Living with mental illness

Lorna Moxham

University of Wollongong, lmoxham@uow.edu.au

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Abstract
This chapter explores how living with mental illness can result in social and economic hardship, and takes a look at policy responses to address mental illness.

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Professor Lorna Moxham

Professor of Mental Health Nursing, Faculty of Science, Medicine and Health
University of Wollongong

Dr Moxham is Professor of Mental Health Nursing in the School of Nursing, Faculty of Science, Medicine and Health. Lorna is also the leader for the Living Well Longer, theme within the University of Wollongong’s Global Challenges program. Lorna has experience as Head of School, Dean of Graduate Research and has held numerous senior governance roles in university’s such as Chair: Research Committee of Academic Board and Chair: University Human Research Ethics Committee.

Initially qualified as a psychiatric nurse at Rozelle Hospital in Sydney, Lorna continued her passion for lifelong learning graduating from UWS with a Diploma of Applied Science and Bachelor of Health Science. She then graduated from UNSW with a Master of Education. Additionally, Lorna has a Graduate Certificate in Occupational Health & Safety and also in Quality Management and has certification in Training and Assessment from CQIT.

Lorna has held numerous university and community appointments including four at ministerial level: These include Chair: Central Queensland Health Community Council, Mental Health Review Tribunal, Regional Planning Advisory Committee and the QLD Priority Housing Committee. Additionally, Lorna was a Board Director for Central Queensland Mercy Health and Aged Care and the Australian College of Mental Health Nurses and a member of the Executive for the Australian and New Zealand Council of Deans of Nursing and Midwifery.

Passionate about health care and its valuable contribution to the wellbeing of our society, Lorna’s specific area of expertise rests within mental health nursing. She is a Fellow of the Australian College of Mental Health Nurses and also the Australian College of Nursing.
WHAT IS MENTAL ILLNESS AND WHO HAS ONE?

The term mental illness, as used in this report, is inclusive of mental disorder(s) and encompasses a wide range of mental health and behavioural issues. A mental illness is a clinically diagnosable set of symptoms or behaviours associated with distress and with interference with personal functions. Mental illness can significantly interfere with a person's cognitive, emotional and social abilities. The most prevalent mental illnesses are depression, anxiety and substance use disorders. Not as prevalent but often more severe are mental illnesses such as schizophrenia, bi-polar disorder and schizoaffective disorder (AIHW 2014).

Anyone can develop a mental illness. It does not discriminate and affects all ages, gender, ethnicity and socioeconomic status. One in five Australians aged 16-85 years had a mental disorder in 2007 and almost one in two (or 7.3 million people) had experienced a mental disorder at some point in their lives (ABS 2009). The rate of mental illness were higher for men aged 16-34 years (23%) and women aged 16-24 years (30%) compared with older age groups.

Mental illness can affect a person's ability to interact successfully with their family, friends, work colleagues and the broader community. It can cause significant distress and disability, and can lead to isolation of, and discrimination against, people who are affected (AIHW 2008). Living with a mental illness and managing the challenges that come with it can mean that people with mental illness may not be able to fully participate in the labour force. This impacts on the individual in terms of personal income, social participation and self-esteem, but also has wider economic impacts.

ENTRENCHED DISADVANTAGE

Despite the fact that Australia has experienced two decades of economic growth and rising average incomes, people with mental illness are among the most disadvantaged in society with many experiencing social and economic hardship as a direct result of their illness (National Mental Health and Consumer & Carer Forum, 2010). Mental illness continues to be stigmatised, and services and research continue to be under funded compared to other illnesses and injury. Many people with a mental illness live in a cycle of entrenched disadvantage. Such disadvantage is not just about low income. It includes social isolation and exclusion, diminished capabilities and deprivation. Diminished capabilities, a measure of disadvantage identified by Amartya Sen, can translate into outcomes such as inadequate income or education, poor health, low self-confidence and a sense of powerless (McLachlan, Gilfillan & Gordon, 2013).

If these ‘measures’ are applied to people with mental illness we find……

*Social Isolation and Exclusion - people with long-term mental illness are among the most excluded in society (Social Exclusion Unit, 2004). The idea that having a mental illness contributes to ‘otherness’ has meant that for centuries, exclusion from society has resulted (Hubert, 2000).

*Inadequate Income - The full-time adult average weekly total earnings in May 2014 was $1,516.90 (ABS, 2014). The maximum rate of the Disability Support Pension (DSP) is $766 p.f. for a single person aged over 21 with no dependents. The Newstart allowance is $510.50
per fortnight for a person in the same circumstances. A person may also be eligible for Commonwealth Rent Assistance of $119.40 p.f. The Mental Health Council of Australia (2014) identify that the proportion of people with disabilities receiving the DSP is 37.3% (825,000 out of 2.2 million Australians identified as having a disability). At any given time, more than 3.2 million Australians are estimated to experience mental illness with 62% currently employed. Of these, there are an estimated 489,000 people living with severe mental illness. In September 2013 there were 258,640 people receiving the DSP due to psychosocial disability (31.1% of total DSP recipients). This is less than 10% of the total number of people living with mental illness in Australia. Any changes in access to the DSP need to be carefully considered, particularly for people with a mental illness who are already marginalised and live with stigma.

*Poor Health and Premature Mortality – Mental illness is associated with increased exposure to health risk factors, greater rates of disability, poorer physical health and higher rates of death from many causes including suicide (AIHW, 2015). People with severe mental illness tend to, on average, die earlier than the general population (Thornicroft, 2013). There is a 10-25 year reduced life expectancy in people with severe mental illness with the vast majority of deaths due to preventable chronic physical medical conditions such as cardiovascular, respiratory and infectious diseases, diabetes and hypertension. Suicide is another important cause of death. Mortality rates among people with schizophrenia is 2 to 2.5 times higher than the general population (WHO, 2015).

*Low self-confidence and sense of powerlessness – the stigma associated with having a mental illness is a major contributor to low self-confidence and a sense of powerlessness. Stigma and discrimination against people with mental illness is a global problem and can lead to lower rates of help seeking, under treatment and social exclusion (Evans-Lacko, Brohan, Mojtabai & Thornicroft, 2011).

**COSTS of MENTAL ILLNESS**

The Australian Institute of Health and Welfare (2013) indicates that over $7.2 billion, or $322 per person, was spent on mental health-related services in Australia during 2011-12, an increase from $282 per person in 2007–08. $4.5 billion was spent on state and territory specialised mental health services, an average annual increase of 4.3% between 2007–08 and 2011–12. Most of this funding was spent on public hospital in-patient services ($1.9 billion), followed by community mental health care services ($1.8 billion).

In addition to the public sector, expenditure on specialised mental health services in private hospitals was $333 million during 2011–12. The Australian Government paid $906 million in benefits for Medicare subsidised mental health-related services in 2012–13, equating to 4.9% of all Medicare subsidies. Expenditure on psychologist services (clinical and other) ($377 million) made up the largest component of mental health-related Medicare subsidies in 2012–13. The Australian Government spent $788 million, or $34 per person, on subsidised
prescriptions under the PBS/RPBS during 2012–13, equating to 8.3% of all PBS/RPBS subsidies.

The costs outlined above are indicative of 'running costs'. They don’t account for indirect costs and personal costs to the person and/or their family. The annual cost of mental illness in Australia has been estimated at something more like $20 billion. This approximation includes the cost of lost productivity and labour force participation (COAG 2006). Significantly, mental illness has been identified as the leading cause of healthy years of life lost due to disability (AIHW 2008).

More than two decades of plans.

The care and treatment provided to people with a mental illness has long been the subject of inquiries and commissions, not only in Australia but across the globe. Many of these inquiries have been on the basis of MISTreatment or perceived unprofessional behaviour. In order to ‘fix’ past issues and identify future directions and approaches, mental illness has also been the subject of numerous government and organisation plans and strategies, nationally and internationally.

In many respects Australia has led the way with these initiatives. In 1992 the Australian Health Ministers signed the first five years of a National Mental Health Strategy. The Strategy contained a statement of Rights and Responsibilities of Consumers (1991), the National Health Policy (1992), the National Health Plan and outlined Commonwealth Funding under the Medicare Agreement. This was indeed a significant document. Given that Australia was the first country to develop a national strategy for the modernisation of mental health services, the National Mental Health Strategy (1992-1998) sent a powerful message that reform of mental health services was very much of the Government’s agenda. The government wanted to assure change by promoting the mental health of the Australian Community, prevent mental illness, reduce the impact if mental illness and assure the rights of people who are living with mental illness. The aims of the National Mental Health Strategy were to:-

- where possible, prevent the development of mental disorder
- reduce the impact of mental disorder on individuals, families and the community
- assure the rights of people with mental disorder

These aims are just as relevant in 2015 as they were when they were originally written in 1992.

The First National Mental Health Plan was written at a time when the mental health system was thought to be in disarray. Within the decade prior to the release of the plan, the shift of psychiatric beds from large, stand-alone mental health institutions to general hospitals and to community based care as a result of deinstitutionalisation, had occurred. It was however, by no means complete and the move to community based care is still the subject of much conjecture. Given the context of the time, the first plan, mainly focused its attention on public
mental health services with changes in structure and mix of public mental health services being identified as the priority. The plan asserted that better integration of care was required. It also emphasised consumer rights.

In addition to the first National Mental Health Plan, 1996 saw the Australian Government recognise the significance of mental illness by identifying mental health as one of the national health priority areas. The Australian government chose mental health because mental illness contributes significantly to the burden of illness and injury in the Australian community. Indeed, the government felt that by targeting specific areas that impose high social and financial costs on Australian society, collaborative action could achieve significant and cost-effective advances in improving the health status of Australians (Australian Government 2015).

The Second National Mental Health Plan (1998-2003) aimed to continue the ‘unfinished business’ of the first plan but it expanded its focus. The second plan was introduced to progress initiatives of the National Mental Health Strategy. It turned its attention to promotion and prevention, partnerships in service reform, and quality and effectiveness. The gaze fell upon general practitioners and private psychiatrists who had previously felt excluded from mental health services. These professionals could provide timely and necessary primary health care. Such, early intervention could mean timely access to treatment and prevent costly and undesirable in-patient admissions. Programmes related to depression were also given significance. The plan had attracted growth in mental health expenditure in real terms, but this growth had simply mirrored overall health expenditure trends and was not sufficient to meet the level of unmet need for mental health services.

In 2003, the third plan was released. This National Mental Health Plan (2003-2008) had a broad approach and described mental health for all Australians. This plan identified 34 outcomes with 113 key directions. This plan did not however, identify specific commonwealth funds. This was not considered appropriate given that sufficient and timely funding is a critical component for innovation and expansion. Evaluation of this plan indicated that continuing the progress that was made since the establishment of the National Mental Health Strategy in 1992 was considered important and overwhelming support remained for the principles which were viewed as fundamental to realising the aims outlined in the plan (Currie & Thornicroft, nd).

In July 2006, the Council of Australian Governments (COAG) agreed to the National Action Plan on Mental Health 2006-2011. Once again, clearly recognising the need for a change in the way governments respond to mental illness. The Plan provided a strategic framework that emphasised coordination and collaboration between government, private and non-government providers. Like previous plans, this one also aimed at building a more connected system of health care and community supports for people affected by mental illness. The five year plan identified five action areas with associated agreed outcomes. These were:
During this time, a new National Mental Health Policy was endorsed by health ministers in December 2008. This revised policy represents renewed commitment by providing an overarching vision and intent for the mental health system in Australia. The policy embeds the whole of government approach first agreed by COAG in July 2006 regarding mental health reform that formed the centrepiece of the COAG National Action Plan on Mental Health.

We now have The Roadmap for National Mental Health Reform (2012-22). Endorsed by COAG on 7 December 2012, The Roadmap outlines the directions to be taken by governments over ten years. It identifies governance and accountability arrangements designed to directly engage stakeholders and ensure that governments are held to account. The new arrangements included the establishment of a COAG Working Group on Mental Health Reform. This group developed the Fourth National Mental Health Plan (2009-2014) which set out through the identification of five priority areas, how the Roadmap will be implemented.

The Roadmap has a great vision that all Australians should see as valuable and worthy of investment. It states:

‘A society that values and promotes the importance of good mental health and wellbeing, maximises opportunities to prevent and reduce the impact of mental health issues and mental illness and supports people with mental health issues and mental illness, their families and carers to live full and rewarding lives.’

There is ongoing debate about whether the plans have achieved their aims or not, what real change has occurred and whether any difference has actually been made. Such debate is
necessary and whether plans have ‘worked’ or not, will continue to be the subject of debate. State, Territory and National plans and indeed global plans and strategies, related to mental health are, in my opinion extremely valuable. Mental health plans, strategies, policies etc, include agreement about collective values and beliefs about mental health service provision, and they identify understanding and commitment about the country’s vision, direction and goals. Quite simply they provide the goals to aspire to and give an overall direction. Mental health service providers can chose to use these plans to advocate for change or they can chose to leave them sitting on a shelf and then complain nothing has changed.

Prioritising Care and Treatment

The increased level of utilisation of mental health care services across all age brackets will have a large influence over which components of plans can and should be implemented as a matter of priority. Australia has the building blocks in place to implement strategies outlined in mental health plans and these can successfully be built upon. Keeping people out of hospital is considered best practice and this should be the focus. GPs, primary healthcare workers and mental health nurses working under the Mental Health Nurse Incentive Program (MHNIP) are important players in this respect. As such, early intervention in mental health can prevent costly admission, the cost of which is both fiscal and often personal.

A specialist workforce

The provision of care to people with mental illness is specialised. A consortium of researchers, advocates and clinicians (Collins et al 2011, pg 29) advise that one strategy to improve the lives of people with mental illness around the world, is to “Strengthen the mental-health component in the training of all health-care personnel”. In Australia, one way this can be achieved is by addressing the lack of mental health content in undergraduate qualifications. Nursing is a good example. The Australian Mental Health Nurse Education Taskforce conducted a national examination of mental health content of preregistration nursing curricula in order to develop a framework for including mental health in future curricula. Qualitative findings from national consultations about the framework suggest that the mental health content of curricula should be increased (Moxham et al 2011). Many universities have little or no mental health content in their degree. Out of 24 subjects, on average there may be one or two mental health courses. Of the minimum required 800 hours clinical exposure, some nursing students don’t even get a mental health placement as part of their training at all. Strengthening the mental health component doesn’t have to cost more. Identifying the minimum mental health content within health programmes will ensure that mental health is part of the curriculum. If universities aren’t given set minimums, they won’t change their curricula. Despite the dearth of mental health training, graduates can begin employment in mental health settings. Clinical staff who work in mental health, should not be employed unless they possess qualifications reflective of the specialised nature of care and treatment for people with mental illness. Nurses makes up the large majority of the clinical workforce, sometimes as much as 70%. Just as Midwifery has a recognised endorsement, so too should the speciality area of mental health nursing in Australia. In fact, this used to be the case. These days this can be achieved by credentialing through the
Australian College of Mental Health Nurses who posit that the minimum qualification required to be credentialed is a Graduate Diploma. Being credentialed is one way to identify to employers, consumers and colleagues who a mental health nurse is.

**Early intervention begins in the community**

Funding for community based care should be the priority. The majority of funding continues to go to in-patient care. The 1980s saw the mass movement from institutional to community based care. Why then, after more than two decades is the majority of funding still going to hospital based care, when early intervention, initiatives in primary health care and increased community support will actually keep people out of hospital? Are we trapped in a mind-set of being too risk averse? Community based care is best practice. Nothing will change if mind-sets and funding models don’t change.

**Peer Workforce**

Increasing the peer support workforce is a no brainer. People with lived experience offer valuable insights and understanding of mental illness. Peer support does not replace treatment, but is complimentary to clinical care and the peer support worker is and should be seen as an active and equal member of the multidisciplinary team. Peer support workers educate people with mental illness about the power and responsibility that each person has in determining their own recovery. The peer relationship enables equality and mutuality and engenders hope.

**The power of language**

Everyone can agree that language is powerful. Words do not just convey meaning, they have a potency that can empower or deflate. The words we use reflect, reinforce and shape perceptions of people. Mental health care and treatment is filled with language that deflates. But… this can and should change. Recovery focused language that is strengths based should be the norm. Such an affirming paradigm is important to move toward in all forms of communication, written, verbal and non-verbal. Forms, documents, policies and procedures, from national, state and territory, right down to local health district level should all use recovery oriented language.

**A sense of purpose**

Everyone needs something to get out of bed for. A motivator, a sense of purpose. Indeed, research suggests that having a purpose in life has the potential to reduce mortality risk (Hill & Turiano, 2014). The purpose is different for different people and discovery of what it is recognises and acknowledges individuality. People with a mental illness are, of course, no different. Engagement in rehabilitation, leisure and therapeutic recreation activities in the community are an excellent means to create meaning. Cost effective programs can be run by organisations which facilitate purpose, decrease social isolation and address stigma.

**Access**

The ability to access mental health services is not evenly distributed across Australia. Pragmatically, with a continent that is 7,692,024 km² in size, the tyranny of distance is always
going to mean that for the most part, services will be located where the majority of the population reside. In order to reach Australians that live remotely and in rural and regional settings, we need to use technology. One can only hope that the National Broadband Network will make a difference. Mental Health services can, in part, be delivered through better utilisation of video and teleconferencing. Such technology can be far reaching and can provide support for people in very remote locations. Importantly this can be done in the persons own home. An example is Lifeline, a 24 hour telephone crisis line founded in 1963 by the Reverend Sir Alan Walker. Services like Lifeline, provide valuable mental health support particularly in the area of suicide. This kind of service, is extremely cost effective yet does not attract anywhere near enough government funding. Funding research that will develop evidence based apps which can empower and educate and can assist people manage their illness at home will be important for future health care delivery. People will have to increasingly manage their lives in ways that promote personal responsibility for health. Apps that can help us all work toward healthier lifestyles, present a way for Australians to enjoy a better quality of life.

Making sure we have good mental health care will play a role in the future prosperity of Australia. We would do well to heed the following advice from a person with lived experience:-

*If we plant a seed in the desert and it fails to grow, do we ask, “what is wrong with the seed?”
No. the real conspiracy lays n this: to look at the environment around the seed and to ask, “what must change in this environment such that the seed can grow?” The real conspiracy that we are participating in here today is to stop saying what’s wrong with psychiatric survivors and to start asking: “How do we create hope filled, humanised environments and relationships in which people can grow?”.*

*Patricia Deegan – keynote address, TheMHS Conference, Brisbane, 1996.*

**REFERENCES**


