RECOVERY APPROACHES

*in Principle
& Practice*
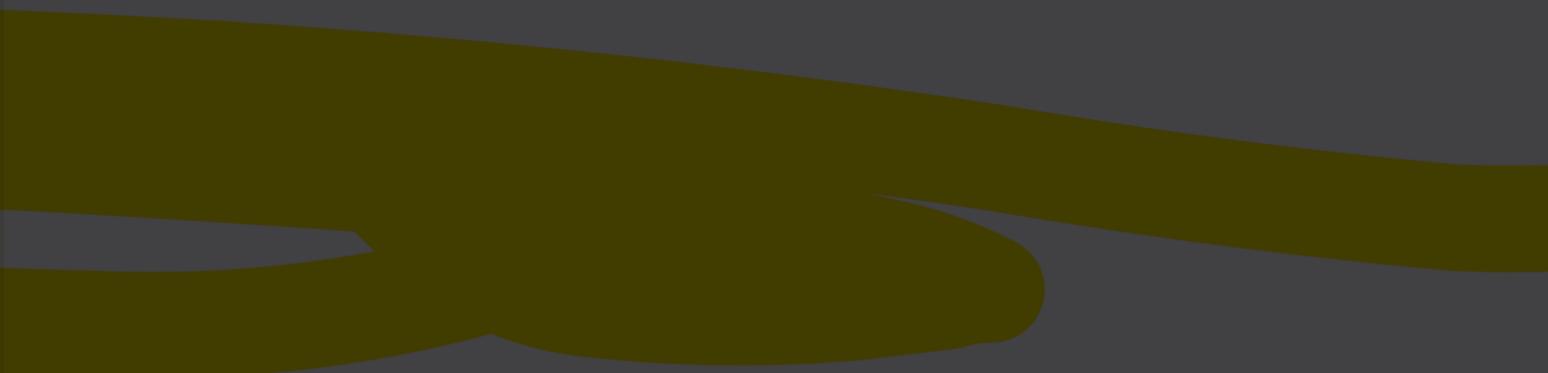
HOW FAR HAVE WE ADOPTED

RECOVERY-ORIENTED

by Helen Glover

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Although the mental health sector has much literature on moving service delivery towards recovery-oriented practice, we are still struggling to create the changes within service provision that people with a lived experience have told policy makers, funders and services, is helpful in reclaiming a life. Why is this so difficult? There are many reasons, all of them requiring us to re-examine the core principles on which we have built societal and service responses to those who experience episodes of mental ill-health.

This article attempts to highlight some of the opportunities available to re-orientate service frameworks, so that they can be fully used by people as they go about reclaiming their lives beyond the impacts of mental illness.

What does recovery mean?

One of the challenges for systemic change is the term recovery in itself. Never has such a term created so much emotion, confusion, anxiety and debate among so many people, including those with a lived experience, family members, service providers, administrators, funders and policy makers. The term has many focal points and prevents more inquiry than it allows. There is no clear direction as to what services should uphold, change or resist. It is then not surprising to hear many mental health workers claim 'we do recovery', or 'this is not new'. On examination their practices remain firmly centred in people's lives, with people heavily relying on them to access their needs. One service leader claimed that because they worked in the community and were not a clinical service, they were, therefore, recovery oriented. Unless we get beneath the term to focus more clearly on the real implications for services, recovery will risk being used in name only.

SERVICE DELIVERY?

To become clearer, we must honour the origins of recovery knowledge, the collective wisdom from those that have struggled and triumphed over the impacts of mental illness. Research and published narratives informed by lived experience include Scottish Recovery Narrative Project (2013); LeCroy and Holschuh (2012)), Deegan (2005: 29–35 and 1996: 91-97); Ridgeway (2001); Tooth (2003: 70-77); and Onken et al (2002); repeatedly attest to people's ability to self-right (Glover 2012) over adversity. Their wisdom reinforces and names the internal efforts to overcome the impacts of mental illness, efforts such as:

- Reclaiming identity.
- Taking control.
- Self direction.
- Self management.
- Taking risks.
- Making meaning.
- Finding connection and community.
- Renegotiating a life beyond illness.
- Living a life beyond service participation.

How to eradicate symptoms and attain the goals within the narratives receives little attention with more importance attributed to the people's recognition of their own self-capacity, role and mastery in creating the shifts, changes and reclaiming a sense of citizenship?

We are in an era of mental health service delivery where it appears that every clinical and non-clinical service has whitewashed programs intimating recovery, giving the impression that merely attending the programs will lead to recovery. Recovery is not a concept that can be owned and delivered by professionals, it is not a model of treatment, cannot be programmed, manufactured or even measured as a service outcome. The role of services, as Chris Munt (2009) states, is to 'have opportunities to avail myself of, in order to recognise my potential'. Services must stretch beyond eradicating and managing illness alone, to offer service environments and opportunities that are conducive for people to exercise and reclaim their capacity to self-right.

Paradigm shift in service delivery

Shifting mental health service delivery to align to a recovery orientation has been described by many as a paradigm shift, if not a revolutionary one. (See Barker: 2003, 6–102; Davidson: 2005 b, 5-26, and 2008); and Glover: 2003 and 2012.) Zucconi (2008) suggests that a genuine paradigm shift occurs only when the current way of understanding or responding to a problem is considered to be no longer useful or valid. It is difficult, if not impossible, for a new paradigm to uphold existing ways while adopting new ones.

Recovery-oriented service transformation requires us to challenge the very premise that mental health service provision has historically been organised around. If the premise underpinning service frameworks considers mental illness as permanent, life defeating, where people cannot reclaim their life from the impacts of mental illness, then services will be compelled to treat, shift, monitor, manage,

We recognise people live within social and political context where inequality exists, and therefore we work with people to advocate for social change.

We are a learning culture that works in ways that encourages and create opportunities for curiosity and innovation. We work in ways that recognise all people and situations are unique, and therefore our approach must be unique.

We understand that to discover, people may need to take risks, and have opportunities for these to be taken. We will resist limiting actions or interventions that prevent this.

We believe each person is the expert and change-agent in their own life. We work in ways to support people to act on this expertise and lead and direct the process.

We intentionally support people to live, love, work, and playing their own community and not within our service.

We will not abandon someone because of the complexity of the issues faced, and that an inability to provide useful support is a problem of the agency and not the individual.

Proactive Proposition developed by Anglicare Tasmania's Community Services Team, 2012

and ultimately adopt responsibility for fixing this as a problem. Despite naming our services as recovery-oriented, the service experience will remain one of managed care, ultimately inviting a person to remain passive at the feet of service providers.

Much of our current mental health and social policies name programs associated with recovery. Yet on closer examination some of these programs may not be aligned to a true recovery orientation, especially if programs are designed to support people for life, require increasing amounts of support, and where others are expected to manage and monitor people's lives as a core focus.

Recovery orientation

A whole-system commitment, starting with a major policy shift and program focus, is required to fully realise a recovery-oriented paradigm shift. Funded programs that dare to name a recovery focus, need to commit to their understanding of working this way, such as following the statements below, developed by a team of community services managers.

Recovery-oriented service transformation is as much an active learning process for services, as individual recovery is for people who experience mental illness. I have been privileged to contribute to, struggle with, and learn from a number of organisations, committed to transforming their service frameworks to a recovery orientation.

Service transformation towards a recovery orientation does not come easily and requires constant vigilance. Workforce training alone is not enough to sustain the required paradigm shift. It requires a multi-dimensional organisational-change approach driven by leadership, ensuring policies, processes and programs align to the service commitment. Reflective practice, supervision and learning circles are helpful in supporting this transformation.

Programs and services that are committed to supporting people to reclaim a life beyond mental illness and beyond services:

- Recognise that working from a recovery orientation can happen at all times in all places with all people and does not refer to specific therapies, models, treatments or programs.

UNLESS WE GET BENEATH THE TERM TO FOCUS ON THE REAL IMPLICATIONS FOR SERVICES, RECOVERY WILL RISK BEING USED IN NAME ONLY.

Recovery is not considered a program within itself or tacked onto to the end of 'treatment'. Services acknowledge they have the potential to both enable and disable and do not just assume their relevance in people's lives. They are vigilant and reflective as to where service structures and processes may impede a person's self-righting, determination and management.

- Recognise the person as the expert on their life and resist inhibiting this by making decisions for people. Workers collaborate with people upholding the principle 'not about me without me'. Services work to resist having conversations about people, complete planning, reviews, or even make telephone calls on behalf of a person, without the person present.

- Value the importance of forming relationships that see a person beyond the experience of illness. They are prepared to go beyond, sometimes outside the square, to meet the person where they are at and resist responding to people through an illness relationship. Working from a recovery orientation does not wait for readiness but relates as if people are

already active in trying to meet their needs. Workers adopt an adult–adult relationship and resist parent–child interactions at all times.

- Acknowledge that services hold positions of power and are mindful not to exercise this power to coerce or manipulate people to their agenda. Such services recognise that while they cannot empower people, they can disempower through their actions. They acknowledge the importance of supporting people to recognise and exercise their own power and active sense of self in creating their desired shifts.

- Develop mechanisms that invite people into an active learning recovery space. Workers recognise the right time to do for, do with, do without and when to challenge. They understand that to do for people, because it makes them feel good, is easier; and that not believing the person can accomplish things themselves, erodes opportunities for learning and mastery. They adopt the role of coach, facilitator, educator (Roberts and Wolfson: 2004, 37-48), as opposed to being a care worker.

Creating a learning environment takes precedent over providing service interventions alone.

- Believe that each of us is responsible for our lives, despite a mental illness, but at times we may need support to hold that responsibility well. Services extend their focus beyond a risk management focus to support a person to master risk-taking behaviour as a key focus when working from a recovery orientation.

- Support people to live, work, love and play in their own community and resist replacing natural relationships with illness saturated/ service relationships and environments.

- Recognise the difference between service plans and personal recovery/ life plans, with life plans belonging to the person covering many things outside the scope of mental health service provision. Services may assist the person to determine a life plan, but resist taking ownership or copies of such plans. A service plan is built from what the person has requested help to master and what a service has the resources to commit to.

- Acknowledge that they are only one of many resources available to people in their recovery processes and do not invite people to meet all their needs within their environment.

In conclusion, as I have said previously (Glover: 2012, 31:)

'To hold space for a new paradigm to fully emerge will be uncomfortable, and from time to time systems of care will lose sight of their intent and retreat to what is more familiar within the existing paradigm. To not be seduced into this lull, services will be required to be constantly vigilant about questioning and testing whether the way in which services are being provided, ultimately enables or disables people's ability to reclaim a full life outside of the context of illness and service responses.'

THE PEER WORKFORCE – HOPE AND CONTAGIOUS RECOVERY

By Keith Mahar

Peer Support Worker, Mental Health Advocate, Activist and Social Worker

Seventeen years ago, I came close to ending my own life in Toronto at the age of 33. I was experiencing symptoms of major depression and had recently been diagnosed with bipolar disorder. I remember being curled in the foetal position on my bedroom floor in absolute despair, tears rolling across my face. Everything felt utterly hopeless. In this state of mind, I was absolutely convinced that I was never going to work or enjoy life again.

I was wrong.

At the end of 2007, I conducted a presentation on my experience of severe mental illness and recovery at the World Psychiatric Association International Congress in Melbourne.

Today, I am a mental health advocate, political activist and qualified social worker. For the last four years I have been employed as a peer support worker by Woden Community Service in the Personal Helpers and Mentors Program (PHaMs), a recovery-oriented psychosocial outreach support program funded by the Australian Government. To be honest, I am enjoying a more satisfying and productive life than ever before.

There is a certain irony respecting my career choice. When I first emigrated to Australia in 2001 with my Canberra-born partner Gail, I originally wanted to hide my experience of anxiety, depression and psychosis from as many people as possible. However, my plans fundamentally changed after coming across Mental Illness Education ACT and learning that sharing personal stories is an effective way to reduce stigma in the community and help others with mental health issues. Coming out of the psychiatric closet as a volunteer educator with the organisation proved to be empowering. It also gave me the opportunity to get to know a number of other people diagnosed with mental illness and hear their stories. My understanding of mental illness and my perception of myself changed in the process.

The Mental Health Community Coalition of the ACT says that 'a peer recovery worker is someone who draws on and shares his or her own lived experience of mental illness and recovery to inspire hope and support others in their recovery journey'. This acknowledges the importance of hope and peer support, which are identified as two of the 10 Fundamental Components of Recovery in the 2006 National Consensus Statement on Mental Health Recovery, issued by the Substance Abuse and Mental Health Services Administration in the United States.

Hope is described in that consensus statement as 'the catalyst of the recovery process' and in the vernacular is defined as 'a feeling of desire for something and confidence in the possibility of its fulfilment'.

The transformative influence of hope and peer support is not an abstract concept to me, and I strongly advocate resources being targeted to further develop the peer workforce in mental health.

In a society where the dominant narrative of mental illness is distorted and overwhelmingly negative, raising awareness of recovery to individuals experiencing mental health issues and emotional distress is critically important for better outcomes. Studies clearly indicate that the news and entertainment media are generally not good at generating hope in this area. Queen's University Professor Heather Stuart, who is also Bell Canada Mental Health and Anti-Stigma Research Chair, has said, 'the media create and perpetuate mental health stigma and discrimination through repeated use of negative and inaccurate images' and this

results in significant negative consequences to individuals with mental health issues, including to their 'self-esteem, help-seeking behaviours, medication adherence and overall recovery' (2006: 99-106).

Lived experience counts

As a result, people with a lived experience of mental illness and recovery are in a unique position to inspire hope by sharing aspects of their own stories, helping others in their recovery process. I like to describe this dynamic as 'contagious recovery'.

According to a literature review by the University of Nottingham's Associate Professor Julie Repper and Research Assistant Tim Carter, a broad range of studies appears to suggest that peer support workers are able to increase self-efficacy and 'promote hope and belief in the possibility of recovery' more effectively than professionally qualified workers (2011: 392-411). This seems logical and is compatible with the human learning process offered by one of the most influential psychologists in history, Albert Bandura. In his work on self-efficacy, the David Starr Jordan Professor Emeritus of Social Science in Psychology at Stanford University writes: 'Unless people believe they can produce desired effects by their activities, they have little incentive to undertake activities or to persevere in the face of difficulties' (2010: 1–3). Bandura contends that 'social models' serve as a highly valuable source of information that can increase the self-efficacy of others. 'Seeing people similar to oneself succeed by perseverant effort raises observers' beliefs in their own capabilities,' he states.

While lived experience is the foundation for peer support work, individuals employed in this role require a range of skills and knowledge. As a result, it is necessary for jurisdictions and organisations to specifically plan how to develop this specialist workforce. For example, the Mental Health Community Coalition of the ACT has formally recognised the valuable role of peer workers and is developing a framework to effectively develop and support this workforce. As part of this commitment, a Certificate IV in Mental Health Peer Support has been developed and pilot course trialled in the territory.

I encourage the Mental Health Council of Australia to progress the further development of the peer workforce nationally, in part by informing governments and organisations of the benefits of peer support and advocating for resources in this area.

In addition, it would be beneficial to help peer support workers develop facilitation skills. There are a number of excellent opportunities for peer-led groups, including the following, which I openly admit to being associated with in one way or another. These are:

- Coming Out Proud: a three-session group program focusing on the issue of disclosure for people with mental health issues. (For the manual and workbook, go to the resource page from the National Consortium on Stigma and Empowerment at www. stigmaandempowerment. org).
- Ending Self Stigma: a nine-session small group course to help people reduce and avoid internalised stigma related to mental health problems. (For more information, contact Alicia Lucksted, University of Maryland Medical School at aluckste@ psych.umaryland.edu).

- PeerZone: 'a series of three-hour, peer-led workshops in mental health and addiction where people explore recovery and whole of life wellbeing' (as explained at www. peerzone.info).

Clearly, peer support workers do not have a monopoly on inspiring hope for people experiencing mental health problems. It is possible for every Australian to help by raising awareness of the reality of recovery. One way to do this is by sharing the personal stories of individuals whose experiences are in the public domain, such as Janet Meagher (see Janet Meagher's article), Ron Coleman, Dr Daniel Fisher and Patricia Deegan. All were diagnosed with schizophrenia. In addition, Mental Illness Education ACT's website includes stories at www. mieact.org.au.

One key feature of peer support is reciprocity. Although I share aspects of my lived experience to support others in their recovery, inevitably people I support end up inspiring me.

SHARING PERSONAL STORIES IS AN EFFECTIVE WAY TO REDUCE STIGMA IN THE COMMUNITY AND HELP OTHERS WITH MENTAL HEALTH ISSUES.

FUNDED PSYCHOLOGICAL TREATMENT *in* PRIMARY CARE

by Prof Lyn Littlefield OAM & Jill Giese

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Over the last decade, mental health reforms in primary care have enabled people with high prevalence mood and anxiety disorders to access funded psychological treatment. The huge community uptake of psychology services under these reforms has indicated a previously unmet need and has had a substantial impact on mental health within the community.

Better Access to Mental Health Care (Better Access), introduced by the Australian Government in 2006, has been the major program that has increased community access to psychological treatment for mental health disorders. The precursor program, the 2001 Better Outcomes in Mental Health Care (Better Outcomes), showed the success of providing funded psychological treatment in primary care settings.

Better Outcomes provided access to psychological services for people with high prevalence mental health disorders funded through the Australia-wide network of Divisions of General Practice (DGPs). The program enabled general practitioners to refer individuals to psychologists and appropriately-credentialed social workers and occupational therapists for evidence-based psychological treatment. Evaluation of the program showed a positive impact on consumers' functioning, symptom severity and/or quality of life (Morley et al, 2007). As a result of this success, community demand for psychological services increasingly exceeded the available funding provided to DGPs under the program.

Mental health in the 21st century

During the early to mid-2000s, the effectiveness of the Better Outcomes program increased interest in psychological treatment for high prevalence mental health disorders in primary care. Around this time the release of a number of important reports also significantly raised the profile of mental health in Australia, including the Not for Service report (Mental Health Council of Australia: 2005) and the report from the Senate inquiry into the nation's mental health system, A national approach to mental health – from crisis to community (Commonwealth of Australia, 2006). In 2006, the Productivity Commission's report Australia's Health Workforce was released, identifying major community healthcare access problems and recommending an extension of Medicare rebates to make better use of non-medical health professionals in delivering health services (Productivity Commission: 2005). The publication of these influential reports led to the Council of Australian Governments (COAG) identifying mental health as an issue of national significance in 2006, and the Australian Government announcing a $1.9 billion increase in funding for the mental health system.

Introducing Better Access

As a result of this new level of interest in the mental health needs of the community alongside the success of Better Outcomes, the Australian Government introduced mental health reforms in November 2006 under Better Access that included psychological services under Australia's Medicare system for the first time. Better Access was based on Better Outcomes, with services targeted to mental health consumers on referral from a medical practitioner for evidence-based psychological treatments delivered by psychologists and eligible social workers and occupational therapists. Mental health disorders that can be treated under Better Access cover clinically

diagnosable disorders based on the ICD-10 Primary Health Care version (World Health Organization: 2004).

When Better Access was first introduced, consumers were eligible to receive up to 12 individual Medicare-funded psychological services per calendar year. The referring medical practitioner could also consider exceptional circumstances in which the consumer required an additional six services, for a maximum of 18 individual services per consumer per calendar year. Consumers were also eligible to receive 12 group Medicare-funded psychological services per calendar year for treatment in a group. Funding cuts in 2013 have meant that a consumer can now only receive a maximum of 10 psychological services per calendar year under Better Access with no provision for exceptional circumstances.

Medicare-funded psychological services

There has been a huge community uptake of Medicare items for psychological treatment since Better Access was introduced in November 2006, with psychologists providing the vast majority of the services (over three million services per annum over the last three years (Medicare Australia: 2013). Millions of consumers have benefited from Medicare-funded access to psychological treatment since its introduction.

The Australian Government's 2011 evaluation of the Medicare-funded mental health program showed very favourable results (Pirkis et al: 2011). The evaluation confirmed consumers receiving services were those with moderate or severe symptoms and debilitating levels of distress mostly associated with anxiety and depressive disorders. With the psychological treatment, these moderate or severe levels of depression, anxiety and stress decreased to normal or mild

levels of these symptoms. Better Access was also found to be a cost-effective way of delivering mental health care.

The evaluation of Better Access also showed that it was reaching large numbers of people who had not accessed mental healthcare in the past. Modelling and surveys quoted in the evaluation report demonstrated that prior to Better Access, 35% of people with mental health disorders in Australia sought treatment and that this previously stable rate had increased to 46% since the introduction of the Medicare-funded psychological services (Pirkis et al: 2011).

The availability of psychological services through Australia's Medicare scheme has possibly contributed to a destigmatisation of help-seeking for mental health problems. The inclusion of mental health psychological services under Medicare has begun to promote mental health interventions to a similar standing as those for physical health services, which is an extremely important development.

The success of Better Access in providing effective, cost-efficient and accessible psychological services for Australians with common mental health disorders is clear. However, this effectiveness has required increased mental health funding and in 2013 under fiscal constraints the Australian Government cut spending by reducing the number of allowable services per consumer. Based on the Government's own figures, these cuts to psychological treatment services affect 87,000 Better Access consumers per annum (including 33,000 per annum who would have required additional psychological treatment under exceptional circumstances), who are no longer able to access the appropriate length of effective and cost-effective psychological treatment.

Conclusion

The Australian Government's mental health reforms over the last decade, and in particular the introduction of Better Access, have enabled millions of Australians with common mental disorders to access affordable, effective and cost-efficient psychological interventions in a non-stigmatising way through the nation's universal Medicare health scheme. This has been a huge advance for mental health within the Australian community and it is imperative that government funding continues to be provided to maintain these gains.

THE INCLUSION OF MENTAL HEALTH PSYCHOLOGICAL SERVICES UNDER MEDICARE HAS BEGUN TO PROMOTE MENTAL HEALTH INTERVENTIONS TO A SIMILAR STANDING AS THOSE FOR PHYSICAL HEALTH SERVICES, WHICH IS AN EXTREMELY IMPORTANT DEVELOPMENT.

FINDING A SUSTAINABLE FUNDING MODEL

by David Meldrum
Mental Illness Fellowship of Australia

Sources of funding for people affected by mental illness, including families and carers, were described in Australia in the May 2013 Medibank publication, The Case for Mental Health Reform in Australia: a Review of Expenditure and System Design. The report highlights a major disparity between the Australian Institute of Health and Welfare (AIHW) estimate of $6.3 billion per annum, based on the costs of specialised mental health services, Medical Benefit and Pharmaceutical Benefit Schemes, and real world whole-of-system costs estimated to be $28.6 billion. While the report considered funding in several areas of government that support people living with mental illness, we would suggest there were still other costs not included.

Neither the current public and policy based discussion, nor the literature have addressed the need for Australia to adopt a model that sustainably funds the overall support required by people affected by mental illness and the people who care for them. There are some models across federal and state governments, but in general each acts in isolation, addressing one or more aspects of support; there is no whole-person model or even whole-of-life model.

The 80:20 principle

It is now widely accepted that about 20% of the necessary overall response to mental illness is of a mental health clinical nature, and the other 80% should be available through the physical health and recovery sectors plus a variety of housing, education, employment, family and other supports.

The WHO (World Health Organization) Pyramid of Optimal Mix of Services and our best current knowledge about recovery from mental illness tell us that long-term support should roughly align with this 80:20 principle, so that mental health clinical services are not left to be the main basis of ongoing support, and that people affected by mental illness are offered the same broader opportunities as those people with other types of need, from experts in those fields.

This is particularly true of other parts of the health system. People with severe and persistent mental illness experience extremely poor physical health compared to the general population, but lack equitable access to key services addressing such issues as obesity, tobacco use, diabetes, respiratory health and cardiovascular diseases.

In 2001 the Western Australian report, Duty to Care —Physical illness in people with mental illness, stated that people affected by mental illness had higher death rates than others in the community including in cancer, stroke and respiratory disease and there is a growing interest in the poor physical health of people with severe mental illness, and the reduced life expectancy they can expect of up to 25 years. Sustainable models to achieve better outcomes for people with mental illness must include the additional costs of providing these health services, along with other costs of re-alignment in housing, education, employment, family support and other service systems.

Several commentators have quoted that mental health receives about 8% of the health budget, as the Royal Australian and New Zealand College of Psychiatrists indicates in its 2010 Mental Health Deserves a Better Deal blueprint for improving the lives of people affected by mental illness. The AIHW estimated in 2007 the total burden of disease for people with mental illness was 13%. The need for increased investment is obvious, but it is important to remember that much of this should not be in the mental health sector of health, and that this figure does not include any non-health costs.

Better understanding and funding

The current development of the National Mental Health Services Planning Framework will lead to a comprehensive map of the health sector service types that a person living with mental illness, and those who care about them, might require across a lifetime. The exercise has highlighted those services delivered in the hospital or outpatient environment and those outside of this, in the predominantly non-government recovery sector. Most importantly, the framework identifies the level of skill and training required to ensure adequate numbers of well-prepared workers to offer this support, including the role of peers, which will lead to a better understanding of the key driver of cost — that is, the workforce.

The FaHCSIA (Families, Housing, Community Services and Indigenous Affairs) funded Peer Helpers and Mentors Service (PHaMS) is a good example of a service that seeks to support people as they set and attain their personal recovery goals encompassing social as well as education and employment outcomes and to be as active in their communities as they wish. Uniquely, the program does not require a clinical standard of diagnosis to enter, and in fact works with people that had previously been considered hard to reach due to their mental illness, their living conditions or their distrust of conventional clinical care. Its costs are modest (about $8000 per participant) and its outcomes appear to deliver good value for money with people with moderate to severe mental illness.

For people with severe and persistent mental illness, some relief will arrive as the National Disability Insurance Scheme — now called DisabilityCare Australia (DCA) — is gradually rolled out across the country over the next several years. This will be restricted to non-health matters, but will be most welcome nonetheless. However, the emerging eligibility criteria suggest that only those with the most severe and persistent mental illnesses will have access to the scheme, which is some fraction of the total need. For people who are not eligible, the sources of assistance will be as complex and unsustainable as ever, in some cases almost impossible to access given regional inequities, and major gaps in service, especially regarding the largely unmet needs of minority groups.

A major new service, Partners in Recovery (PIR), is about to begin operating across Australia. Many regions, delineated by the Medicare Local boundaries, have formed consortia of agencies to assist the people most in need of support when living with a severe and persistent mental illness, with complex multi-agency needs. Rather than replacing existing services, PIR will focus on breakthrough collaborations across all the sectors that bear on each individual's chances of building a pathway to a better quality of life—recovery in that sense — including clinical mental health and physical health, family support, welfare, justice, education, employment and others as required.

The total costs attributable to each individual's package of services will be difficult to track across so many agencies, but capturing this data from PIR will be an important aspect of working toward a better understanding of the overall resources required.

Crisis, coordination and navigation

The state mental health systems are continually characterised as overburdened in supporting people with severe and persistent mental illness. State systems and the hospital sector tend to be the resources sought first at times of intense need, when people

with severe and persistent mental illness are at high risk. All sectors, including a well-resourced community recovery sector, must contribute to supporting people during periods of acute illness, and in finding the way back to a recovery-oriented life. The National Mental Health Services Planning Framework has grappled with these issues to ensure that, despite acute illness, choices can be offered to reduce the need for inpatient and/or intensive clinical supervision. Their work is beginning to map out those choices, and their likely costs.

Research and prevention

These examples of on-the-ground practical support for adults with moderate to severe mental illness do not address the need for evidence-based good practice, and prevention strategies that may in time reduce the number of people who are severely disabled by mental illness, both initially, and through the course of their life. The sector requires a greater emphasis on researching prevention strategies that will limit the downstream effects of mental illness but also show a commitment to more thorough investigation of what works now.

Conclusion

Working towards a sustainable response to mental illness in Australia involves two main elements:

- Understanding the components that make up the whole range of supports required.
- Understanding their costs.

Some of that costing can be done well now; some needs a much better coordinated collection of relevant data.

Key attributes of a sustainable system that can begin to understand its costs will be:

- Accessible and well-resourced crisis services that respond to urgent mental and physical health needs.
- Intensive resourcing of coordination strategies like pir, to join up the dots for the highest-need individuals, and lead to a better understanding of the total cost of support required.
- Further development of the publicly-funded recovery sector, with a remit to work with moderate to severe mental illness as well as severe and persistent mental illness requiring complex multi-agency responses.
- Full inclusion of people with mental illness, especially severe and persistent mental illness, in all the targeted resources aimed at high need/risk

groups for all relevant health, welfare, social services, employment, justice and education services.
- Evidence-based good practice and prevention strategies to reduce the future burden on individuals, families and the community.

The mental health sector, the general health sector and the community care and research communities all appear to agree that people affected by mental illness, particularly those experiencing severe and persistent mental illness, need more support than that currently available. Several new initiatives, including PIR and DCA, go some way to ensuring a more equitable distribution of health and other dollars. However, advocates for people affected by mental illness must continue to highlight the much broader funding and policy priorities that still leave in place widespread barriers to attaining good mental and physical health. Mental health dollars will never be more than a partial response to the need.

We know that many people with mental illness and/or emotional distress are the people most likely to fall between the gaps in Australia's complex human service systems. People with intricate, diverse health and social problems, including high levels of psychosocial disability, can become more disadvantaged and even traumatised and re-traumatised by the very treatment, rehabilitation and support services intended to help them recover.

It is clear that the increasingly complex and disjointed mix of health and community services seeking to respond to the needs of people with mental illness or distress is poorly coordinated. Consumers and carers often describe how difficult it is to access the care that they need and consistently navigate the mental health system when they need it (Durbin, J, Goering, P, Streiner, DL and Pink, G: 2004, 279). They report that they often feel overwhelmed and disempowered and that services are 'fragmented' (Ehrlich, C E; Kendall, E; Muenchberger, H and Armstrong, K: 2009, 619-627; Bodenheimer, T: 2008, 1064-71).

One consumer said, 'The agencies are out there — you just wouldn't believe how many are out there — but they are not working together! There is no hub for the spokes of the wheel' (MHCC: 2012, 16).

A service provider said, 'I think there is a lot of skill involved in care coordination. I think it is sort of one of those aerosol [throw out] terms that everyone is expected to know what it means and know how it is done but just to work alone, that takes skill, but to work with other people takes a lot of skill and to work with different people,

different organisations with philosophies, different backgrounds …' (MHCC: 2012, 16 Interviewee 9).

In discussing the four priority areas for action for achieving 'a contributing life', the National Mental Health Commission (NMHC) states that: 'we need to see where

the gaps are … to see mental health as a coordinated and integrated system' (NHMC: 2012, 14). In considering 'What we know' about achieving a contributing life, the Commission goes on to say that it: … 'believes that to ensure effective support, care and treatment for people

living with a mental health difficulty, there needs to be an integrated and coordinated mental health service system in place' (2012: 81).

The revised National Statement on Mental Health Rights and Responsibilities states that service providers

should 'expect that social, health and mental health services will be integrated and coordinated while retaining their specialised focus, identity and funding' (2012, p21). However, this is far from what is happening (Commonwealth of Australia: 2012).

PRACTICE SKILLS FOR COORDINATED + INTEGRATED SERVICES

by Jenna Bateman
Chief Executive Officer

& Tina Smith
Senior Policy Officer

MENTAL HEALTH COORDINATING COUNCIL

The mental health sector in Australia consists of public/government, private for-profit and not-for-profit non-government community-managed organisation (NGO/CMO) service providers with multiple layers of Commonwealth and state/territory government policy, planning, and funding levers. The emergence in mental health service delivery of the new primary healthcare Medicare Locals, including as population health planners, will also bring an additional — but much needed— layer. This is the result of past and current ad hoc mental health planning despite 20 years of a national mental health strategy, and of a failure to effectively support the implementation of policy to practice.

The diversity of workers in public, private and community sectors across primary, secondary and tertiary levels of care is a challenge in itself. Each of these workers has been trained in different disciplines often with opposing philosophies and practice methods (Norman, I J and Peck, E: 1999, 217-230; National Health Workforce Planning Research Collaboration: 2011). The resulting knowledge, skills and attitudes are so different their impact on practice can lead to conflict and other barriers to collaborative care.

Contemporary concepts of coordinated and integrated mental healthcare and related actions were first introduced in the Council of Australian Government's National Action Plan for Mental Health 2006-11, specifically, Strategic area 5 — Care coordination (COAG: 2006) and Fourth National Mental Health Plan 2009-14, Priority area 3 - Service access, coordination and continuity of care (Commonwealth of Australia: 2009).

Unfunded, they are also still largely unrealised. While the changes and activities to coordinate are now better understood at a systems and structural level, the practice skills for such coordination are not.

In 2012, the Mental Health Coordinating Council (MHCC) researched how to better understand service fragmentation from the consumers, carers and service providers' point of view. This research focused on the workforce competencies, skills and attitudes to support both client self-directed care coordination and work coordinated with other service providers. Through this research, and also an earlier literature review by the MHCC, it is clear that the structural aspects of integrated service delivery (i.e. Service Agreements, Memorandum of Understanding and so on) are better understood than practice skills and the workforce developments required to achieve those skills (MHCC: 2011).

'A common assumption is that workers already have the skills needed to deliver the specified outcomes, and there is a lack of understanding of the support and training workers require', the Australian Health Workforce Advisory Committee (2005) has argued.

In addition to identifying the skills, knowledge and attitudes for good service and care coordination, MHCC's research also identified important reasons why such attempts have often failed to better support consumers and carers. Interviewees identified:

· Lack of recognition that service coordination takes resources, time and skill.
· Job descriptions and funding formulas failing to recognise that service coordination is a practice.

· Too large caseloads and lack of clarity about who is responsible for coordinating care.
· Ineffective relationships between community, hospital and primary healthcare providers including not speaking the same language and not appreciating what other services contribute.

· Obstructive approaches to confidentiality and privacy specific to the mental health sector.
· Misconceptions about the nature of recovery and the principles of self-directed care (MHCC: 2012, 45).

It is increasingly evident that higher education providers – both university and vocational

education and training – must embed and teach not just the skills required for recovery-oriented and trauma-informed practice but also those for effective service coordination. Professional development opportunities within – and across – all mental health settings and work roles, should be informed by the competencies and capabilities required for coordinated delivery of human services.

It must, however, be reiterated that while worker education and training is important to improving delivery of services, it is only one level of the system and in itself will not be

enough to change the way they operate (Battersby, Lawn, Wells, Morris, Wong, Lindner, Mathews, Reed and Litt: 2008). There also need to be changes at systems, organisational and individual levels (Productivity Commission: 2005; Battersby et al: 2008); these factors will impact how training can go on to become practice (Battersby: 2008).

The government's 2011 commitment to fund the new national Partners in Recovery (PIR) mental healthcare coordination initiative is commendable and programs commence in July this year. The planned PIR evaluation strategy provides an important opportunity to explore and further develop understanding of the practice skills needed for effective service coordination. Likewise, DisabilityCare Australia will open the way to explore the interface between complex health and psychosocial disability programs and services that encourage the consumer to navigate and coordinate their service needs and options.

Mental health (and other complex health and social issues, including substance misuse) service delivery sits squarely at the interface of the health and disability and community service sectors. Failure to address the enormous and growing gap between these sectors will result in our most vulnerable Australians continuing to fall between the cracks. The development of the respective health and community and disability workforces needs to follow the same direction; including better recognition and focus on the practice skills of individual workers and teams to more effectively coordinate services across service settings.

IT IS INCREASINGLY EVIDENT THAT HIGHER EDUCATION PROVIDERS IN BOTH UNIVERSITY AND VOCATIONAL EDUCATION AND TRAINING SETTINGS MUST EMBED AND TEACH NOT JUST THE SKILLS REQUIRED FOR RECOVERY-ORIENTED AND TRAUMA-INFORMED PRACTICE BUT ALSO THOSE FOR EFFECTIVE SERVICE COORDINATION.

STRENGTHENING THE INFORMAL COMMUNITY CARE NETWORK

By Dawn O'Neil AO

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specialising in governance, strategic
and organisational development
and change management

AN UNWELCOMING OR HIGHLY BUREAUCRATIC FIRST ENCOUNTER WITH FORMAL SERVICES MAY DISCOURAGE FAMILIES FROM FURTHER ATTEMPTS, LEAVING THEM ISOLATED AND VULNERABLE.

PEOPLE WITH A MENTAL ILLNESS OR SUICIDAL CRISIS DO NOT LIVE IN VACUUMS. THEY ARE USUALLY PART OF FAMILIES, FRIENDSHIP NETWORKS AND COMMUNITIES AND THESE CAN BE ASTONISHINGLY HELPFUL AND OFTEN CRUCIAL TO RECOVERY.

Yet, policy makers have long underestimated the work of informal and community-based mental health and wellbeing activities. Further, service design can overlook the seemingly obvious task of considering what is needed for good mental health.

Although this is beginning to shift, formal recognition in government policy remains limited and there is minimal investment in community engagement and informal community care compared to the billions of dollars invested in direct services, such as hospitals and acute care.

We speak of the mental health system but no coherent system is in place. It is noted that the National Mental Health Commission's A Contributing Life: the 2012 National Report Card, does not talk about the mental health system. Yet there is growing recognition that deficiencies in system design are critical, especially as there has been little serious work to remedy this.

In addition, it is clear that national and state and territory policies need a clearer understanding of how the informal and formal sectors can more effectively cooperate. This requires recognising the crucial roles families, friends and community organisations play and what further investment at these grassroots levels could achieve, rather than implying services alone can meet Australia's growing mental health needs.

For example, we know that by changing thinking and behaviour (e.g. Cognitive Behavioural Therapy) we can greatly improve mental health and wellbeing and prevent mental illness. Yet these therapies often remain available only to those with the funds and networks to access them. Much could be done to make this knowledge more available, through investment in new technologies or by democratising the science, and no longer restricting it to professionals. These skills should be practised and shared in the community.

Despite knowing that trauma, abuse and neglect, particularly in the early years, can contribute to later mental illness, most investment has gone into treatment, rather than prevention or early intervention. We spend more than $28 billion in direct health and non-health expenditure to support people with mental illnesses. This does not include indirect costs, such as lost productivity, a very real burden that many businesses are just beginning to come to grips with. This staggering figure is unlikely to diminish without drastic change.

Shift in spending required

If Australia were to spend just one of those billions on building on the strengths of families, neighbourhoods and communities, much progress could be made towards meeting a widespread need. Those working in the informal sector know much more investment in community-based care, in addition to mental health and wellbeing services, is needed.

There is much untapped potential. Families often wish to contribute, but either feel helpless or that the system does not allow them a role and sometimes shuts them out deliberately. An unwelcoming or highly bureaucratic first encounter with formal services may discourage families from further attempts, leaving them isolated and vulnerable.

This pattern is repeated for community groups, which are often extensions of family support networks, but are not well integrated into a complicated sector that is dismissive of informal care.

In 2009 the World Health Organization (WHO) produced as a part of a mental health and service

THE GAP IN OUR SERVICE DELIVERY SYSTEM, WHERE THE BURDEN OF CARE MOST HEAVILY FALLS, IS ACROSS THE ENTIRE LOWER PORTION OF THE SERVICE PYRAMID, WHERE HUNDREDS OF THOUSANDS OF AUSTRALIANS STRUGGLE TO CARE FOR THEMSELVES AND EACH OTHER, WITHOUT FORMAL SUPPORT.

guidance package a document entitled Improving Health Systems and Services for Mental Health (WHO: 2009). It defined self-care and informal community care as parts of the services system:

'Most people manage their mental health problems themselves, or with support from family or friends. Self-care is thus the base of the service pyramid, upon which all other care is based. Self-care is most effective when it is supported by formal health services. The formal sector has an essential role in providing information such as how to deal more effectively with stress, the importance of physical activity in staying mentally well, effective ways of dealing with relationships and conflict management, and the dangers of hazardous alcohol and drug use. Self-care should be facilitated through all services and at all levels of the WHO service pyramid.'

Australian policy is largely silent on what an optimal service mix should look like. The National Mental Health Commission adapted the WHO framework to combine self-care and informal family and community care, while spreading community mental health services among primary care and family counselling and support services, as well as within the informal group. This, however, does not truly

clarify a useful service mix and the role of self-care, informal supports and other community wellbeing efforts. A more serious analyis of system design is needed.

Most mental health and suicide prevention policy over the past decade or more has referenced the Mrazek and Haggerty spectrum of mental health interventions, but this has not been translated into any kind of service system design. In recent years there has been a shift in understanding about the importance of community-based care and in government policy and spending towards youth, with the establishment of the headspace consortiums. These resulted from Dr Patrick McGorry's work (see his chapter in the book), among other place-based policy and funding changes, such as the establishment of Medicare Locals.

There is also general agreement by the sector and government that acute care investment is unsustainable. This alone necessitates a shift towards the community, though what such a service system should look like has not been articulated or agreed on.

Australia's mental health, suicide prevention and other support services have emerged in an environment of funding silos and in the absence of a clearly articulated service design. Therefore, there is no clear logic or basis for estimating the size of each service response and the required scale.

To meet immediate and future needs and encourage policy shifts and consequent funding decisions, we must rethink an optimal system design for Australia.

In October 2012, the first ever Council of Non-Government Organisations on Mental Health (CONGO) brought together organisations in the mental health and associated sectors to pursue shared outcomes and system-wide improvement. A range of key agreements were reached and summarised below in the briefing paper sent to all participants in December 2012:
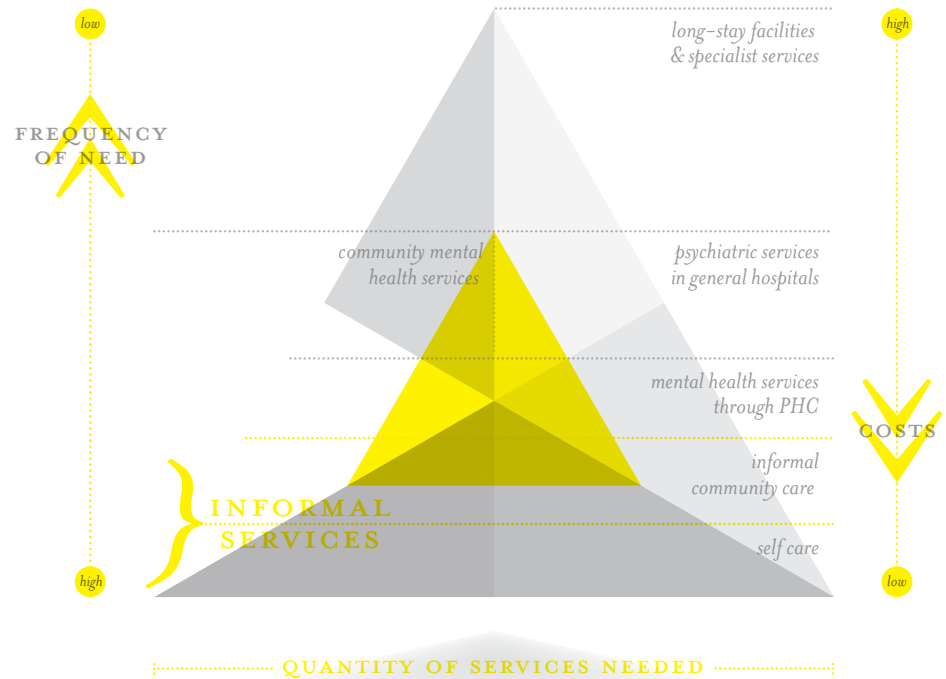
'The gathering committed to establishing a national vision for Australia to lead the world in mental health by 2022, so that within 10 years Australia is acknowledged internationally as a world leader in mental health services, programs, and outcomes.

CONGO members overwhelmingly agree that gains in new spending and the re-prioritisation of mental health by governments has not, as yet, resulted in lasting improvements for people affected by mental illness or their carers. The change is still too slow and the demand for services still significantly more than we can provide for people who need them. Fragmentation and a lack of coordination across the many systems that people need are uppermost in the range of factors impeding potential gains in new spending and slowing momentum towards successful outcomes for people with lived experience.

A lack of coordination between NGOs, businesses, governments and within jurisdictions is leading to fragmented decision making and lack of clarity regarding respective roles and responsibilities. As a result, service delivery remains uneven and inequitably spread across Australia. In this environment, the need to address socioeconomic factors in health and social care is an aspiration as yet unrealized' (CONGO: 2012, 11).

In Australia, the vast majority of our national spend on mental health is invested in the specialist psychiatric and inpatient services that sit at the top of our pyramidal system. Yet we know that only a fraction of people who experience mental illness ever use these services.

Current gap in Australian service design & policy

FREQUENCY
OF NEED

low

high

COSTS

high

low

long-stay facilities
& specialist services

community mental
health services

psychiatric services
in general hospitals

mental health services
through PHC

informal
community care

INFORMAL
SERVICES

self care

QUANTITY OF SERVICES NEEDED

Most, if they receive any specialist support at all, will do so through the doors of general practice, or else find connections with those under-funded community organisations who struggle to meet demand across the middle of the service pyramid.

The gap in our service delivery system, where the burden of care most heavily falls, is across the entire lower portion of the service pyramid, where hundreds of thousands of Australians struggle to care for themselves and each other, without formal support. There are almost no resources being invested in this informal system of care. This disparity is shown in the accompanying diagrams.

The challenge ahead is to shift our efforts to where services and supports are most needed and for better collaboration between informal and formal activities to maximise our current and future effectiveness. Poor mental health and wellbeing in an increasingly complex world is going to place enormous demands on our current public health systems if we do not have a clear system design in place, which draws on all its resources.

01
02
03
04
05

Derived from the world health organization's *the optimal mix of services pyramid framework* developed to provide guidance to countries on how to organise services for mental health.

QUANTITY OF SERVICES NEEDED

01 forensic / intensive care

02 specialist services

03 community mental health services GPs, primary care, early intervention

04 professional non-clinical care, counselling personal support, housing support, family support

05 ourselves, family, friends, community employers, co-workers, promotion & prevention

STIGMA/ DISCRIMINATION /AWARENESS

by Jack Heath

Chief Executive Officer, SANE Australia

& Kate Carnell AO

Chief Executive Officer, beyondblue

'The stigma of mental illness is, in some ways, worse than the illness itself. Unless the stigma can be removed to such a degree that it does not become a barrier to acknowledgement, treatment and hope for the future, the reduction of [the impact of] some mental illnesses will be nothing but a pipe dream.'

People living with a mental illness

Stigma and discrimination are major barriers to recovery for many people affected by mental illness and their carers.

The relationship between the two is close: stigma is a primary cause of discrimination. It is the perception that a group of people is less worthy of respect than others and shares characteristics with other forms of prejudice, such as racism and homophobia.

Stigma against people with a mental illness may involve inaccurate and hurtful representations — for example, being perceived as violent, comical or incompetent, and being feared or ridiculed. It may be associated with social or cultural stereotypes; it may also be unintentional and result from a genuine lack of understanding about mental illness.

Inaccurate and negative attitudes and discriminatory behaviours towards people affected by mental illness inhibit social inclusion. As the person living with a mental illness suggests, many people report that the experiences of stigma and discrimination associated with mental illness can be as bad as, or worse than, the symptoms of the illnesses themselves.

Stigmatising attitudes cross all facets of life — people with a mental illness, and their carers, report that stigma can prevent them using health services; limit their access to employment, housing and insurance; and impact on personal relationships. There are many different types of stigma, which include:

- Personal stigma — a person's stigmatising attitudes and beliefs about other people ('people with depression should snap out of it').
- Perceived stigma — a person's beliefs about the negative and stigmatising views that other people hold ('most people believe that a person with depression should snap out of it').
- Self-stigma — the stigmatising views that individuals hold about themselves ('I should be able to snap out of my depression').
- Structural stigma — the policies of private and governmental institutions that restrict the opportunities of people with mental illness ('mental health services and research don't deserve as much funding as other health problems').

Efforts to reduce the stigma and discrimination affecting people with a mental illness should support broader anti-discrimination strategies. This is an important part of acknowledging and responding to the complexity of stigma and discrimination, and the impact that multiple forms of stigma and discrimination can have on people's mental health and wellbeing.

Working to reduce stigma

Evidence suggests there are two major strategies to reduce stigma:

- Educational approach, which provides people with information resources that challenges inaccurate stereotypes and replaces them with factual information.
- Contact-based approach, which facilitates personal contact with people with a mental illness.

Community attitudes towards people affected by mental illness have certainly improved in recent years. The work of beyondblue has changed social attitudes towards depression, and encouraged high-profile people with depression to speak publicly about their condition and how they manage it. This has contributed to a growing normalisation of depression as part of the everyday human experience, rather than something which is kept quiet and is seen as shameful.

Portrayal of mental illness in the media also plays a major role in determining public attitudes towards mental illness. Therefore, to influence public attitudes it is important to improve the way the issue is reported and represented in the media. The Australian Government's Mindframe initiative has a comprehensive approach to this challenge. The SANE Media Centre and StigmaWatch program are integral to it, taking a positive approach to educating and working with the media — filmmakers, scriptwriters, TV, radio and online producers/journalists, as well as staff working on magazines and newspapers. Much of SANE's work in this area is conducted behind the scenes, ensuring that stigmatising attitudes do not appear in the media in the first place.

Limitations of legislation

Direct discrimination towards an individual because that person has a disability (including mental illness) is unlawful under the Disability Discrimination Act 1992. This relates to the equal access of provision of services such as employment and education. In employment especially, many people report they have been treated unfairly and even sacked or forced to resign after an episode of mental illness.

However, widespread lack of knowledge and understanding about the Act, and the difficulty of proving a case, as well as the stress involved, mean that this legislation has been of limited use to people with mental illness. The provisions of the Act are also limited in that there is no protection for people who have experienced stigmatising practices, behaviour or attitudes. While it is unlawful to vilify or publicly invite contempt for people on the basis of religion, gender, culture, or sexual preference, it remains legal in most states to do this on the basis of someone having a mental illness or disability.

A long way to go

Reducing the stigma and discrimination associated with mental illness is one of the key aims of Australia's national mental health policy and reform agenda and of organisations like SANE Australia and beyondblue. Yet despite this, and despite significant improvements in awareness of common mental illnesses such as depression and anxiety, we have not seen commensurate changes in stigmatising or discriminatory behaviours. Public attitudes towards people affected by mental illness remain complex, and there is still widespread misunderstanding regarding many mental health conditions. Stigma towards people affected by conditions such as schizophrenia is particularly resistant to change, and improves only slowly.

Charting the direction

To reduce stigma effectively, research has shown that a comprehensive, long-term, collaborative and multi-sectoral approach incorporating the two major strategies is needed. This approach should be based on the reported experiences of people with a mental illness,

and their carers, and include:

- Conducting research to determine the best way to deliver stigma-reduction strategies that include contact and educational approaches, in a sustainable and ongoing manner.

- Continuing to work with traditional and new media to promote accurate and positive reporting and portrayals of people living with depression and anxiety, with a particular focus on personal stories.

- Facilitating personal contact between people who have experienced mental illness, and others who have not — in line with recommendations that contact is targeted, local, credible and continuous.

- Developing and delivering educational approaches, which promote attitudinal change, challenge inaccurate stereotypes, and replace them with factual information.

- Delivering interventions that reduce stigma and discrimination in multiple settings — for example, workplaces, schools, housing/accommodation services and healthcare centres.

In summary, a combination of well-funded, sustained, nationally-led (top down) and locally-driven (bottom-up) contact-based approaches, which are targeted to key groups and settings, seem to offer the most promising way forward in stigma reduction.

IN SUMMARY, A COMBINATION OF WELL-FUNDED, SUSTAINED, NATIONALLY-LED (TOP DOWN) AND LOCALLY-DRIVEN (BOTTOM-UP) CONTACT-BASED APPROACHES, WHICH ARE TARGETED TO KEY GROUPS AND SETTINGS, SEEM TO OFFER THE MOST PROMISING WAY FORWARD IN STIGMA REDUCTION.

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