Living well in our community

Towards a Strategic Plan for Mental Health in NSW

Paper 1 - May 2013

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Commissioner
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Introduction

This is the first of two companion papers designed to set the scene for the development this year of a Strategic Plan for Mental Health in NSW. It reflects the issues and challenges I have found since I was appointed Commissioner in August 2012 and sets out my initial thinking in relation to a vision and a set of principles to guide mental health reform in this state.

The second paper will provide a statistical and historical context to describe the current state of mental health in NSW.

Together, these papers aim to provoke a discussion among people with a lived experience of mental illness, carers, people working in the mental health system and the general community about what we need to do to improve how we prevent mental illness and provide services for those who need them. It is time for a different approach, one that builds on the quality services and deep skills we have in NSW to create a mental health system that works for people.

It will take all of us to change things for the better as we strive to make a mentally healthy NSW.

There will be formal opportunities over coming months for public input into the development of the Strategic Plan but in the meantime the Commission is eager to hear from anyone who has an experience of mental illness, or an idea about mental health care.

Please do consider contacting me at:

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I welcome your views.

John Feneley
Struggling people, fractured services

Our mental health system is under-resourced and fractured. In NSW it is common for people who experience mental illness to fall through the cracks between services, become sicker and get lost, despite the best intentions of those working in the sector.

The Mental Health Commission of NSW has been established to drive change in the system by providing Government with a draft plan for change and then monitoring implementation of reforms that follow. And when we talk of the ‘system’ we are describing multiple agencies, providers, funders and services.

Our focus is much broader than health and health services. It is the whole of government and the whole of the community. We need to consider the sum of people’s lives as they manage their mental illness or help a loved one. Housing, employment, income, education, justice and social inclusion more broadly can have a greater influence on a person’s mental health than any health service.

Each year in NSW, around one million people have a mental illness. Only 350,000 of these people actually receive assistance. Our ‘system’ is not currently configured to provide what works to those who need it. How have we reached this point?

The Commission has heard from many people about their experience of care in the NSW mental health system. People who experience mental ill health and their families and carers frequently share disturbing accounts of their difficulties accessing care and support even at times of crisis.

The bar for entry to our system is already high and still rising. People with a lived experience of mental illness report that they cannot access community supports at the first signs or early stages of becoming unwell. Without the opportunity to prevent their illness progressing to the acute phase, they may experience longer periods of ill health and may lose jobs, friends and homes as a consequence of being isolated from their ordinary lives. Families and carers express concern about not being kept informed about loved ones’ treatment. Public community mental health services are commonly under-resourced.

The community’s stories of course echo the findings of numerous parliamentary and other inquiries.

There is still significant stigma and misunderstanding about mental illness and its care and treatment, which all too frequently leads to discrimination. The community can readily accept efforts to reduce or treat heart disease and diabetes, but mental illness is less well understood. This is particularly the case for community-based care. What do mental health services actually do? Do they really make people ‘better’? Is the spending worthwhile? Do they keep people out of hospital, and why does it matter if people have to go hospital anyway? Why are people with psychiatric illness now the largest group receiving the Disability Support Pension - don’t they want to work?
These questions and the attitudes that underpin them reinforce the old focus on hospitals and make it easier for a health system administrator to remove funding earmarked for mental health and reallocate it to underwrite the cost of running a hospital. This is unacceptable when we know how hard it is for people to access mental health services in the community. It reveals a system out of touch with contemporary understandings of what supports recovery from mental illness.
What we believe

Insisting on quality

To achieve a mentally healthy NSW it will be necessary to agree on some basic principles.

We must acknowledge that mental health is a combination of mental, emotional, social and cultural wellbeing that encompasses much more than just ‘not having symptoms of a mental illness’.

Our policy recommendations will need to promote personal agency and strong communities with good social support, because education, community services, urban planning and workplaces all have powerful effects on mental health.

We must insist on first class health services for people who experience mental illness, to meet their physical and as well as mental health care needs.

In consultation with the community we aim to develop a mental health strategy for NSW that embodies these principles in a consistent and achievable vision.

The NSW Government has been clear that in the current environment it cannot promise additional funding to drive mental health service reform. Consequently we must commit to examining every funded activity, stop doing things that are ineffective and redirect the money towards what works. We must commit to ensuring every dollar allocated to mental health is spent on mental health. We must also look to maximise every possible new opportunity to secure Commonwealth funding for NSW mental health services.

In addition, we believe some fundamental, non-negotiable approaches will be essential to successful reform.

Putting people first

An effective mental health strategy must be predicated on the engagement of people with lived experience of mental illness, their families, carers and supporters in designing reforms that meet their needs and aspirations. They must be part of the decision-making process.

People who require mental health care in NSW deserve to be treated with dignity and respect, to have choice about the type of care they receive, and to be able to find high quality services when they need them. Families and carers must be supported in the vital role they play, and their own needs must also be met.

The community needs clearer signposts about where to get help and how. Current pathways into care are haphazard and too often rely on luck or the knowledge of individual general practitioners, social workers or others. This is inefficient and inequitable.

Services and programs need to clearly demonstrate their capacity to collaborate with clients rather than act as their caretakers. Approaches such as Trauma Informed Care and Practice offer new guidance to service providers about how to build more respectful therapeutic relationships.
Living well, aiming high

People who experience mental illness can become well and thrive. However many aspects of our system currently appear to focus on merely maintaining some modest level of functioning.

It is time for mental health care in NSW to really challenge itself to drive recovery.

We need policies and practices that emphasise the autonomy of the individual receiving care, supporting their goals, choices, and personal journey. With their permission and wherever possible, their families’ and carers’ concerns also need to be taken into account. This is important for all people who experience mental illness but may be especially so for children and young people, indigenous people, and those from diverse cultural backgrounds.

We need to engage people in planning and implementing their own treatment, through non-threatening, non-stigmatising services. Peer workers promote empathetic services and are known to improve health outcomes for clients, but Australia and NSW have been conspicuously slow to build a peer workforce, leaving potentially valuable experiences and expertise untapped. This must change.

As well, we need strong consumer and carer advocacy organisations, empowered to advise the Commission and the Government about those parts of our system that are working well and those that need improvement.

Body and soul

The association between mental ill-health and physical illness is intimate and real. People with schizophrenia suffer coronary heart disease at close to twice the rate of the general population under the age of 55. Rates of diabetes and stroke are significantly higher too, contributing to a situation in which the life expectancy of people with schizophrenia is reduced by a shocking 18 to 25 years compared to the general population. Mental health reform must consider people as a whole, rather than just body parts or illnesses.

Across life and across cultures

Patterns of mental illness vary with age, culture and life experience.

Indigenous and ethnic communities have particular mental health issues and needs. In 2010, Aboriginal people in NSW were 2.2 times more likely to report high or very high levels of psychological distress than non-Aboriginal people.

As many as a quarter of Australians between the ages of 15 and 25 experience a period of disengagement and are at risk of enduring separation from lives as healthy, productive citizens. But these young people, whose need for mental health care is greatest, have the lowest access to care; only 13% of young men with a mental illness get any assistance with it.
Today 13% of our population is over the age of 65 years; by 2051, that proportion will double to 26%. Up to 15% of older Australians experience anxiety and depression; this rises to 35% for persons living in residential aged care facilities.

Less common conditions, such as schizophrenia, are more common in older people. Mental disorders in older people frequently accompany general health problems, and the two must be managed together.

Particular attention needs to be directed towards meeting the well-documented needs of asylum seekers and refugees, some of whom face overcoming trauma and torture in addition to the challenge of starting a new life in a new country.

In these areas – to mention just a few examples – our response is currently inadequate, leaving vulnerable people more vulnerable. We must commit to meeting the mental health needs of everyone in our community, regardless of age, ethnicity or cultural background.

**Not just the health system**

As we shift our emphasis away from acute hospital treatment towards prevention and community care, we must meaningfully address the links between a person’s social circumstances and their physical and mental health by ensuring they have access to housing, employment, education and community services. We need to acknowledge that circumstances and needs will change through different phases of life, and that culture and background are critical influences.

Young people who miss out on care typically struggle at school, and are then excluded from the labour market – with profound, lifelong implications for those individuals, their families, the community and Australia’s economic future.

Education and training opportunities protect against mental health problems, and an extra year of schooling has even been shown to reduce the chance of dying early. Education is critical to maintaining a young person’s trajectory towards a fulfilling life. A strategic plan for NSW must recognise this, encouraging education providers – who are the experts in their own sector – to come up with new ways to keep vulnerable youth on the path of learning.

The very high rate of mental illness in our prisons is powerful testimony also to the critical importance of the justice system and the police. It has been said previously that as the asylums closed across Australia a proportion of their residents were simply transferred to new long term accommodation in our prisons. This is unacceptable.

Individual agencies hold data that shows how mental illness dramatically increases people’s use of community services or their likelihood of arrest or conviction. In isolation, this data amounts to a series of anecdotes. Combined, it would form a potent and irrefutable record of the need to intervene early and comprehensively when people experience mental ill health, to prevent patterns of dependence from becoming deeply entrenched. We should encourage the linking of de-identified data between departments so we can tell that story.

The Commission’s legislation gives it a strong mandate to work across all NSW government agencies to build a better approach, one that acknowledges mental and physical health is in large part a consequence of the life we live.
Everyone’s business

As we try to make real change, nothing is as powerful as own attitudes. Do we have the empathy and skills to first identify and then respond effectively to mental illness? Do we build our cities and towns so as to minimise social isolation and maximise opportunities for social engagement? Is the issue of mental health given as much prominence in our workplaces as other aspects of occupational health and safety?

We need new tools to fight the continuing stigma associated with mental illness. We also need new fighters.

We should foster mental health literacy through schools, equipping teachers, students and parents with the requisite skills not just to respond to the first signs of mental illness but also to promote good mental health among the school community.

So many people who experience mental ill health are not in contact with formal services, and we must try to reach them through a renewed and more structured community effort, equipping those with whom they may come into contact to better recognise mental illness and respond to it.

Beyond health service providers, we need to include local governments, employers, teachers, the police and many others in taking active responsibility for the mental health of those around them.

Standing together

The sectors and communities concerned with mental illness, drug and alcohol addiction, and disability often distance themselves from each other.

Yet the space between us is strewn with the diminished lives of those who live with multiple conditions because our alienation has left us ill equipped to care for them. The divisions also weaken our capacity to pursue reform and as a result people are further stigmatised within the wider community.

As we pursue reform, we must dismantle the stigma that exists between us in the broad health and disability sectors, which results in discrimination against people we should be helping.
What we need to change

Hooked on hospital

NSW has maintained an excessive reliance on hospital as the place to get mental health care, in contrast to some other states and territories. This must end.

Psychiatric institutions have been closing in Australia since the 1960s. NSW has been part of this deinstitutionalisation but as asylums have closed, many of their beds have been transferred to the psychiatric wards of our general hospitals. NSW has 2650 mental health beds – more than double the number in Victoria though NSW’s population is less than one-third larger.

Many people with mental illness experience hospitals as traumatic and coercive and fear they may be turned away unless they are critically unwell. This may cause them to avoid seeking care.

A national snapshot survey conducted in 2006 showed 43% of all patients with mental illness in acute care hospital beds could be, in the view of the clinical director, more appropriately cared for in other settings if proper services were available.

It makes no sense to organise mental health care around inappropriate in-patient treatment, which is also the most expensive part of NSW’s current system.

New rules are being developed for the definition and counting of mental health care episodes under Activity Based Funding, a major element of the health reform agreement between the Commonwealth and states. This reform should reveal for the first time exactly what treatments people are receiving through the NSW public health system.

But despite this valuable transparency, we must be mindful of the risk that this reform might further skew the field towards hospital-based care - which may conform more readily to the new administrative measurements – and ensure instead that the new data is used to enhance the development of community-based approaches to better mental health.

NSW needs to be especially attuned to this risk because it has failed to adequately invest in a genuine system of community mental health care, designed to permit people with a mental illness to live well in the community, in their own homes. We cannot shift our approach from crisis management to prevention and early intervention while this continues.

There is good evidence for the effectiveness and cost-effectiveness of community care, supported by close links to primary health care, over hospital-based care in most contexts. NSW already has contributed to this understanding already through its Housing and Accommodation Support Initiative (HASI) program, which combines housing with clinical and social support.

Evaluations have shown HASI program users experience better physical and mental health, more secure housing, increased community participation and friendships, increased employment and massive decreases in hospitalisation.
Community-managed organisations have the potential to become much larger partners in community mental health service provision in NSW, where their present role is relatively limited. This sector offers the advantage of close ties to local communities, and the ability to work effectively in narrow niches of need that are difficult for governments to service.

Among all Australian jurisdictions, NSW directed the smallest per-capita proportion of total mental health spending to support community-managed mental health service provision in 2010-11. New Zealand directs almost 30% of annual mental health expenditure towards such services - about four times the NSW rate – and as a result can draw on a more vibrant and well-supported sector. This is a critical element to consider in developing a new approach to mental health care in NSW.

Bankstown, Bega, Brewarrina

It has been said that NSW stands for Newcastle, Sydney and Wollongong. A genuine Strategic Plan for Mental Health in NSW must advocate equally for the needs of all people living in this state of 800,000 square kilometres, regardless of geographic and demographic challenges.

Care is less readily available to people living in non-urban areas, partly because mental health professionals are in shorter supply. But specific needs and challenges in rural and remote communities, such as patient transportation, must be critical considerations if this new strategy is to serve people who live outside major cities.

We must be open to bespoke mental health solutions for non-urban areas, rather than expecting to impose uniform services and programs. The Far West Local Health District covers an enormous area. What is required and what will work here will differ from south east Sydney, and these differences need to be respected and accommodated.

We need to propose governance models that will permit local or regional approaches to be trialled, evaluated, implemented, supported and celebrated.

Regional solutions will be particularly important to better meet the needs of indigenous people. Aboriginal people living in regional or remote NSW often rely on the local Aboriginal Community-Controlled Health Services which are largely funded by the Commonwealth, another key point of intersection for any new Strategy.

More generally, indigenous people have shown a distinct disinclination to use existing mental health services. There is no point continuing to invest in services people do not want to use. We must think differently and be more willing to understand the needs of Aboriginal people so as to deliver the right services in the right way.

In fact, this principle applies across much of mental health. We must make sure the services, facilities and buildings of the future do more than just continue current approaches. There are big gaps in our system demanding new models of care, not just more clinics in hospitals. Innovation will be required across all facets of care, health, housing, community and other services.
Working to make things better

Mental health care in NSW must offer the kind of places people want to work, and a pattern of work practices which encourage recovery and restore full citizenship. The sector should support and promote the mental health of the people who work in it, empowering them as well as those who use its services.

The ageing of the workforce combined with the lure of alternative occupations has created unsustainable pressures in the sector.

Wages and conditions are important, but even more essential is to ensure that people working in the system can feel they really make a positive contribution to people recovering from mental illness.

Large volumes of data are currently collected within the NSW mental health system, but little of it is returned to service providers to help them understand the consequences of the care they have given, and improve service quality. A critical feedback loop is missing and must be addressed.

Peer workers, who themselves have experienced mental ill health, have vital roles in the mental health workforce. There is good evidence to show peer workers can be uniquely valuable in changing culture, reducing stigma and improving the quality and results of care and treatment. So far our commitment to establishing a strong cohort of peer workers in NSW has been minimal. This must be addressed. Peer workers can also take some pressure off an over-extended workforce if they are employed within multi-disciplinary care teams or establish peer-led programs.

One state in a federation

The Commonwealth and the NSW Government share responsibility for health care, including mental health care. Real partnership is required to deliver effective services, but in reality the two tiers of government work together very poorly. The intersection between them is marked by lack of joint planning, confusion, conflict and waste.

The Commonwealth provides millions of dollars each year in mental health funding in NSW through Medicare payments directed toward general practitioners, psychiatrists and psychologists. It also provides community programs such as Personal Helpers and Mentors and Partners in Recovery, while the NSW Government funds community mental health services both directly and through community-managed organisations.

These services often do not work together well, nor do they link up effectively with the NSW Government’s hospital-based services to, for example, ensure timely community follow-up for a person just discharged. Dangerous gaps in care commonly appear.

Commonwealth-funded Medicare Locals offer real hope in this area provided they can work cooperatively with state-based Local Health Districts and the range of community-managed organisations supporting people who have mental health conditions.
It is time for both tiers of government to better integrate mental health care planning and funding, to champion services and policies that prevent illness and keep people out of hospital, and to focus on what works rather than who pays.

The National Mental Health Commission has already offered a blueprint for change to the Commonwealth, in its *A Contributing Life* report card last year. Reform planning in NSW must recognise that work, and ensure it is compatible with the Commonwealth’s efforts to improve the experience of people who have a mental illness.

**A national disability scheme**

The National Disability Insurance Scheme, or DisabilityCare, has overcome political hurdles and will soon be rolled out in NSW and elsewhere.

Some have expressed concern about Government being distracted by DisabilityCare and neglecting commitment to mental health. Others are concerned that the concepts of disability within the scheme do not sit well with ideas about recovery from mental illness.

But access to DisabilityCare by individuals with severe and persistent mental illnesses and their families is essential and we must unambiguously embrace its potential to assist those who live with severe psychosocial disability to thrive in their communities and not just survive.

Of course we need to proceed with caution because the qualification rules for people with a mental illness are still being determined. It is not yet clear how they will affect the level of care available to those eligible for support under DisabilityCare or, perhaps more importantly, those not eligible. The scheme’s impact on the Commonwealth and NSW Government’s responsibility towards people with long-term mental illness cannot yet be forecast so we will need to monitor this area closely.

**Stopping illness early**

Another impact of the hospital-centric approach in NSW has been to diminish efforts in relation to self-care, mental health promotion and mental illness prevention and early intervention.

This is despite mounting evidence not only of the effectiveness of promotion and prevention activities in minimising the impact of mental illness but also on the colossal social and economic benefits to be derived from programs in areas such as supporting parents, preschool and school-aged children and young people.

There is proven value in schemes to assist people with mental illness who are already in the workplace and to help others enter the workforce. There is also strong evidence that programs to assist people with housing, to support the development of grassroots community organisations, and to prevent suicide, are among the most sustainable and valuable approaches we have.

New e-mental health programs, such as MoodGYM from the Australian National University and the Black Dog Institute’s myCompass, let people monitor their own mental health and
identify distress triggers and have been proven effective in treating depression and preventing relapse.

Such technologies could play a much more significant role in meeting the workforce and geographical challenges faced by NSW. They may also be more acceptable to younger people who are comfortable with technology use, and others who may wish to use it to augment or substitute for face-to-face interaction.

There is no national mental health promotion and prevention strategy. Real reform of mental health needs to focus on this and NSW could play a significant and exciting role in reigniting Australia’s efforts in this area.

**Backing up what we do**

Mental health care in NSW should be informed by the best evidence about what works, but there are many areas where evidence-based approaches are yet to be deployed.

Some approaches, such as intervening early to treat young people who are at high risk of psychosis, have been closely studied and developed according to evidence as it emerges. But other routine aspects of mental health care do not have robust research backing to justify their continued funding.

Urgent research into and evaluation of existing and proposed treatments are necessary to guarantee the NSW community quality care.

Beyond better understanding of treatments and services, we also need to learn how to better identify, analyse and redress failings in the way our system works. We need to know the ingredients of an agile and intelligent response to mental illness.

**Keeping the system on track**

Mental health now accounts for just over $1.4 billion out of NSW’s total health budget of $17.3 billion, or about 8% of total health spending. Meanwhile mental illness accounts for 14% of the total burden of illness in this state. Spending on mental health is disproportionately small.

Expenditure on health and mental health is coming under increasing scrutiny amid government pressure to make savings, and arguments to maintain let alone increase the mental health budget are becoming harder to mount and sustain.

The figures that are collected, which might be used to make such arguments, are typically derived from hospital administrative datasets, which measure services, programs and systems. They can obscure the diversion of resources out of mental health to underwrite general hospital services, and they fail to reflect the actual experience of people with a mental illness.

Sophisticated information about people with cancer means we can now reflect on the tens of thousands of lives saved directly as a result of better care. In mental health the main issue is not survival but long term illness. Existing data will not tell us how many people with
a mental illness are under-served and under-supported, unemployed, under-employed, isolated, living in poverty or homeless. They do not demonstrate whether life for people with a mental illness in NSW is getting better or worse.

A mental health strategy for NSW must encompass new approaches to performance reporting that will facilitate a new understanding of how well NSW is managing mental illness, based on the experience of those who live with it. It must reflect not only health care, but other markers of social inclusion, such as social and family networks, employment and housing. We need to know which forms of care and which services help people who have a mental illness to recover and lead fulfilling lives.
Conclusion

The story of mental health care in NSW is one of confusion, struggle and all too often, tragedy.

The configuration of our current mental health system is wrong. The mix of funding and services needs to change. There are of course exceptions, islands of excellence across all areas of mental health care, but time and again these have failed to translate into a positive story state-wide. Effective services have not been further developed to deliver care on a statewide scale, despite an abundance of ideas, expertise and goodwill.

Starting now, it is time to tell a better story about mental health; a story which properly reflects the evidence that quality services can and do help people with a mental illness recover to live as productive, healthy and valued citizens.

The preliminary principles and values articulated in this paper are intended to provide a useful starting point as we embark in earnest on the process of reforming a NSW mental health system that has developed over 150 years.

Change will not occur overnight, but leaving things as they are is simply not an option.