumer and carer participation continue to operate at a superficial level, Australian mental health system reform may spend another 15 years without achieving meaningful and substantial improvement. We have to gain a deeper understanding of 'Nothing about us without us' (Charlton, 2000)!

ACKNOWLEDGEMENTS

The author would like to thank Mr Wayne Weavell and Miss Sally Woodhouse for their unconditional support.

References

- Anthony, W. A. (2007). *Toward a vision of recovery for mental health and psychiatric rehabilitation services*. Center for psychiatric rehabilitation, Boston University.
- Australia Institute of Health and Welfare (2010). *Mental health Services in Australia 2007-2008. Mental Health Series no. HSE 88*. Canberra: AIHW.
- Charlton, J. I. (2000). *Nothing about us without us – disability oppression and empowerment*. Berkeley, CA: University of California Press.
- Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, 11(4), 11–18.
- Lawson, A. (2007). The United Nations convention on the rights of persons with disabilities: New era or false dawn? *Alternative Law Journal*, 32(1), 22–23.

Meagher, J. (2002). *Partnership or pretence*. NSW: Buck Printing.

O'Hagan, M. (2010, March). Newsletter of ourconsumerplace.com.au

Slade, M. (2009). *Personal recovery and mental illness: A guide for mental health professionals*. Cambridge: Cambridge University Press.

The Australian Health Ministers (1991). *Mental health statements of rights and responsibilities*. Canberra:

Australian Government Publishing Service.

The Department of Human Services of the Victorian Government (2009). *Strengthening consumer participation in Victoria's public mental health services action plan*. Melbourne: Department of Human Services.

The Senate, Standing Committee on Community Affairs (2008). *Towards recovery: Mental health services in Australia*. Canberra: Parliament House.

FORTHCOMING FROM eCONTENT



Migration and Mental Health

Special Issue of *Advances in Mental Health*

ISBN 978-1-921729-08-9 ~ Volume 9 Issue 3 ~ ii + 126 pages ~ December 2010

Edited by: Nicholas Procter, Professor and Chair: Mental Health Nursing, University of South Australia; Monica McEvoy, Nurse Practitioner Candidate Multicultural Mental Health, Child Adolescent Mental Health Services, South Australia; and Irena Papadopoulou, Professor and Head, Research Centre for Transcultural Studies in Health, Middlesex University, UK.



Advances in Contemporary Nurse Education (2nd edn)

Special Issue of *Contemporary Nurse*

ISBN 978-1-921729-26-3 ~ Volume 38 Issue 1 ~ ii+126 pages ~ April 2011

Edited by: Professor Debra Jackson, University of Western Sydney, Australia; Professor Roger Watson, University of Sheffield, UK; and Professor Tom Mason, University of Chester, UK.

Informs the important issue of nurse education, highlighting the progress made in these areas as well as the many challenges faced in education and training curriculum development and delivery.



Mental Health and Illness: Practice and Service Issues

Special Issue of *Health Sociology Review*

ISBN: 978-1-921348-57-0 ~ Volume 20 Issue 2 ~ ii+126 pages ~ June 2011

Edited by: Pauline Savy, Anne-Maree Sawyer and Katy Richmond, Faculty of Humanities and Social Sciences, La Trobe University, VIC, Australia.

This special issue is prompted by ongoing claims about escalating mental health problems and their management in Australia and other affluent countries.



Mixed Methods Research in the Health Sciences

Special Issue of *Multiple Research Approaches*

ISBN: 978-1-921348-93-8 ~ Volume 5 Issue 1 ~ ii+126 pages ~ February 2011

Edited by: Elizabeth Halcomb and Sharon Andrew, School of Nursing and Midwifery, University of Western Sydney

Contributions are invited to a special issue of the *International Journal of Multiple Research Approaches* (MRA) dedicated to Mixed Methods in the Health Sciences.



Mediating Family Disputes

Special Issue of *Journal of Family Studies*

ISBN 978-1-921729-32-4 ~ Volume 17 Issue 3 ~ ii+112 pages ~ December 2011

In Australia, the introduction of a default position of mandatory family dispute resolution (FDR) as part of the 2006 family law reforms heightens the need for ongoing rigorous analysis of and discussion about these processes.

eContent Management Pty Ltd, PO Box 1027, Maleny QLD 4552, Australia
Tel.: +61-7-5435-2900; Fax. +61-7-5435-2911; subscriptions@e-contentmanagement.com
www.e-contentmanagement.com