LIVING WELL

PUTTING PEOPLE AT THE CENTRE OF MENTAL HEALTH REFORM IN NSW: A REPORT
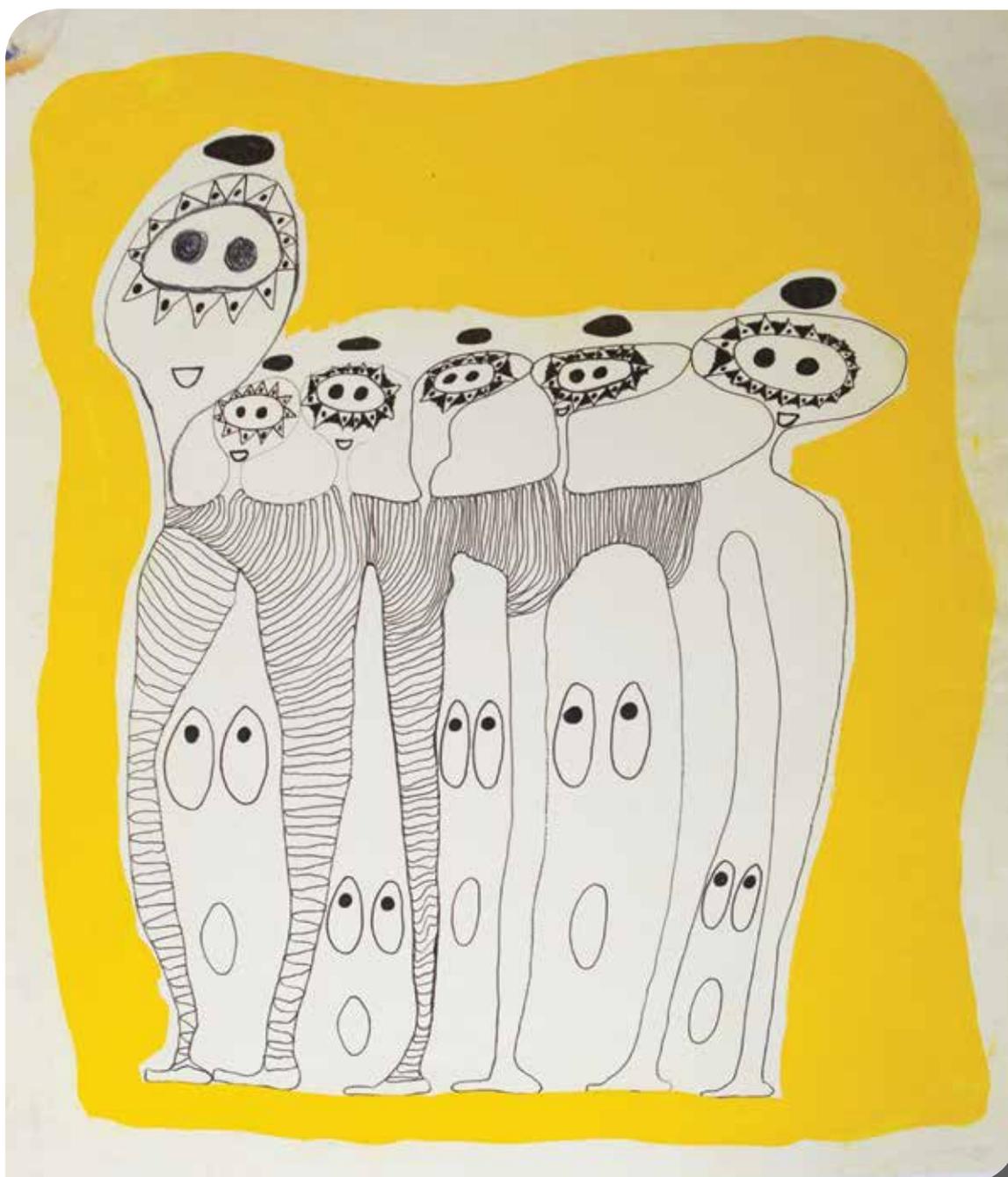
OCTOBER 2014

Mental
Health
Commission
of New South Wales

Cover image by Anthony Mannix:
The Beast of the Unconscious is Vivid

Inside details from other works by Anthony Mannix

Anthony Mannix's art works are created mainly on paper using inks, oils, watercolours, tea and ballpoint pen. They have been widely exhibited in Australia and are part of collections in the US and Europe.

Mannix spent time medicated and under involuntary treatment in psychiatric hospitals, including the old Gladesville psychiatric hospital where the NSW Mental Health Commission offices are now housed. His works are confronting yet compelling, and often humorous. They express his experiences of mental illness and institutionalisation, and also of exhilaration and joyfulness.

A LETTER FROM
THE COMMISSIONER

This Report tells the story of mental health in NSW from the perspective of people who live here.

This includes people who live with mental illness and pursue their recovery through work, art or connections to their communities – and those who are striving to change our systems of mental health support, so that they respond more effectively and more proportionately to people in distress. This includes Aboriginal people, people who live in the country and the inner city, children and adults, and people from diverse cultures who bring all manner of life experiences to this document.

Some people speak directly, through the personal stories presented here. These stories are testimony to the extraordinary resourcefulness and resilience of the human spirit, and to the strength and generosity of families and communities.

The voices of thousands more are embedded in the words on every page.

During 2013 the Commission undertook what we believe is the most extensive mental health consultation conducted in NSW. We travelled the state, holding public meetings and barbecues in small and large towns and Aboriginal communities. We held meetings in Sydney to hear the concerns of people from diverse cultural backgrounds.

We established working groups, based on common mental health experiences at different times of life, in which people with expertise gained from living with mental illness joined academics and service providers to get to the heart of how our system responds now and to develop ideas for how we could improve it.

Those people were joined by hundreds of others who participated online in the reform planning project, contributing their views and commenting on drafts.

The pages that follow present a powerful and at times emotional case for a new generation of mental health reform in NSW – one that puts people firmly at the centre. I am confident that this Report contains is a faithful articulation of the ideas and experiences shared with the Commission during our long and deep conversation with the community, which will continue as we drive reform forward.

People have been let down in the past. Three decades ago, Australia began in earnest to reform mental health care, recognising that isolating unwell people in secure hospitals could not be justified in a humane society. We began to close the asylums; the subsequent history in which we failed adequately to support people in the community is well known.

We live with the consequences of that failure every day. Our state of mind is the bedrock of our whole life – affecting personal relationships and family roles, interactions in our community, the work or occupations we pursue, and the fundamental ways we view ourselves and our abilities and aspirations. The whole of society loses out when we squander human potential, when we limit the capacity of people to be our friends, colleagues or leaders because we do not offer them the right assistance when they need it.

This Report is a companion document to the Strategic Plan for Mental Health in NSW, in which the Commission has developed what we heard about people's experiences, needs, wishes and priorities for mental health support and community wellbeing into specific advice for government.

Together, the Report and the Plan set an ambitious but achievable agenda for mental health reform in NSW.

The Commission exists to promote change, and to guide and monitor it. But the Commission cannot make change happen. Positive reform that really benefits people who live with mental illness is everyone's responsibility.

I look forward to working with the Government, the mental health sector and the people and communities of NSW to ensure that this time round we fulfil the promise of reform.

JOHN FENELEY

NSW MENTAL HEALTH COMMISSIONER

A NOTE ON LANGUAGE

Language is how we express the ideas in our minds, and is therefore a most powerful agent that can reinforce separation, stigma and discrimination or, instead, work to overcome our differences and emphasise the things we have in common.

The Commission has attempted in this Report to ensure the language used reflects and respects the experience of people who live with mental illness, and includes the whole community in shared ideas of mental health and wellbeing.

But we know that some terms are contested, and may carry different meanings for different people. People who experience mental illness have different perspectives from those of their families and carers. Doctors may see things differently from nurses, social workers or health system administrators. Aboriginal people's understandings of psychological and social wellbeing may diverge from those of other people born in NSW, or of migrant communities.

Those nuances may be contained in a single word or phrase.

This is particularly problematic when we encounter the language of the past, when people with mental illness were marginalised and not expected to be active participants in their own support.

Some institutions, programs and models of care were known by names we would now consider stigmatising and undignified.

In this Report we have updated our use of language wherever practical, to emphasise a more progressive understanding of mental illness and to reassert the continuing worth and capacity of people who experience it. Occasionally, we have needed to retain historical language to allow readers to understand precisely the issues we discuss, and to seek out further references if they wish to.

This will not please everyone all the time, but we hope readers will accept our good faith in the choices we have made.

Some of our considerations in making these choices are set out here:

Mental illness is the term we have typically used. Some people prefer *mental ill-health* because they consider it implies a less medical perspective. We have generally avoided *mental health disorders* or *conditions*, unless the instance refers to a particular report or study in which these terms were used.

Mental health consumers (or just *consumers*), p*eople with lived experience of mental illness, people who experience*

mental illness and *people who live with mental illness* are used interchangeably. The term consumers may imply that people consume or use mental health services, when not everyone who struggles with their mental health does so.

Client is used only to refer to clients of particular services, such as housing. *Patient* is sometimes used to refer to people who are undertaking treatment, especially if this is in hospital.

Mental health support is our preferred term both for clinical and medical intervention and for social support offered to people with mental illness. It carries the notion that a person is still responsible for their own life and choices. *Care* is used sometimes, and refers to people who are currently unwell. We have tried to avoid *treatment* because it may imply a paternalistic relationship, usually with a doctor, in which the person is a passive recipient.

We refer to *drug and alcohol use, drug and alcohol misuse* and *drug and alcohol problems,* depending on the circumstances. We avoid the terms *abuse* or *addiction*, which are imprecise and stigmatise people.

We have moved away from the term *non-government organisation (NGO)* in favour of *community-managed organisation (CMO)* though both appear in this Report.

VALUES

In developing the directions for change described in this report, the Commission has been guided by a set of core principles. These apply at all stages of life, across all cultures, and for all communities in NSW.

RESPECT

Acknowledging the equal value of every human life should underpin everything we do to support and promote mental health and wellbeing. In particular, we must ensure that government, community-managed and private services always assure the autonomy, dignity and individuality of people who experience mental illness.

RECOVERY

Those of us who live with mental illness have the right to expect to lead fulfilling lives, and to pursue our own choices about how we live and about the support we accept, regardless of whether are experiencing symptoms. This should also be so for our families and carers.

COMMUNITY

Strong connections among people are the foundation of mental health and wellbeing and resilience for individuals, families and our wider society. These connections nurture social inclusion and respect for diversity and are particularly important for people who experience mental illness and for their families and carers.

QUALITY

In partnership with consumers, mental health professionals, service planners and policy-makers must ensure supports and services meet contemporary standards and are effective.

EQUITY

People who live with mental illness should expect to be supported equally in their recovery, regardless of their age, gender, culture, sexual or gender identity, where they live or any other health problems they have.

CITIZENSHIP

Responsibility for individual and community mental health and wellbeing is shared across our society. All of us, whether or not we experience mental illness, should expect to contribute to that shared mental health and wellbeing, and to be able get support when we need it.

HOPE

We should create an environment where people whose lives are affected by mental illness can experience the benefits of positive change and be optimistic for a better future.

CONTENTS

A LETTER FROM **FAY JACKSON**

Thank you for taking the time to read and hear my voice as a person who has lived experience of mental ill health.

I am writing to you on behalf of my community of brothers and sisters with lived experience, and also to our younger and older peers who may be experiencing their first episode of mental ill health. And I am writing to you in the hope that you will do all you can to create the best possible opportunity for future generations to grow up in a society that values and supports each person so that we all reach our full potential.

I am also a 'carer' although I just see myself as a wife, friend, mum, daughter, sister and grandmother. However, there have been long periods when the caring role was the focus in my life. I do know the fear, pain and exhaustion this can bring, especially when mental illness affects more than one generation in a family.

However, I believe that all of us - people with lived experience and carers – can and deserve to live with hope, recovery and relief. Those of us with mental health issues want to be able to access support and help in the individual ways we need it, to prevent our distress increasing and our wellbeing deteriorating. We need person-centred services that encourage us to actively and responsibly lead our own recovery and prevent future ill health.

> **"… I believe that all of us ... can and deserve to live with hope, recovery and relief."**

Early intervention and prevention are not just words that pertain to young people's mental health. People who have experienced mental ill health for years and older people need to be able to prevent further episodes and to get early intervention should their mental health be challenged. They need to know that recovery is absolutely possible.

We need clinicians who will consider the big picture of our lives - our past traumas, our present and our future – to help us enhance our wellbeing over the long term. Meditation, the arts, caring for pets, spirituality, exercise and volunteering are vital parts of our lives, and we need professionals and services to respect their importance in our lives.

In the new age of mental health and wellbeing, clinicians will work alongside the peer workforce and peer-run services. Workers with a lived experience of mental ill health will be employed at all levels of services, where they can innovate and lead. We make great directors, managers and front line staff.

Easy, early access to people who care and recovery support services that are eager to help are incredibly important. It is my hope that the next generation will move beyond recovery into an age of prevention of mental ill health, and of wellbeing.

Easy. Early. Eager. What will you do to help this come about?

DEPUTY COMMISSIONER

ANTHONY
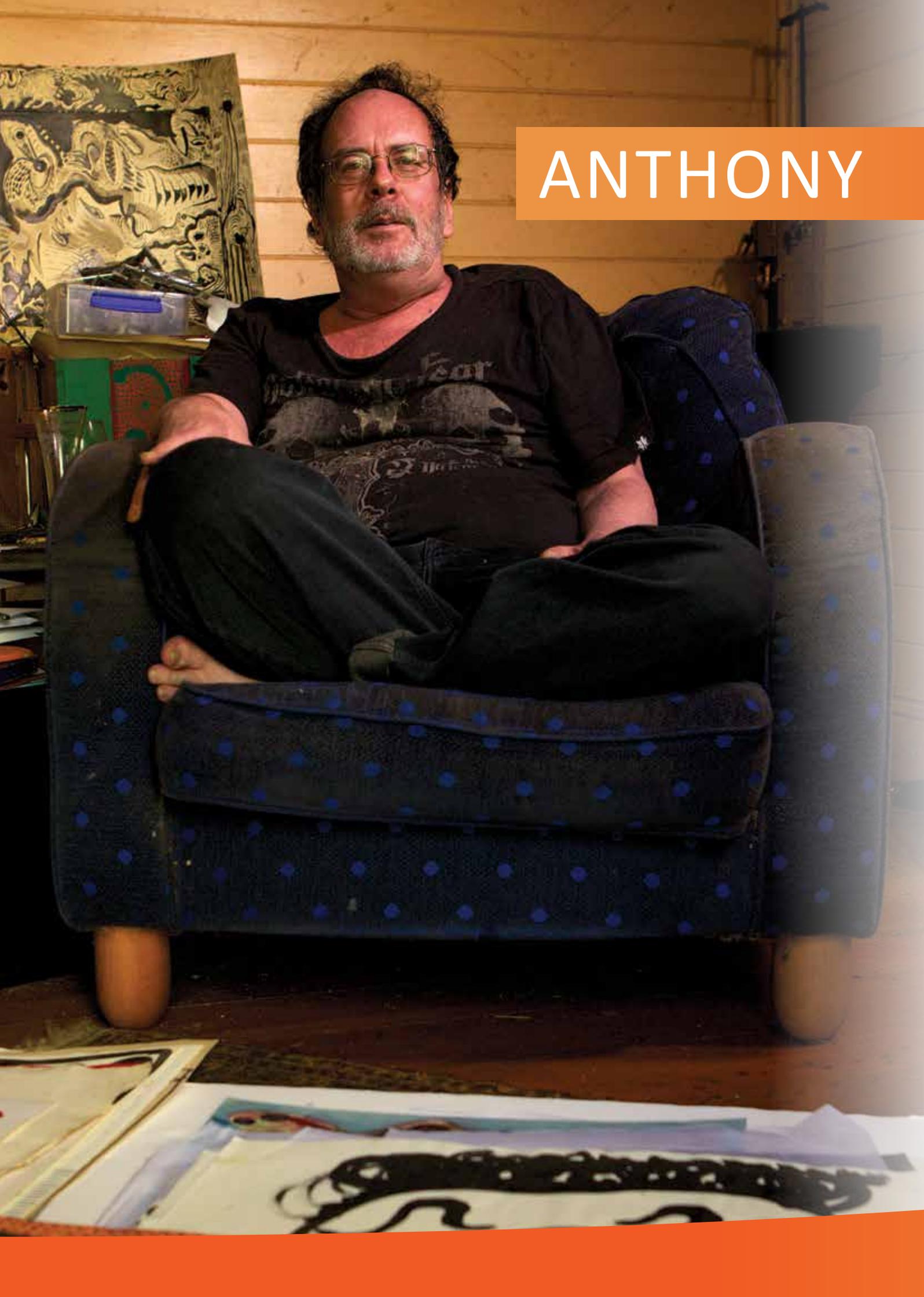
MANNIX

At times, the most personal connection in Anthony Mannix's life has been with the extraordinary works he creates.

"All those drawings, they may just be bits of paper, but it was fundamental to who I was to make those things and that's a unique relationship and the most prized relationship," Mannix says.

"The big thing it did for me was to make an environment that's friendly … I really can't say that art has saved my life but it did produce a place where I could go and at least be comfortable."

At a 2013 retrospective of his work at the Sydney College of the Arts, on the former Rozelle Hospital grounds, Mannix was heralded as "Australia's most celebrated Outsider Artist".

Though he has not had any formal training, his dark and humorous works have been widely exhibited in Australia and are part of collections in the US and Europe. Inspired by the occult, eroticism and mysticism, he works mainly on paper, using inks, oils, watercolour, tea and ball point pen.

The artworks are an extended portrait of Mannix's psyche as he spent two decades in the grip of recurrent mental illness, and an escape from the brutal hospital environments in which he found himself. Throughout the 1980s and 90s, Mannix was periodically involuntarily admitted to Rozelle and Gladesville psychiatric hospitals.

> **It was all very, 'bring somebody in for six weeks, patch them up and send them out. And don't worry about ongoing medication, give them a bottle of pills when they leave and they can sink or swim' … That's an indictment of the mental health system that they should let you wallow for 20 years.**
>
> *Anthony Mannix*

"The overall theme was violence. There were a lot of rough edges. After the first couple of times you figure it's the norm and you'd better handle it."

He remembers the culture at Gladesville as particularly inhumane. He speaks of patients being "herded" out of the hospital gardens every afternoon to the locked-in space where they would spend the next 20 hours. Or of being herded in the name of exercise "from one side of the grounds to the other, back and forth, back and forth. It felt really strange, like I'm a bit of a cow, or a steer or a heifer".

He says the staff saw the patients "as the cause of everything bad in their life. It's still quite a mystery to me why at those mental hospitals we were not quite human".

His mental illness, diagnosed first as paranoid schizophrenia and later as schizoaffective disorder, was "a horrible card to be dealt, but if you can get at it, madness is really a resource – all that visualisation and all that intellectualisation".

At age 60 he still receives a monthly medication injection and says he no longer experiences mental illness. "I'm no more mentally ill than anyone else." His life and his art practice are gentler than at the height of his illness. At his home in the Blue Mountains, hundreds of Mannix's works are stored in piles on the floor; he appreciates them as they age, acquiring a patina of ash and grit.

WHAT WE KNOW

NSW has the second lowest per capita spending in Australia on support for people who experience mental illness, and we spend a higher proportion of that budget on inpatient hospital care.

But we know that hospital care is more costly and, in most circumstances, less effective or no more effective, than care offered by community-based teams while people continue to live at home.

Admitting people to hospital, even if their health improves, dislocates them from their family, friends, work or education, which can have real negative consequences as they seek to readjust after a period of illness.

Even for people with severe mental illness, the average hospital stay in 2013 was about two weeks, confirming that they usually live in the community.

A balanced approach to mental health care sees the community as the key place where services are provided, with hospitals playing an important role as a back-up. NSW lacks this balance.

Our challenge is to radically realign mental health support, while ensuring we improve access to care – and maintain and improve the skills, knowledge and goodwill of the thousands of excellent professionals who work within our system.

1 IN 5 Australians experience mental illness in one year

about **1 in 2** experience mental illness in their lifetime

707 PEOPLE DIED BY SUICIDE IN 2012

2.7 MILLION work days lost each year because of mental illness

54% NSW MENTAL HEALTH BUDGET SPENT ON INPATIENT CARE

GETTING THE SUPPORT WE NEED

We know that in NSW many people do not get the mental health care they need.

- Among Australians who had a mental illness in the past 12 months, only 35% received any formal care. We know little about whether they need or want help, or why they don't seek care.

- The number of Medicare-funded psychology services has increased in recent years, but the percentage of the population seen by NSW public mental health services has been static.

- Rates of mental health care use are uneven across NSW, and services are harder to find outside of the cities.

We spend the least per capita on public community-based mental health services and on mental health services provided by community-managed organisations. Other states are spending more on services designed to keep people healthy and out of hospital.

Recurrent expenditure on specialised public mental health services 2011–12
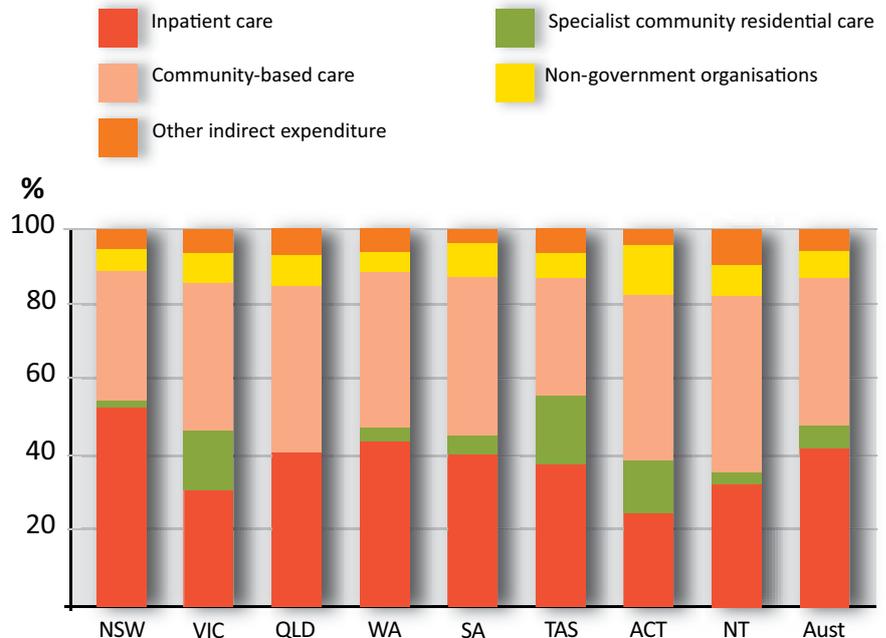
Legend:
- Inpatient care
- Community-based care
- Other indirect expenditure
- Specialist community residential care
- Non-government organisations

NSW needs to create easier pathways for people to get the care they need much earlier, so they do not become acutely unwell.

Services provided by the NSW government are principally inpatient hospital admissions and outpatient services. Despite recent funding increases, largely directed towards hospitals, there is no evidence that more people are being cared for by those services.

The Commonwealth Government provides mental health services through Medicare-funded consultations with general practitioners, psychiatrists and psychologists. These services have seen a massive and rapid expansion, particularly since the start of the Better Access program in 2006, which for the first time provided Medicare rebates for psychology consultations. The percentage of the NSW population receiving mental health services under Medicare increased by more than 4% to 7.3% in the five years to 2012.

However, we do not know whether the program is extending care to people who did not previously receive any. Nor do we know much about the quality of care provided under Better Access or its impact on the course of mental illness.

The same is true for other Commonwealth-funded mental health supports. We cannot determine the degree to which the Personal Helpers and Mentors, headspace and Partners in Recovery initiatives may extend support to people who might otherwise not have sought or found it.

NSW needs to create easier pathways for people to get the care they need much earlier, so they do not become acutely unwell.

WHAT WE SPEND

Mental health in the 2013–2014 financial year accounts for $1.45bn out of a total NSW Health budget of $17.9bn or about 8% of total spending.

This does not include costs in other government agencies, such as the justice system, corrective services, education, police, disabilities and home care, community services and Aboriginal affairs.

In 2011 – the most recent year for which consistent national data is available – NSW directed almost 54% of its total mental health budget towards services in psychiatric hospitals or psychiatric wards of public hospitals, the highest proportion of any state. The national average expenditure on these services was 43% and in Victoria 31%.

NSW also spent least on community mental health care – $65 per capita across the population, versus a national average of $74. Additionally, most of what is defined as community mental health care in NSW operates from a hospital campus rather than a base in the community.

What this means is that NSW is spending most of its money on the most expensive type of care, responding only once a person is acutely unwell.

Community mental health services spending by jurisdiction

$ = $ Per Capita 2010 - 2011

Average annual change 2006/07–2010/11		
National Average	4.0%	▲
NSW	4.1%	▲
VIC	1.5%	▲
QLD	7.9%	▲
WA	2.1%	▲
SA	5.8%	▲
TAS	2.4%	▲
ACT	-1.5%	▼
NT	2.4%	▲

$90.79
$81.95
$95.46
$83.07
$64.87
$ —$88.82
$67.06
$ —$71.07

National Average $74.17

BUILDING THE COMMUNITY SECTOR

The NSW mental health system also relies heavily on services run by government. Per capita in 2011, NSW directed the smallest proportion of any jurisdiction – 6% of its total mental health spending to support community-managed mental health services, though growth is higher than the national average.

The community-managed sector is characterised by a strong local focus and the ability to be flexible and responsive to the needs of consumers, families and carers and has the potential to become a bigger provider of the psycho-social recovery services people may require when they experience mental illness.

These services can help people gain or regain the ability to live as independently in the community as they wish, including assistance with daily living activities such as shopping, cleaning and cooking, and counselling and connection to leisure and training programs.

There is a need to develop new community services as alternatives to hospitalisation. At the same time, we need a better understanding of the performance of the community-managed sector and its impact on mental health and wellbeing in NSW.

HOW PEOPLE FARE IN CARE

For people admitted to state and territory public psychiatric inpatient units 72% are assessed as having a significant reduction in their symptoms by the time they leave. Still, most remain unwell at discharge, pointing to the need for continuing care in the community. And for 4%, their health worsens while 24% leave hospital with no significant change in their condition.

But knowledge about the impact of care is imperfect and incomplete. Formal data generally emphasises the clinician's perspective, not the person's viewpoint, and a diagnosis of mental illness can define people and encourage them to depend on services.

Australia is yet to implement a set of holistic indicators, to reflect the experience of people with a mental illness, emphasise their autonomy and normalise the concept of recovery – that people can get better.

Housing, education completion and social inclusion are central concerns for people with a mental illness, but are not reported in NSW. Employment status is collected only for people who use public hospital mental health services.

Also, there is a need to classify the type of mental health services provided by the community-managed sector, recording its client interactions and the results.

All services need to be able to demonstrate clearly the consequences of the support they provide. Expanding the measurements we use to assess progress is a key challenge in NSW.

Public community mental health services in NSW tend to operate from a hospital campus rather than from within the community.

NOT JUST HEALTH CARE

We need to understand more about investment directed at people with a mental illness right across government, to better meet people's needs and to target resources where they make the most difference.

The Department of Family and Community Services calculates 31% of its clients are affected by mental illness. The cost of providing services to these clients is estimated at $1.8bn a year.

- Just under half of NSW's 10,000 prison inmates in 2009 reported having been assessed or treated for a mental health problem.

- NSW Police attend about 100 mental health-related incidents every day, about 2% of total police activity. NSW Police will provide mental health intervention training for 10% of all operational police by the end of 2015, to improve their response to people experiencing mental distress.

- Total housing costs associated with mental illness have not been calculated, but NSW allocated $118m to the Housing Accommodation and Support Initiative (HASI) alone, between 2007 and 2011. More than 1000 packages of care are being provided under this program.

- Schools are recognised as important locations for addressing student wellbeing, because of their reach and familiarity to students and families, and the opportunities they afford for mental health promotion and prevention. In 2011, the Department of Education and Communities employed nearly 800 full-time school counsellors and district guidance officers.

It is hard to think of a NSW government agency that does not have a material interest in working to improve our response to mental illness.

ECONOMIC IMPACT

About 680,000 work days a month are lost in Australia for mental health reasons – half for depression.

Mental illness accounts for about $2.7bn in lost productivity in Australia each year. If NSW mirrors the rest of Australia, about 225,000 work days are lost each month because of mental illness. The impact on the NSW economy is colossal.

These figures do not include lost productivity from unemployment because of mental illness. The rate of unemployment among people with a mental illness is much higher than among the general population.

EDUCATION COMPLETION

Education and training opportunities protect against mental health problems.

Participation in education is critical to maintaining a young person's trajectory towards a fulfilling life, building skills and improving employment prospects. Mental illness in young people can lead to poor academic performance and higher drop-out rates.

One-third of Australians who experience psychosis have no school or post-school qualification, compared with a quarter of the general population, and their rates of achieving TAFE, trade certificate or higher education qualifications are also substantially lower. One in five struggles with literacy, and the main source of income for 85% is a government payment.

EMPLOYMENT

In 2009 the employment participation rate of Australians with a disability was 54%, compared with 83% for people without a disability. People whose disability was psychological had the lowest participation rate (29%), and the highest unemployment rate (19%). This disparity in part results from prejudice towards people with mental illness.

In the OECD countries, the employment rate is between 55% and 70%. Australia has one of the worst unemployment rates for people with mental illness.

HOMELESSNESS

The University of NSW report, *Down and Out in Sydney,* states that 75% of participants in the study of the Sydney's inner-city homeless population had at least one mental illness compared with 20% in the general population. Extrapolating from national figures, about 30,000 people may be homeless in NSW. Effective solutions must address the reasons people with mental illness lose tenancies or are not offered suitable housing.

PHYSICAL HEALTH OF PEOPLE WITH A MENTAL ILLNESS

We know that people affected by schizophrenia have a life expectancy of up to 25 years less than the general population.

Between 35% and 40% of adult smokers have a mental illness.

We also know of the intimate and dangerous relationship between severe mental illnesses and a range of physical health problems, such as heart disease, diabetes and stroke. While medications play a critical role for many people in supporting recovery, we must acknowledge their effects on physical health.

SUICIDE & SELF-HARM

Suicide still occurs too often in NSW, though the rate has fallen slightly in the past decade. In 2012, 707 people died by suicide. In the past 20 years, the rates of self-harm have increased among young women aged 15–24, in contrast to both men and the general community whose rates have remained stable. The reasons are poorly understood.

WHERE WE GO NEXT

The mental health of people in NSW is too important to merely continue the strategies of the past, which have largely failed to create alternatives to hospital care, or provide the support needed afterwards. A lack of service integration has diminished NSW's capacity to keep people out of hospital and living well in the community. As well as health services we need the involvement of community services, housing and employment support.

The community must become the locus of care, and any new approach to accountability must have at its heart a commitment to measure personal experiences of support. There can be no clearer feedback on the performance of our mental health system.

Ben Roberts, left, and Charles Thompson

A NEW APPROACH
TO ACUTE CARE

The mental health team leaders and nursing staff agreed that far too many people were coming to the emergency departments (ED) of Gosford and Wyong hospitals while experiencing episodes of acute psychological distress.

Charles Thompson, director Central Coast Mental Health says: "It's clear it's not optimal to assess clients in the emergency department and have them waiting if they're acutely psychotic or suicidal or extremely anxious."

Loud noises, bright lights and constant arrivals and departures characterise busy hospital emergency departments and may be powerful stimuli that may worsen the condition of someone already in the throes of mental distress.

In late 2012, Mr Thompson and his team decided to progressively switch the emphasis of their assessment service from the two hospitals to the community, even for people in the grip of an acute crisis.

But first the team had to build understanding of the ED diversion project, and consensus for it, among psychiatrists, emergency department managers, mental health consumers, and unions representing staff. This also included briefing GPs, Medicare Locals and community-managed mental health service providers, sending newsletters and engaging with local media.

> **Staff accepted and understood that people should be seen in their home … rather than seeing them in isolation in the ED with perhaps one carer.**
>
> *Charles Thompson director Central Coast Mental Health*

The NSW Nurses Association voted overwhelmingly in a secret ballot in favour of the new structure, despite rostering changes. "Once people felt supported it freed up a lot of the anxiety," Mr Thompson said.

"Staff accepted and understood that people should be seen in their home, where you can do a full psychosocial assessment and you're seeing the home environment and the dynamics of the family, rather than seeing them in isolation in the ED with perhaps one carer."

By early 2014, the community team was conducting on average 15 additional acute assessments a month in people's homes. Since the end of 2013 more people have presented to the service because of a greater awareness of how to get help. The ED mental health team has been able to redirect many of these assessments to the community.

The brief was to be cost neutral, says Mr Thompson. "We've probably saved a little bit of money but what we've saved we've pumped back in to a full-time clinical nurse educator, which we didn't have before."

Ben Roberts, the nurse unit manager for emergency department mental health teams, says: "We're hoping that as the diversion starts working better and people start using community services more, the demand during the afternoon shift will start to diminish.

"If we can reduce presentations to requiring only one clinical nurse and a registrar in the emergency department 24/7, and that is sustainable, that's the ultimate goal."

Elaine wants two things for her son: respect and justice. She has fought for them every day for 14 years since he was diagnosed with schizophrenia.

"I just do it. I live with it," she says of her daily battles to have the realities of severe mental illness accommodated by government services. "For me, there is no choice. He is my son."

Stigma, discrimination and systemic exclusion are the backdrop to the lives of Elaine, her 28-year old son, and her husband and daughter who share his care and support.

"We not only had to see all his potential forgotten about and not able to be pursued, but then we have had to support him in a system that really isn't geared to support people who have very complex mental health issues," Elaine says.

> " My son, because of his illness, may accept mediocre services but as his mother I won't accept mediocre services on his behalf. "
>
> *Elaine, carer*

Elaine believes organisations such as Centrelink and Housing NSW could reduce demands that weigh heavily on someone with mental illness. "Even though those services know ... that my son lives with a debilitating mental illness, they still seem not to understand that on a day-to-day basis he struggles."

She says he is often penalised because of non-compliance. Front-line services, including the police, paramedics and counter staff at government agencies, should have ongoing training, says Elaine.

In her experience, society's structures and expectations routinely discriminate against people with mental illness, sometimes with very serious consequences.

She recalls that when her son had to go to court over a driving offence, he was told to attend in the morning but was not called until the afternoon. "It's too much to expect anyone would be OK, but for someone who lives with paranoid schizophrenia it's impossible."

During the hearing, he kept his hood up, sat down without being invited, and did not make eye contact with the judge, who took exception to his "obvious lack of respect". It wasn't disrespect, she says. "He doesn't have social niceties."

Elaine is routinely excluded even from the most routine information about his health care because service providers say they are bound to protect his privacy. She cannot even be told whether he has had his fortnightly injection of anti-psychotic medication.

"If he starts to become erratic and I know he hasn't had his injection, at least I know what he's dealing with," Elaine says. Living with enormous responsibility and uncertainty has taken its toll on Elaine but she throws her immense energy into advocacy and reducing stigma.

Grief and sadness haunted Elaine in the early stages. "Now I rarely have those moments because it's difficult for me to reconcile what we're dealing with now with what we had 14 years ago," she says. "My son's my son but it's not that boy ... You either hang on to the past, or you can say, 'Well, that was a beautiful part of our life'." ◼

THE REFORM STORY

Mental health reform does not happen in a vacuum. What we do now builds on the work of previous generations – in NSW, Australia and overseas – to make things better for people who experience mental illness, and it requires us to be frank about both their successes and their failures.

Our work in 2014 responds not only to the actions, inactions and injustices of the past, but also to an evolution in the way we understand the human mind, society and the nature of our responsibility towards those who are vulnerable or struggling.

The changes we are proposing in NSW set us at the vanguard of a global movement which emphasises the equality and citizenship of people who experience mental illness and promotes the shared and individual benefits of positive mental health. These philosophies reverse a traditional focus on systems and processes, aiming instead to support and empower people who live with mental illness and their families, carers and communities.

WHERE WE HAVE COME FROM

The 1983 Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled led by David Richmond for the NSW government was a landmark. Mr Richmond, a highly experienced public administrator, had previously worked closely with community-based psychiatrists and social workers providing services to public housing residents.

The report enshrined the notions of deinstitutionalisation and integrated community-based care networks, setting in motion major changes in NSW. Mr Richmond identified – as we do again in this report – the need to fund and provide services that allow consumers to remain "in their normal community environment", and recommended – as we now do – a parallel reduction in the use of specialist psychiatric hospitals.

Mr Richmond emphasised the critical importance of funding and training of front-line staff, and recommended a move towards local responsibility for services. He anticipated the need for co-ordination across government departments and agencies to respond to social as well as health needs; in this Report we develop these ideas, providing examples of how this can work in practice and bringing in the growing role of community-managed organisations.

We are also indebted to the Richmond report for raising ideas of "people's rights" and "normalisation and integration", within the public conversation about mental health support. These ideas, which originated with consumers and advocates, have evolved into our present understanding of recovery.

ANOTHER DECADE ...

The first Australian human rights commissioner Brian Burdekin released the report of the National Inquiry into the Human Rights of People with Mental Illness a decade after the Richmond report. Mr Burdekin said his inquiry was prompted by evidence presented to the earlier National Inquiry into Homeless Children, Human Rights and Equal Opportunity Commission (1989), which suggested the human rights of individuals affected by mental illness were routinely ignored or seriously violated.

He attributed this in part to ignorance and misconceptions about the nature and prevalence of mental illness, and to a widespread belief that people with mental illness did not recover. Groups including Aboriginal people, children, those in rural or isolated areas and prisoners were particularly likely to experience discrimination and "violations of the most fundamental rights", Mr Burdekin wrote.

The money that should have been redirected to community mental health after the closure of institutions that followed

... ANOTHER INQUIRY

the Richmond report, had not materialised, the Burdekin report found, while a lack of co-operation among government and non-government agencies, and the private sector had contributed to a lack of appropriate services.

Like Mr Richmond, Mr Burdekin nominated employment opportunities and housing as critical to people who live with mental illness, and called for greater focus on prevention and early intervention and the rights of carers. He highlighted the need for mental health legislation grounded in the human rights of people with mental illness.

In a 2002 report by the NSW Legislative Council's select committee on mental health, Brian Pezzutti highlighted a need for stronger governance to protect the needs of people with mental health problems within the wider health system.

He called for regional mental health directors to have direct authority over mental health budgets, and for health regions to include in their annual reports both their mental health funding allocations and direct expenditure.

AROUND AUSTRALIA

Notions of recovery, resilience, choice and human rights for those experiencing mental illness, as described in the Richmond and Burdekin reports, are at the heart of reforms being implemented across Australia.

Western Australia created Australia's first mental health commission in 2010, paving the way for reform initiatives set out in the strategic plan Mental Health 2020: Making it personal and everybody's business. The reforms are built on principles of respect and participation; engagement; diversity; quality of life; and quality and best practice.

South Australia's Mental Health and Wellbeing Policy 2010-2015 focuses on recovery, a whole-of-community approach and a commitment to ongoing development of partnerships with government and community-managed organisations, consumers, carers and the general community. The policy supports targets set out in the statewide plan and builds on actions set out in Stepping Up: A Social Inclusion Action Plan for Mental Health Reform 2007-2012.

Queensland's Plan for Mental Health 2007-2017 promotes collaboration among agencies including housing, education, training, employment, community support, health, corrections, justice, disability, police, emergency services and child safety, and endorses an expanded role for the non-government sector in community-based care and support. Queensland established its Mental Health Commission in 2013.

Tasmania's Mental Health Act came into effect in February 2014. The legislation enables people to make choices about the support they receive, while facilitating treatment for others who lack decision-making capacity – if they need it for their health or safety, or for the safety of others. The Act also recognises the important role of carers and family members of people with a mental illness.

Australian Capital Territory's Charter of Rights promotes the interests of people who experience mental illness by outlining their right to respect, safety, communication, access, participation and privacy. It augments the ACT's Human Rights Act 2004, requiring public authorities to protect human rights and take account of human rights in decision making.

Victoria's Mental Health Reform Strategy 2009-2019 signals that Victoria is determined to improve social and economic outcomes for people with mental illness and their families and carers. This reflects principles underpinning A Fairer Victoria, a plan to reduce disadvantage and strengthen social inclusion.

Northern Territory's Mental Health and Related Services Act 1998 was informed by the United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (1991) and the national Mental Health Statement of Rights and Responsibilities (1991).

A WORLD OF CHANGE

When the 194 member states of the United Nations adopted the World Health Organisation's (WHO) Comprehensive Mental Health Action Plan 2013-2020, they committed to mental health foundations of prevention, social equity, community and recovery.

The WHO plan sets out aspirations and a timetable for change. It supports the notion of comprehensive, integrated services in community-based settings and recognises the need for effective leadership and governance, strong research, and human rights protections for people who experience mental illness.

The plan moves away from the concept of mental illness as a medical problem and addresses the need for opportunities for education, employment, housing and social services, presenting them as critical to people's ability to live well according to their own choices. It argues for partnerships among public sector agencies, community-managed and private sectors in areas such as health, education, employment, legal, housing and social services.

It also describes a central role for people who experience mental illness in mental health advocacy, policy, service planning and provision, legislation development, monitoring, research and evaluation.

WHO says people with a lived experience of mental illness should be able to exercise the full range of human rights, find high-quality, culturally appropriate health and social care when they need it, enjoy good general health and participate fully in society and work, free from stigma and discrimination.

England

The British Department of Health's No Health Without Mental Health strategy was published in 2011 and is underpinned by principles of freedom, fairness and responsibility. The idea of choice is also key.

Like NSW, England is addressing this next generation of mental health reform with the acknowledgement that things are already much better than they were in the past. For the future the strategy calls for acceleration in the pace of change, and increasing devolution to local rather than centralised decision making.

These reforms are intended to minimise bureaucracy, empower communities, support more personalised service packages, increase local accountability for spending and services, promote more diversity of service providers and increase social inclusion.

Canada

Released in 2012, Changing Directions, Changing Lives talks about recovery, prevention, choice, removal of barriers, engagement, community, removing stigma and listening to those who have a lived experience of mental illness.

The strategy, developed by the Mental Health Commission of Canada, describes recovery as the ability to live a satisfying, hopeful and contributing life, even when there are continuing limitations caused by mental health problems and illnesses.

Canada's strategy calls for people living with mental illness and their families to become more engaged in the planning, delivery and evaluation of mental health services, and for increased funding with an emphasis on services proven to make the most difference in people's lives. It advocates for the public sector to become a model employer in creating workplaces that support mental health, and for all Canadians to accept responsibility for reducing stigma about mental illness.

The Canadian strategy emphasises the importance of honouring personal stories – to inform policy development but also to affirm and acknowledge a person's experience, both positive and negative, of mental health care and support.

New Zealand

Blueprint ll – Improving Mental Health and Wellbeing for all New Zealanders (2012) extended the recovery approach advocated in the first blueprint in 1998 to include people with less acute mental health issues and those whose mental illness is complicated by alcohol and drug use.

It emphasises the role of family and the community in partnering with professionals in the support process, and the need to see psychological support not simply as a health activity but integrated across government and non-government agencies, including employment, education, housing and social inclusion.

It prioritises the reduction of stigma and discrimination, early intervention and improved support for people with severe, complex or episodic mental health needs, and calls for more focus on improving the experience of care and recovery for consumers.

THE ROLE OF THE CONSUMER MOVEMENT IN REFORM

The Commission formally acknowledges all individuals in NSW, Australia and the world who have contributed to the mental health consumer movement, for without them reform would not be possible. The voices of people who experience mental illness are the heart and soul of reform. The participation and joining of forces of everyone in the community must occur to achieve positive systemic change in mental health.

Although this change has been frustratingly slow, the consumer movement in Australia has had some major achievements. They include:

- focus of consumer rights under the First National Mental Health Plan

- development of consumer advisory groups in every state as part of the First National Mental Health Plan

- development of a national statement of rights and responsibilities (1991 and revised 2012)

- development of the Charter for Mental Health Care in NSW

- commitment and development of A National Framework for Recovery-Oriented Mental Health Services

- establishment of the National Mental Health Consumer and Carer forum in 2002 by the Australian Health Minister's Advisory Council's Mental Health Standing Committee

- support for the development of the national consumer organisation

- support for the establishment of Mental Health Commissions

- appointment of people with lived experience of mental illness as commissioners (National Mental Health Commission) and deputy commissioners (Mental Health Commission of NSW)

The motto "nothing about us without us" was adopted by the consumer movement and emphasises the need for consumers to be at the table in decisions that affect them.

We all owe the consumer movement recognition for ensuring that mental health care now and into the future is: beginning to be based on human rights; moving away from coercive treatment; becoming more recovery focused; and will be provided within frameworks that consider trauma and personal histories and ask a person what happened to them rather than what is wrong with them.

We acknowledge our responsibility to ensure that the sacrifices individuals have made for this movement become the pillars upon which we strive for positive mental health for the people of NSW.

A LETTER FROM **ALAN ROSEN**

In the 1970s we set out on a journey towards the development of a strong, responsive and supportive system of community mental health care. Forty years later, we still have not arrived at our destination.

The first 24-hour mobile community mental health services, on Sydney's lower North Shore, were in part a response to some inhumane practices and conditions in psychiatric institutions, and in part an acknowledgement of emerging evidence that even people with more severe mental illness could be effectively supported outside the old asylums.

As that evidence has grown, we might have expected the transition to community support to have accelerated; instead it has moved forward fitfully and at times stalled or even gone backwards as specialist hospital reinvestment has nosed further ahead of spending in the community.

A succession of national mental health plans during the 1990s and 2000s proved insufficient to create sustained change. States were not offered compelling enough incentives to remodel entrenched mental health systems; evidence-based community services were short funded, diluted or drawn back to hospital sites.

It is true that mental health reform in NSW sometimes looks good on paper, and true that community-focused and recovery-oriented directions are enshrined in existing policies. But in practice, reforms have been fragmented and keep losing momentum. Meanwhile, our human and financial resources are soon dissipated – ineffectively but completely spent.

> **"It's time for us to challenge 'fortress psychiatry' and the regressive influence that an 'elite-in-charge' can exert …"**

We need to rebuild the proven elements of community mental health support into a system that keeps faith with the scientific evidence and which we know will work reliably for consumers and their families. Contemporary evidence supports the inclusion of crisis teams, one-stop shops for every age group co-located in shopping hubs with primary health care, community-based residential respite facilities and assertive community treatment teams.

These interdisciplinary teams should include as appropriate clinicians, peer workers, drug and alcohol, vocational, housing and family specialists, Aboriginal and transcultural mental health workers, pharmacists, dietitians and life coaches.

It is time for us to challenge 'fortress psychiatry' and the regressive influence that a traditional institutional mentality or an 'elite-in-charge' can exert, even after institutions have been downsized or closed.

We must get beyond isolated models of best practice in the community separated by vast wastelands of poor service, and instead develop a transformative culture that can finally fulfil the promise we made 40 years ago to mental health consumers.

DEPUTY COMMISSIONER

RESPONDING TO PEOPLE'S TRAUMA

"It's all about talking and listening", says Alison Green. "We should always be asking questions and considering that people don't behave in a particular way because they just choose to," says Ms Green, the nurse unit manager of the Missenden unit, an inpatient mental health facility at Sydney's Royal Prince Alfred Hospital.

The Missenden unit is embedding a new approach that centres on the expressed needs and wishes of clients. It is called trauma-informed care and recognises that anyone experiencing mental illness brings a history of distress and that hospital care is often highly distressing. Sensitivity to the person, and the willingness to work together to create safety, are part of its core principles.

But beginning to redesign the practices of an acute hospital ward has proved a huge challenge. The active support and involvement of nursing staff is crucial to success. A survey of the more than 50 unit nurses identified areas where they felt they could use more training and support, such as in de-escalating tense situations. Workshops were organised to support staff to develop, through role play, more advanced strategies.

Another issue was the inconsistency and unnecessary restrictiveness of some of the unit's rules. "If someone was hungry then there was absolutely no reason to not let them have a sandwich or toast. There didn't seem to be any reason why someone couldn't have a cup of tea at 2am if that's what they needed, or to go out on the verandah." Ms Green says that with unnecessary and illogical

> **We've got a long way to go with engaging other multidisciplinary staff and staff who have been around a long time. We're looking at another two years at least before we will probably see any obvious change.**
>
> *Alison Green,*
> *nurse unit manager*

rules out of the way, nurses are less likely to end up in confrontation with patients, and have more time to do things that are beneficial. Evaluation of the whole model of care includes surveys, interviews and feedback from consumers, carers and staff.

There is strong evidence, particularly from the US, of the benefits of a trauma-informed approach. But as the first acute facility in Australia to attempt a major redesign along these principles, the Missenden unit's project remains a work in progress.

A formal project management approach ensures progress does not stall. Senior nurses are responsible for addressing the concerns of other nurses in one-on-one conversations, and a steering group that includes a consumer representative, senior managers, clinicians and affiliated staff meets monthly to keep things moving.

Ms Green says a trauma-informed approach is a way to cohesively and overtly recognise that the mental health system can be traumatic to navigate for vulnerable people and that collaborative care involving all disciplines, the consumer and their family is paramount to achieving positive outcomes and recovery.

For the nurses who support patients every day, the challenge is to draw them away from a culture that has increasingly emphasised paperwork and risk aversion, towards a fundamental of nursing – a caring relationship.

SUPPORTING REFORM

Reform is not only about ideas and policies. It is also about securing the commitment of organisations and individuals at all levels to invest their time, energy and resources in a long-term program of change.

The nature and pace of change in the mental health system in NSW will depend on broader government policies, the shape of national programs and funding arrangements, the economy, emerging philosophies and research evidence relating to mental health support, and many other elements of the environment that are dynamic and unpredictable.

The reform directions presented in this document are offered with a 10-year horizon in mind. While some changes can occur immediately, and we must never lose a sense of urgency, the Commission believes it will take a decade to thoroughly re-engineer a mental health support system which now focuses on practices and episodes of care into one which is genuinely configured around a person, family or community.

It is inevitable that during that time, some changes will be achieved faster than we anticipate while others will fall behind. The Commission will revisit these reform directions, assess progress, and inform the public about any revisions that become necessary to the reform goals or the timetable for achieving them.

EVERYONE'S BUSINESS

Sometimes reforms fail because organisations or individuals do not pick up an opportunity for change but wait for a higher authority to request it.

To make a real difference – across all levels of government and community organisations and across the entire spectrum of services that people require – we need everyone to take responsibility for change.

The Government is already devolving decision-making authority in health and community services to regional managers, in recognition that communities across the vast 800,000 square kilometre expanse of NSW know their own needs and are best placed to develop their own solutions. But it takes time and strong individuals to challenge organisational cultures that have been used to accepting instructions from head office.

Large-scale changes are important, such as funding streams that allow people to select their own support packages rather than having an inflexible model imposed on them.

Local and regional changes are important, when organisations are empowered to work together across traditional operating boundaries to respond to communities' particular circumstances – whether those are drought, disadvantage or workforce shortages.

Small-scale changes are also critical, because they can transform the experience of mental health support and establish person-centred, recovery-oriented thinking as an automatic reflex in entire organisations and systems.

When a front-line worker takes the time to ask the reason for someone's distress, or a nurse in an acute unit knocks before entering a consumer's room, they are championing reform.

In this report the Commission showcases the people and organisations who are picking up the challenge and making change happen, at all levels and in all sorts of roles.

THE COMMISSION'S ROLE

The Commission will champion change through its legislated functions of reviewing and advising on services and programs or other issues affecting people who have a mental illness, advocating for the general health and wellbeing of people who live with mental illness, educating the community about mental health, and undertaking and commissioning research and facilitating the sharing of knowledge and ideas about mental health issues.

It will independently and authoritatively monitor and report on the progress of government and other mental health service providers in implementing the reforms generated by the Strategic Plan for Mental Health in NSW, and report this progress to consumers and carers, the community, the Minister for Mental Health or to Parliament.

The unique role of the Commission allows it to

- **review and evaluate services and programs across agencies as well as those outside government**

- **highlight to government particular issues and challenges**

- **provide a separate, independent level of evaluation or review in circumstances where it is concerned about the adequacy, independence or consumer focus of existing monitoring activities.**

It will do this with regard for the roles of government departments and agencies in reviewing and evaluating programs and services within their own portfolios, and the monitoring and reviewing roles of bodies such as the Ombudsman, Auditor-General and the NSW Commission for Children and Young People.

The Commission will also bring together agencies and organisations that can contribute to change at state and regional levels, and support them to build positive collaborations focused on producing real, measurable improvements in people's lives.

It will advocate publicly and behind the scenes for policies and practices that support community wellbeing and assist people who experience mental illness to live well according to their choices and priorities.

And it will ensure its own work and that of others reflects the priorities of consumers and carers by involving them at all stages.

A LETTER FROM **ROBYN SHIELDS**

The Australian Aboriginal people have been acknowledged as the oldest living culture in the world.

To consider mental health recovery and social and emotional wellbeing for Aboriginal and Torres Strait Islander people, we as a society need to understand and acknowledge the journey.

Our traditional ancestral land continues to have symbolic meaning, which is etched into our cultural understanding of the landscapes, gives respect to our identity as a people and is designed to sustain and guide current and future generations.

Our cultural existence and interconnectedness among Aboriginal groups over many generations is a result of the powerful collaboration, negotiation, communication and mutual understanding among the groups.

Today, most Aboriginal people live with the traumatic consequences of the destruction of these powerful and protective cultural tools, alongside the more visible cultural destruction that breaks families and communities.

Despite the positive changes in the lives of some Aboriginal people, there are the constant reminders that true recovery is complicated, difficult and that we still have a long way to go.

Aboriginal people still suffer from poor physical health and from chronic mental distress and mental illnesses. There are high rates of premature and preventable deaths and some of these are associated with high suicide rates particularly in our young men.

"These problems should not and cannot be handed to our next generation."

Poorer literacy skills and lower educational attainment continue to reduce opportunities for Aboriginal people to gain meaningful employment, own their home and live life to their potential. Instead, many Aboriginal people live in overcrowded conditions or experience homelessness. Others are part of the over-representation in juvenile and adult prisons.

For real change to happen we must carefully consider issues about power and control; acknowledge that past policies have largely been a failure; recognise that Aboriginal people must be included in all levels of discussions; and have an all-of-government approach to ensure that empowerment comes through self-determination.

Despite many past reports highlighting these very issues, recommendations have been largely ignored, underfunded, made unsustainable, or not implemented.

These problems should not and cannot be handed to our next generation. My hope is that government and the Aboriginal community, with providers of support services, will rise to this challenge with genuine conviction and with a true commitment. That can come only through acknowledging the wrongs of the past, learning from them and never repeating them.

DEPUTY COMMISSIONER

Donna Stanley

USING CULTURE TO IMPROVE CARE

Donna Stanley is the vastly experienced clinical leader of Aboriginal mental health at the Western NSW Local Health District, based at Bloomfield Hospital in Orange, where 21% of patients are Aboriginal despite making up only 7% of the population of its catchment.

But she is used to other people's confusion about her position. "We have Aboriginal people admitted to the units here and … people often misunderstand the [clinical] role and you get referred to as a liaison officer."

Though supported by the hospital executive, her role is poorly acknowledged. Ms Stanley says system-wide neglect of Aboriginal mental health and social wellbeing can mean even senior doctors and nurses lack confidence to talk to an Aboriginal person about their life.

"One of the first things I'd want to ask is, 'Who are you? Who's your mob? Where's your country?' she says. "I think people can learn how to actually engage in that conversation."

Ms Stanley says those conversations may have a direct bearing on the person's mental health. If people are away from "country" there may be a longing or yearning to return there for healing processes to happen. "As a clinician it's your job to find out a bit about the person, their community, what the dynamics might be like in that community, how they accept and relate within that community context, because at the end of the day they're going to go back to that community."

Ms Stanley is one of about 100 people in NSW who have qualified through Charles Sturt University's

> ❝ **There's always going to be a place for Aboriginal people. We bring a unique set of skills in terms of our cultural knowledge.** ❞
>
> *Donna Stanley,*
> *clinical leader*
> *of Aboriginal mental health*

Djirruwang program, a three-year bachelor of health science (mental health) degree exclusively for Aboriginal students. The program prepares graduates to be mental health workers, with particular reference to the issues and needs underpinning Aboriginal people's higher rates of psychological distress, and their experience of emotional and social trauma.

She recently led Bloomfield's positive response to a request by an Aboriginal man to take bush medicine, having determined his physical symptoms came largely from psychological distress and his strong belief meant traditional medicine was likely to give him relief.

"Some of the staff were asking, 'How do we know it works? What's the efficacy?' Ms Stanley says. "I said, given that it's been used for 40,000 years, that must be some evidence to say it works. Our people believe it works."

She is often called on to interpret issues of grief, loss and trauma, common among Aboriginal people arriving at hospital in acute distress.

When a man was asked recently by a family member not to attend a funeral, his grief escalated, exacerbating his mental health problems. Ms Stanley was able to help his care team appreciate the magnitude of his distress because of her training and understanding of the significance of funerals.

"I believe there is a role for both identified Aboriginal positions and for Aboriginal people who sit in mainstream positions," Ms Stanley says. ■

JASON

Embedded in Aboriginal traditions are many powerful tools for healing. Healing happens through connection with country, culture, language, family, song, dance, art and more.

Cultural concepts of wellbeing are crucial for Aboriginal people to address all their needs – physical, emotional, spiritual, cultural, community – in the context of the devastating and lingering impact of colonisation on their communities.

Traditional Aboriginal culture underpins the Gamarada healing program. Meaning comrades or friends in the Gadigal language of the Eora Nation, it emerged out of the recognition of unmet needs and lost potential among men in Redfern.

Ken Zulumovski, founder and director of Gamarada Indigenous Healing and Life Training, was running a social and emotional wellbeing program for men at the Aboriginal Medical Service in Redfern and "this was the cornerstone of the program and where some of the first Gamarada participants came from".

The program isn't restricted to Aboriginal men. "Since 2007, we have run back-to-back weekly programs of 7-10 weeks' duration. More than 1,000 men, women and youth have been through our doors," he says. Practical techniques and life skills help participants deal with their energy, emotions and reactions, to empower them to break damaging patterns of behaviour and achieve positive goals. He says the sessions support the organic emergence of leaders in the group, who are encouraged and trained. The program is flexible enough to be expanded and has already been adapted to address suicide prevention, depression, anxiety, social phobias, and drug and alcohol issues.

> **"**
>
> **If we fail to strive for community-wide healing, then all future investment in social programs in Indigenous communities will be like building a house on quicksand. Any success in achieving the decolonisation of the psyche of Indigenous Australians has the potential to increase wellbeing of the broader Australian society.**
>
> **"**
>
> *Tom Calma, Aboriginal and Torres Strait Islander social justice commissioner, 2008*

For Jason, a participant and aspiring leader, Gamarada has been life changing. He says he's become a new person through the camaraderie, the family and the spiritual wellbeing within the program.

He says since he left jail last year Gamarada has enabled him to get back on his feet and feel confident in today's society.

"I was in an isolated position and the only way to break out of that was to get among my own people and get back with my community." Jason has lived with schizophrenia for more than 24 years.

"I find Dadirri … the most satisfying [part of the program]. Dadirri is a breathing exercise and once you harness the breathing in and out through the nose your senses are enlightened," says Jason.

He loves using all his senses to connect with "what's going on around you while you're doing your breathing exercises, getting back in touch with Mother Nature. And I like that bit because when I stress … I do Dadirri … and that enables me to function for the day".

"I'm on a campaign at the moment where I'm going to try and see if I can take Gamarada … into my local area, for local people around there to get some identity and spiritual healing inside themselves …" he says.

"My main concern is the homeless and the prisoners … it would be beneficial for them to seek alternative therapy into healing …" Jason says.

"I'll recommend this program to anyone because it's changed me, it really has. I don't have my family around but I've got support, I've got community and I've got kinship. Kinship is most important." ■

ABORIGINAL WELLBEING

Special strengths exist in Aboriginal culture, which considers mental health to be part of a continuum that applies not only to individual people but to extended families and entire communities and is not separate from physical health and spirituality.

This perspective, which is sometimes described as social and emotional wellbeing, has much to teach all of us as we increasingly recognise the intimate connections between our mental health and our backgrounds, cultures, beliefs and experiences.

Aboriginal people also have particular mental health needs as disadvantage and discrimination combine with the devastating grief and trauma that are a consequence of the past systematic removal of children and destruction of communities, and the continuing experience of loss from incarceration, illness and premature deaths of family members.

Even when Aboriginal people appear valued and successful by the measures of our wider society, they may still feel marginalised by the power imbalance between Aboriginal and non-Aboriginal Australia and by the dominance of non-Aboriginal voices in all our public agendas.

Aboriginal people have made it clear they do not want non-Aboriginal people telling them what they need. Aboriginal people want to decide and build their own destinies, but they recognise this cannot be achieved in isolation. A delicate balance between self-determination and support, separateness and mainstream involvement needs to be found.

Through the Commission's consultations and continuing engagement with Aboriginal people and communities and with the help of our own Aboriginal colleagues and advisers, we have identified the following areas for urgent action. We have also begun to develop approaches to implementation that aim to honour Aboriginal people's autonomy while offering support on their terms.

1/3 of Australia's Aboriginal population **lives in NSW** (208,500 people)

8.5 – 9.3 YEARS LIFE EXPECTANCY GAP between Aboriginal and non-Aboriginal people in NSW

MENTAL ILLNESS PROBLEMS account for **10%** OF THE GAP

In 2013, **Aboriginal and Torres Strait Islander prisoners made up 23%** OF THE NSW PRISON POPULATION

Aboriginal people are **TWICE** as likely as non-Aboriginal people to experience high or very high levels of distress

Aboriginal people are **3 TIMES** as likely as non-Aboriginal people to be hospitalised for intentional self-harm

SUICIDE RATE OF ABORIGINAL PEOPLE IS 1.4 TIMES THAT OF NON-ABORIGINAL PEOPLE IN NSW

RESPECT, KNOWLEDGE AND UNDERSTANDING

Many of the Aboriginal people of NSW do not feel they have the respect or understanding of the mainstream community, including its mental health professionals. This is clearly a poor foundation for mental health generally and it bodes poorly for interactions with the mental health system in particular.

Many Aboriginal people also feel that the mainstream community still has little knowledge or understanding of Aboriginal culture and history as first Australians and as traditional owners of the land.

People describe feeling worn down by the repeated need to educate doctors, front-line emergency service workers and health workers in basic Aboriginal history, which should be well known in the entire community. This includes the impact of the Stolen Generations and the effects of grief on the mental health of their loved ones.

They describe the stigma they experience on the basis of their Aboriginality, and its effect on the type of support they are offered – in particular a common assumption that drug and alcohol use must be involved when an Aboriginal person experiences mental illness. They report a general cultural insensitivity, including a lack of awareness that many Aboriginal families fear their children will be taken from them, which can make them wary and reluctant to seek help for a mental health problem.

TOWARDS CHANGE

- This fundamental lack of understanding is being addressed at multiple levels, but most importantly through school education, which reaches nearly everyone at a time when their beliefs and attitudes are being formed. Aboriginal culture and history are already key areas of learning for both Aboriginal and non-Aboriginal children, and we need to continue to celebrate and reinforce this knowledge across the curriculum and throughout the community life of schools. This encourages a sense of cultural identity and pride among Aboriginal children, and enhances their psychological resilience.

- School education about mental health should encompass an understanding of Aboriginal concepts of social and emotional wellbeing.

- Professional education, training and development for all health and mental health workers needs to strongly emphasise Aboriginal perspectives on health and wellbeing – including the importance of family and community, cultural sensitivities, and the impact of the Stolen Generations and the role of intergenerational grief and trauma. This education and training must be ongoing and evaluated.

- We should support a quality improvement approach towards the cultural safety of mainstream mental health services, including the development of culturally safe feedback mechanisms so that Aboriginal community perspectives are included when health service performance is being evaluated. Mainstream mental health services need to be culturally and trauma informed.

PARTNERSHIPS

It is already NSW Government policy that departments and agencies should work in formal partnership with Aboriginal communities to plan, design and implement health services, including the provision of mental health support.

This is the first strategic direction under the NSW Aboriginal Health Plan 2013-2023, which recognises the NSW Aboriginal Health Partnership Agreement between the NSW Government and the Aboriginal Health & Medical Research Council of NSW and recommends the replication of this partnership – intended to bring Aboriginal expertise and experience into the heart of the health system – at a local level within communities.

The central challenge now is to ensure partnerships – among wider community groups and government agencies and Aboriginal organisations such as regional Aboriginal Medical Services, Aboriginal land councils, Elders and Aboriginal-controlled community organisations – are strong enough to deliver all they can in terms of improved mental health and social and emotional wellbeing for Aboriginal people.

TOWARDS CHANGE

It will be essential to measure the quality, commitment and effectiveness of partnerships from the perspective of Aboriginal people and communities – not merely record the fact of their existence. Aboriginal people should be invited to develop indicators that measure the success of these relationships.

ABORIGINAL HEALTH WORKERS – MORE PLEASE

When Aboriginal people encounter the health system they want to be able to talk to Aboriginal health workers, but there simply are not enough of them to meet demand. The desire to speak to someone from one's own cultural background has clear links to the need to be understood and respected. Having more Aboriginal health workers in the system would foster cross-cultural understanding – everyone learns, everyone benefits.

But there are challenges for Aboriginal people already working in the health system such as Aboriginal liaison officers (ALO) and Aboriginal mental health workers.

They can feel isolated and over-stretched; they feel there are pay inequities, and roles can be too generic, resulting in staff feeling they are spread too thinly and not supported in developing specialist expertise.

Aboriginal people also need to feel safe working in the system and in their individual roles; people can feel discouraged and vulnerable if their position is not explicitly valued and integrated in service provision.

Ensuring safety extends to supporting the mental health of Aboriginal workers, who may be traumatised by their continuing exposure to problems and tragedies in their communities, and to ensuring roles are culturally appropriate – for example in matters of men's business and women's business.

TOWARDS CHANGE

- We should promote initiatives to encourage and support Aboriginal children through the education system and towards higher education. Education of young people 'pulls up' the community as a whole.

- Establish more Aboriginal-designated positions within the health system and ensure they are filled. Ensure that training places and jobs are linked geographically to maintain a flow of new people into real roles.

- Establish a regular state wide survey of Aboriginal health workers and mental health workers within the local health districts, community-managed organisations and Aboriginal medical services, to learn their views on how well services and programs are meeting the needs of Aboriginal people.

- Increase supervision, mentoring and support for Aboriginal trainees in the mental health system.

KEEPING OUR PROMISES

There has been no shortage of goodwill towards Aboriginal people and communities, expressed in reports, plans and inquiry findings. But the action has generally failed to live up to the words.

Aboriginal people have told us they are tired of reform that runs out of steam, of grand commitments that lapse from lack of energy or follow-through.

As we seek to move further in supporting Aboriginal people to achieve better mental health and social and emotional wellbeing, we must at the same time acknowledge and revisit the commitments that have already been made, and ensure we either redouble our efforts to keep earlier promises or else identify more meaningful aims. It is not acceptable simply to ignore the past and move on.

We must also recognise the time and expertise generously given by Aboriginal people who have been extensively consulted in the development of those previous commitments. By doing this we will honour Aboriginal people and show them that we are serious in our intentions.

TOWARDS CHANGE

The Commission proposes a comprehensive review of commitments made in NSW that address the mental health of Aboriginal people and communities, and of the progress made towards them.

This review should be followed by an assessment of whether any outstanding goals or actions should be maintained, or formally replaced by new commitments that respond better to our understanding of what people need.

SERVICES DESIGNED FOR PEOPLE

Many Aboriginal people living in NSW find the state's health, mental health and social services provision confusing, fragmented and inflexible. They want services that can respond effectively to the nuances and complexities of their individual circumstances. This becomes particularly important when a mental illness is part of the picture and an individual or family is dealing with more than one department or agency.

TOWARDS CHANGE

Create flexible systems that allow workers from different departments, services and agencies, as well as the individuals and families involved, to collaborate.

Establish what works in improving the social and emotional wellbeing of Aboriginal people. Opinions sometimes seem to outweigh evidence.

Everyone working in mental health needs to consider how they can make things better for Aboriginal people. Care and support need to be culturally appropriate – not simply an add-on but a first principle that is part of all service delivery.

FOLLOW THE MONEY

Aboriginal people are calling for greater transparency about funding arrangements for Aboriginal health and mental health services. There is a concern that money is not allocated where need is greatest, and a desire to know how spending decisions are made.

This is linked to a perception that money is being subtly diverted away from Aboriginal-specific or community-controlled programs, towards large mainstream services that do not understand the needs of Aboriginal people.

Competitive tender processes must be designed in ways that complement government commitments to Aboriginal self-determination.

When communities identify that a service needs to be co-designed or delivered by Aboriginal people, the tender specifications must reflect this.

We must also build the capacity of Aboriginal community-controlled organisations to respond to tenders and be partners within consortiums.

TOWARDS CHANGE

- **Ensure Aboriginal views are prominent in spending decisions that relate to mental health and wellbeing support services for Aboriginal people.**

- **Ensure competitive tenders and other forms of contract or spending allocation do not disadvantage – even unintentionally – organisations that may provide valuable services in the community but have less expertise in government processes.**

- **Support Aboriginal controlled community health organisations to work together to access government funding, for example through consortiums.**

HEALING

The need for healing centres, places and programs was raised by Aboriginal communities and organisations as a way to increase focus on appropriate mental health services for Aboriginal people in rural and remote NSW.

The NSW Government's OCHRE (Opportunity, Choice, Healing, Responsibility, Empowerment) plan recognises that healing is a key step towards any reconciliation, especially as many previous government programs and policies contributed significantly to the trauma, loss and pain felt by many Aboriginal people.

Healing includes promotion of self-determination, leadership and ownership of healing by Aboriginal people.

The Commission believes the OCHRE initiatives – which emphasise education, opportunity, self-determination and strong governance – can have a positive impact on the mental health and social and emotional wellbeing of Aboriginal people in NSW, and are essential in adopting a whole-of-life, whole-of-community, and whole-of-government approach to individual and community wellbeing.

In working with NSW Aboriginal communities and NSW Aboriginal Affairs in supporting the implementation of the OCHRE plan, the Commission will advocate for:

- **improving the access of Aboriginal people to culturally appropriate mental health services provided by mainstream and Aboriginal community-controlled health organisations**
- **Aboriginal community-managed healing services that embed Aboriginal cultural perspectives within mental health recovery and peer-managed support services**
- **the need for culturally appropriate mental health first aid and mental health literacy training in Aboriginal communities.**

TOWARDS CHANGE

- **We must recognise Aboriginal intergenerational and individual trauma, grief and loss, and make a true commitment to supporting healing and providing trauma-informed care.**

- **We need an increase in cultural competency of NSW government mental health workforce and the relevant workforce of other sectors that provide services to Aboriginal people with a mental illness and their carers.**

- **We should support culturally appropriate mental health first aid and mental health literacy training for Aboriginal communities, which includes Aboriginal trainers with a lived experience of mental illness.**

EVERYONE COUNTS

Many people seek mental health support without telling the service provider that they are Aboriginal. Sometimes they are not asked, although it is generally policy that everyone should be asked whether they are Aboriginal or Torres Strait Islander. On other occasions people feel inhibited from mentioning their Aboriginality by the fear of stigma or discrimination; it is a common experience that professionals may attribute mental health problems in Aboriginal people to drug and alcohol use or take their distress less seriously. Because of their recent history, people may also fear adverse consequences if their Aboriginality is linked to their mental distress – for example the fear their that children might be removed from their care.

The Commission supports concerted efforts to establish the Aboriginal status of anyone who seeks mental health support. Only then will we be able to gauge the real patterns of mental distress among Aboriginal people, and provide services that are adequately funded and truly aligned to people's needs.

TOWARDS CHANGE

- **We need to ensure people feel safe when they tell a doctor, psychologist, social worker or other professional that they are Aboriginal, and ensure workers always ask.**

- **We also need to systematically measure and publicly report on Aboriginal people's experience of the quality and cultural appropriateness of the support they receive, from government, community-managed and Aboriginal community-controlled organisations.**

WHAT SUCCESS MEANS

The connectedness that characterises Aboriginal communities, and their perspectives on health and mental wellbeing, mean it may be difficult to break change down into simple, clear performance scores. We need to find new ways both to insist on reform that is meaningful to Aboriginal people, and to measure the progress we make across many domains of social and emotional wellbeing. We need Aboriginal people to take a central role in describing what successful reform looks like for their communities.

THE COMMISSION BELIEVES

- efforts to support Aboriginal mental health and social and emotional wellbeing should always be grounded in respect for Aboriginal self-determination, and programs must be co-designed, implemented and managed in partnership with Aboriginal people and communities. It should not be assumed one person or group speaks for others

- Aboriginal communities should be empowered to develop ground-up approaches, owned and driven by the communities themselves – including by Aboriginal people with a lived experience of mental illness

- The Aboriginal community is best placed to advise on the provision of culturally appropriate services

- All service providers need to be accountable for the results of the work they do for Aboriginal people and communities, and should be required regularly to show how they support improved mental health and social and emotional wellbeing.

Peter Bryant, left, and Eamonn Corvan

A GROWING CONCERN

BRINGING SERVICES TOGETHER

The fruit and vegetables have been a roaring success, transforming the diets of the people who tend the Mudgee community garden – clients of the community mental health service, some of whom have experienced severe long-term problems.

Clients take the produce home, and Housing and Accommodation Support Initiative (HASI) workers help people learn to cook. There are also regular barbecues.

"We're talking about really, really unwell clients who don't get the chance to socialise, who have often been abused," says Eamonn Corvan, nurse unit manager of the community mental health team. Most visitors to the garden – built with local business donations on a disused tennis court tucked behind a church – have schizophrenia or bipolar disorder.

The project has grown out of an extraordinary depth of co-operation between the mental health service and a local general practice group, to ensure people's physical and psychological health are supported in parallel.

It centres on a full-day clinic with Dr Peter Bryant, a mental health worker and GP, in attendance. This gives better support to people with more complex mental health needs than either service could offer independently. This is important in a small town such as Mudgee – with a population of 9,000 but which draws on a catchment of about 18,000 – which does not have a resident psychiatrist.

> "Because the GPs are managing more of the clients' medical issues, we aren't getting as many people coming in to see the psychiatrist to have their scripts reviewed. The waiting list for the psychiatrist has dropped and … [that specialist resource] is actually being utilised much more effectively.
>
> *Eamonn Corvan,*
> *nurse unit manager*

The idea is to monitor and treat physical health problems that may be more common in people with mental illness because of medication side effects and poor access to healthy food and exercise; and to extend GPs' skills and confidence in supporting people with mental illness.

Community mental health nurse Teresa Lulund says that before the clinic started, clients' physical health went relatively unattended. "They told us the GPs would concentrate on the mental health issue, even if they were there for a skin check, and they weren't being offered other health interventions such as flu injections or pap smears."

Dr Bryant says he and his colleagues have learnt from the mental health team. "It's experience and it's confidence and it's being exposed to things. General practice can be quite isolating."

While it is difficult to measure, Dr Bryant believes the service "may possibly have reduced hospital admissions" as a result of monitoring people's health more closely and acting to stabilise any problems soon after they emerge.

Mr Corvan says establishing the joint clinic was not difficult. "It's having people who want to really see it work, it's just commitment. It doesn't have to be big. It can actually start off being just a couple of hours, or a couple of clients and a mental health worker accompanying the clients to a GP appointment."

BEYOND THE CITIES

People in rural and regional areas feel they are short changed, and do not have the access to basic services considered standard in metropolitan areas.

Shortages of appropriate supports, networked together to provide service when it is needed by all age groups, areas and times of day, mean people in rural and regional NSW risk being channelled towards forms of care that are not ideal for their circumstances or severity of illness.

In particular, emergency services frequently have to step in when community mental health outreach teams – if available – would be better skilled and equipped to support someone experiencing distress. And hospitals or ambulances may be people's only option out of hours, even for something as simple as needing a new script, if they live in a centre with no out-of-hours medical centre.

The Commission believes in equity for everyone in NSW in terms of the quality and range of mental health support they are able to access.

But we have a problem. NSW is vast and its population widely distributed. A quarter of us live outside the major centres of Sydney, Newcastle and Wollongong. That is nearly 2 million people along the coast, in regional centres, and in rural and remote areas that may be a half day's drive or more from a town with a hospital or GP clinic.

People who live in regional, rural and remote areas experience mental health problems at about the same rate as those in the cities but they face greater challenges as a result, because of the difficulty of accessing the support they need and to the greater visibility of mental illness in a smaller community, which may lead to stigma and the fear or reality of discrimination.

> **Police are a de facto mental health service. Ambulance are a de facto mental health service.**
>
> *Forum participant*

Social isolation can have a disproportionate effect for country people, who may be less able to reach out for companionship in their area, and may struggle more to find meaningful work and activities in a context of higher unemployment and longer travel distances.

And there is evidence of links between mental illness and prolonged drought, and other adverse environmental factors including floods and fires, the loss of markets for rural produce, economic hardship, climate change and de-population – all key issues affecting people in the bush.

People living in rural and remote NSW are more likely to experience socioeconomic disadvantage, and greater exposure to the risk of physical injury, which can have major psychological consequences. And for Aboriginal people living in country areas, disadvantage and higher risk of distress may be compounded by geographic isolation and lower access to culturally appropriate support services.

Some specific challenges and needs in rural and remote communities include transport issues as well as suicide prevention and response. People in country Australia complete suicide at 1.2 to 2.4 times the rate of city dwellers.

People living in the country may also come from diverse cultures or have other physical or social problems that complicate their experience of mental illness and make it harder to identify appropriate supports, while young and older people also have particular difficulties and needs.

These must be critical considerations as we seek to spread the benefits of good mental health as fairly as we can right across the state.

LOCAL PEOPLE ARE THE EXPERTS

Country NSW is not one entity. It is an endlessly rich collection of unique communities.

The people who live in a town or region – including those who experience mental illness, professionals and the wider community – understand the mental health needs of their town or region better than anyone, but their knowledge has often remained relatively untapped as we have insisted instead on one-size-fits-all solutions designed at head office.

TOWARDS CHANGE

- We need to power up the ability of local communities to develop their solutions. This does not mean everything will have to be re-invented from scratch. We can develop broad approaches to care and support that may be generally suitable in smaller or more remote communities, and we must insist on certain standards of support. But we must be prepared for people to modify those templates and go off script when they need to, to make the most of resources or respond to particular local situations. And we must get better at promoting locally developed solutions to other communities that might benefit from applying them.

- We must explicitly authorise people to work at a local level across agencies, across tiers of government, and with the community-managed and private sectors, wherever this provides the most rational and effective solution to a local problem. Such relationships are particularly valuable when a community needs to respond to adversity, such as a natural disaster.

- We must also ensure local services and solutions are communicated clearly to local people, so everyone knows where to go in a crisis and for more long term support.

¼ of people in NSW live OUTSIDE major cities

800,000 square kilometres – the area of NSW

91% of psychiatrists have their main practice in a major city

People per square kilometre

UK 263
US 34
NSW 9

MORE SUPPORT FOR MORE PEOPLE

We know people outside our main cities are more likely to struggle to find appropriate mental health support.

Mental health professionals are in shorter supply, which results in differences in rates and types of care between rural and urban populations. Delays before seeking help for anxiety and depression appear to be far more prolonged in rural areas compared with urban Australia – implying that people may be isolated and unsupported while they experience symptoms of mental illness.

Even uniform national programs such as the Better Access scheme – which provides Medicare-funded mental health consultations with psychologists and GPs – are less available for people who live in the country. Overall, Better Access has greatly expanded the number of people Australia-wide seeking support from these professionals, but compared with capital cities, people in rural areas used the services 12% less and people living in remote areas used them 60% less, a Commonwealth government analysis found in 2011.

This may be a reflection of the lower availability of GPs and psychologists in country areas, or of the higher co-payments people may need to make to see them – the proportion of professionals who bulk bill is lower in the country. Distortions and unintended consequences of this sort are common, and they undermine people's ability to seek support.

TOWARDS CHANGE

- We need to do much more to ensure the equitable availability of relevant support for people who seek it outside major towns and cities. This may mean accepting a wider range of support services, provided they are effective. There is growing evidence to support: the development of neighbourhood 'clubhouses' – where activities focus on members' strengths and abilities rather than their illness; the use of peer workers; community wellbeing centres; and outreach services that do not depend on the availability of psychiatrists, psychologists or GPs.

- Tele-consultations may fill the gap when someone needs access to a particular service that is not available in their area. We should develop a coherent, statewide approach to the delivery of tele-consultations via videoconferencing links to support people who experience mental illness – and create an expectation that city services and professionals will share their expertise. But we accept that this cannot replace face-to-face professional services.

- Emerging eHealth services, such as mobile phone applications that support people directly to manage their mental distress, may be particularly relevant to people in rural and regional NSW because they are truly universally accessible and may be less stigmatising than using a bricks-and-mortar service. They may also be more acceptable to young people in the country, whose use of services is particularly low. We must be prepared to support the development of e-mental health programs and monitor their quality, as they are likely to become an important resource for people outside the main centres.

NO SHAME

Many people who live in country areas pride themselves on their resilience. Rural communities live at the mercy of the elements much more than people in cities. They are more likely to be directly affected by the impact of droughts or floods, as entire local economies – especially those based on agriculture – may depend on the weather.

Living and working to the rhythm of climate cycles requires great personal strength, and this toughness can translate into a reluctance to admit vulnerability or seek help when in trouble. Mental health difficulties may be interpreted as weakness by people who expect themselves and others to push through times of trouble, and who may therefore be hesitant to seek or offer support for psychological distress.

Compounding this reticence, people in small communities avoid seeking help from professionals who are already known to them as neighbours or through local networks. People may fear their difficulty will be revealed, and that this will reduce their standing in their community.

TOWARDS CHANGE

- **Stigma and discrimination about mental illness need to be challenged wherever they occur, but a different approach may be necessary in rural and regional NSW. We should involve people in the country in co-designing anti-stigma campaigns that respond to the particular fears and concerns experienced by people in their communities.**

- **We should promote helplines and e-mental health services which, because of their anonymity, may be more acceptable to rural people as an initial way to seek help, but accept that they cannot replace face-to-face support services.**

WORKING IT OUT

Mental health professionals are unevenly distributed across NSW and while some country regions are relatively well supplied, people in other areas struggle to see psychiatrists, psychologists and even GPs. In this context, emergency hospital services are frequently used to compensate for a lack of community-based support, which may lead to inappropriate care.

The mental health workforce and its limitations – both in numbers of professionals and the scope of their practice – is one of the most important bottlenecks that prevent people in rural and regional NSW having equitable access to mental health support.

TOWARDS CHANGE

- Peer workers have a particularly important role in rural settings, where geographic isolation may be more intense and the opportunity to share personal experience more limited. We should support the expansion of peer worker training and development in rural areas.

- We should ensure the mental health system supports links between GPs and acute and other community services to develop GPs' skills and confidence in helping patients manage their mental health issues. If GPs know there is always someone they can call on for consultation and advice, they will feel more empowered to assist people with more complex mental health conditions, and keep them out of hospital.

- A comprehensive approach should be developed to attract and retain mental health workers in rural and regional areas. This may include enhanced career pathways and incentives to encourage psychiatrists, psychologists, Aboriginal mental health workers and peer workers to relocate from urban practice.

- To better meet needs and target resources, we must understand more about investment across government directed at people with a mental illness.

Inside my house it's Italia. Outside it's Australia," says Anna, who migrated to Sydney with her husband Dante and two toddlers in 1969, when she was in her late 20s.

As she has grown older, Anna has been beset by health problems. She has a muscle degenerative disorder, which leaves her stooped and with poor mobility. Heart disease, diabetes and thyroid problems compound her disability, and are major factors in a lasting depression that has drained Anna of any optimism and caused her to withdraw almost entirely from the wider world.

"I don't think I will get better. I am constantly angry. I act out and things get on my nerves," Anna says with the support of an interpreter. "Why can't I do what I want to do?"

> **I am constantly angry. I act out and things get on my nerves. Why can't I do what I want to do?**
>
> *Anna*

Anna used to own and run an Italian restaurant. For 12 years until her retirement in 2006, she worked in food services at St Vincent's Hospital in Sydney. Anna looks back fondly on this period. It was the first time she had worked in an English-speaking environment, and she liked the fact that her experience and skills were valued, regardless of her poor English.

Now she is preoccupied with her family – the two children who migrated with her and twins born in Australia. She worries ceaselessly about their relationships and careers.

Anna follows Italian politics but otherwise mentions no interests or pastimes. She has returned to visit family in Italy only once since migrating and her mother and brother have died since then. Her grief coincided with concern and fear for Dante, who was diagnosed with bowel cancer about the same time.

Her children are supportive of Anna; she has never been to a medical appointment without one of them to accompany her and translate. Anna can give her

Medicare number and spell her name in English but defaults to Italian to talk in detail about her health. But her connections to the wider community were never strong and now barely exist.

Anna and her husband moved from Leichhardt – the hub of Sydney's Italian community – to Earlwood, another inner-west suburb. An Italian family lives next door; a Turkish family lives on the other side. Anna stays away from the local Italian church. The people she knows are acquaintances, she says, not friends.

An emergency department visit some years ago when Anna was experiencing an episode of acute anxiety, led to her first consultation with a psychiatrist and then a number of psychologists. Anna takes medication for her continuing depression, and does not expect to manage without it.

She now sees an Italian-speaking counsellor, provided through Italian community organisation Co.As.It. and funded by a grant from the NSW Government.

Italian-speaking mental health professionals say older members of the Italian community often lack understanding of counselling and other forms of psychological support and what they can achieve: "They aren't engaging with the notion that they can help themselves," says one. "Indeed the opposite is often truer, with clients wanting to know what the mental health professional can do for them, and more specifically to fix them."

Anna likes the fact that in her counselling sessions, she feels listened to and has someone who understands the feelings she describes. But she expresses no particular expectations from the counselling process and is guarded on the question of whether she has hope for the future. "I don't know. I can't tell you yes or no," Anna says. "If I wake up, it's a good thing."

A QUESTION OF DIVERSITY

Australia is a successful multicultural, multi-faith, multilingual nation. So, it might be tempting to think a convenient, one-size-fits-all approach can meet the mental health needs of people from an immigrant background.

While individuals or communities might fall into this category, they by no means form a homogeneous group.

NSW is very culturally and linguistically diverse (CALD) with more than 27% of our population born overseas. More than 23% of us speak a language other than English at home, and nearly 4% don't speak English well or at all. More than 260 languages are spoken in NSW.

In NSW, Chinese languages – mostly Mandarin and Cantonese – are the most commonly spoken other than English. Arabic is the next most common, followed by Vietnamese, Greek and Italian. For people aged over 55, Italian is the most common language other than English, followed by Cantonese and Greek.

The relative youth of recent arrivals – they are younger than the general population – is an important consideration for the issue of mental health because adolescence and young adulthood is the peak period of onset of most mental illness.

In contrast, older immigrants as a group are older than the general population. We need to consider health issues such as post-traumatic stress disorder, depression, anxiety, stress-related psychosomatic illnesses, and age-related memory loss which may trigger suppressed memories of trauma.

It's also important to recognise the mental health and wellbeing needs of the children of immigrants – those born here who make up the second generation – and indeed of subsequent generations. While their experience varies by their parents' country of origin, they too can experience stress in finding their identity between their family's traditional culture and the culture of the society in which they are now living.

ARABIC SPEAKERS are the largest group of carers

20,735 PEOPLE PROVIDE SOME FORM OF UNPAID ASSISTANCE

This represents **11%** of the Arabic-speaking population in NSW

compared with **9%** in NSW overall

x2 NUMBER OF CARERS IN ARABIC-SPEAKING COMMUNITY IS ALMOST DOUBLE THE NUMBER IN OTHER CALD COMMUNITIES.

Other communities with relatively high carer numbers are

15% OF ITALIAN SPEAKERS

14% OF GREEK SPEAKERS

> **…schizophrenia
> … means you should hide your children…
> in the five years while my daughter was being diagnosed …
> in my culture I felt isolated … so many people in the Greek community
> are uneducated about mental health.**

Campsie stakeholder and carer

A HISTORY OF TRAUMA

The act of migration itself is a significant risk to mental health, especially when the circumstances have been very traumatic.

A person's capacity to cope is impaired.

They may have arrived as an asylum seeker, as an unaccompanied minor, from a refugee camp or a country experiencing conflict. They may also have spent a long time in mandatory detention.

Refugees and asylum seekers are particularly vulnerable. Traumatic experiences such as being exposed to violence, war or torture can affect people long after the events have passed.

It takes time for immigrants, refugees and their families to adjust. Reshaping your personal identity can be stressful and it's different for each person. Our culture not only influences the experience, expression, course and outcomes of mental illness and wellbeing, but also how, when and if we seek help and how we respond to health promotion, prevention or treatment interventions.

Access to services is fragmented because of issues such as language, low levels of mental health literacy, limited knowledge of types of services available, shame and stigma, lack of interpreter use by service providers, confidentiality concerns and so on. Visa types can also affect Medicare eligibility. Detained asylum seekers are not eligible for Centrelink services.

TOWARDS CHANGE

A society that lets us express our multicultural identities, beliefs and practices can help us to adjust – and that bolsters our mental health. But it is crucial that care and support services take any history of trauma into account and be aware of the health and wellbeing needs of all age groups.

GPs and ethnic community organisations must connect directly with their communities in relation to mental health support and education. We need to ensure there are structures in place to make this happen.

STIGMA AND TABOO

Stakeholders tell us there is considerable stigma and taboo associated with mental health issues, not only in recently arrived communities, but even in more established communities such as Greek, Italian and Russian. The stigma about issues, such as suicide, can be so significant they are not even acknowledged in the country of origin and so are not seen to exist.

TOWARDS CHANGE

Education about mental health issues as well as mental health services needs to be tailored and delivered by appropriately trained care and other professionals who are sensitive to and knowledgeable about our diverse communities.

RISK FACTORS

ISOLATION
is a particular risk for smaller, more recently arrived communities, women and people in rural areas.

PERCEIVED RESILIENCE
of more established communities means their needs are often overlooked because it is assumed they already have supports in place.

POOR GENERAL PHYSICAL
of immigrants tends to be prioritised over mental health.

UNDER-RESOURCED
and culturally inappropriate mental health services are seen as limited in dealing with multicultural communities.

TOWARDS CHANGE

WE NEED

- **more research on mental health issues in our multicultural communities**
- **a stronger multicultural mental health workforce**
- **flexible funding arrangements for services**
- **support services for carers**
- **early intervention services.**

SEXUALITY AND IDENTITY

Being lesbian, gay, bisexual, transgender or intersex doesn't mean you have an intrinsically higher risk of mental illness or suicidal feelings. But there is an increased risk for those of us who belong to LGBTI communities and it's the result of being subjected to discrimination and exclusion.

Most international and Australian studies have found LGBTI people experience mental health issues at a significantly higher rate than heterosexual people.

- They are more than twice as likely to have anxiety disorders (in particular lesbian and bisexual women).
- They report higher rates of depression and mood disorders.
- They have significantly higher prevalence of past suicide attempts.
- Same-sex attracted youth in particular have significantly higher risks of self-harm and suicidal behaviours.
- Australian data on suicidality confirms that LGBTI groups have elevated rates of suicidal thoughts, plans and attempts.
- Gay men with HIV have higher rates of depression associated with factors such as socio-economic deprivation, isolation and withdrawal.
- Nearly three-quarters of LGBTI people report some experience of depression.

The highest rates of almost all forms of violence are perpetrated against transgender people. Little data is available on the experiences of intersex Australians.

- In Australia, 2.7% of men and 2.3% of women identify as homosexual, bisexual or undecided/other sexual identify.

- 6% of men and 8.5% of women report some same-sex sexual experience.

- Transgender (which includes transsexual) people have an internal sense of gender that differs from their birth sex.

- Intersex people are born with a physical variation that differs from expectations of male or female sex.

Up to 80% of same-sex attracted and gender-questioning young Australians experience PUBLIC INSULT

20% explicit threats   **18%** physical abuse   **26%** 'other' forms of homophobia

80% of this abuse occurs at school

Homophobic abuse and rejecting reactions are associated with feelings of SHAME, ISOLATION and LOW SELF ESTEEM, and may contribute to HIGHER RATES OF SELF-HARM, DEPRESSED MOOD and SUICIDAL BEHAVIOUR

TOWARDS CHANGE

Mainstream mental health services and initiatives must be inclusive of LGBTI people and their diverse issues. True inclusion means they and their issues must be visible, particularly in programs, services and resources; policy frameworks and guidelines; and research, monitoring and reporting.

LGBTI community and mainstream services must work in partnership to build the capacity of both. But we also need to invest in enabling the LGBTI community sector to engage with the mental health sector as partners. Leadership, participation and ownership by the community must be a focus of all services.

CULTURAL AWARENESS AND INCLUSION

A lack of LGBTI knowledge and cultural competency leads to poor-quality service

TOWARDS CHANGE

Health professionals and other organisations can respond appropriately only if they develop greater knowledge and understanding. Training for the broader health workforce, community organisations and human service professionals – along with education within the community – are important ways to improve services.

ACCESSIBLE AND APPROPRIATE SERVICES

Issues including economic, geographic, timeliness, care co-ordination and continuing care for people undergoing gender transition – as well as the perception of a lack of LGBTI sensitivity and responsiveness – challenge accessibility for LGBTI people.

TOWARDS CHANGE

In NSW, most people who identify as LGBTI use mainstream mental health services so it's vital these services meet their needs. Good-quality research and rigorous evaluation will improve our understanding and responses.

PREVENTION AND EARLY INTERVENTION

The current focus is on crisis intervention and predominantly medical models of mental health.

TOWARDS CHANGE

Prevention of mental illness should also be a priority within LGBTI communities. Mental health issues are preventable, and interventions such as supportive counselling during adolescence can reduce the risk of later mental health problems or drug and alcohol misuse. We need a comprehensive approach that builds protective factors into people's lives but also addresses social factors that contribute to people developing mental illness or suicidal behaviour.

TACKLING STIGMA AND DISCRIMINATION

Discrimination and stigma are problems not only in the general community. Historically, the relationship between LGBTI communities and psychiatry has been very sensitive. This is because being LGBTI has itself been seen as a mental illness rather than the mental illness being acknowledged as a likely consequence of the discrimination, violence or exclusion they experience.

TOWARDS CHANGE

We need training for service staff in LGBTI mental health and wellbeing and must support an increase in the LGBTI mental health consumer workforce. We also need community responses to combat stigma and discrimination.

SPECIAL CONSIDERATIONS

LGBTI people from culturally and linguistically diverse backgrounds face additional barriers, such as discrimination within their own community.

It's a challenge to find an LGBTI responsive and inclusive service in rural and remote areas of NSW, where access to mental health services in general is already limited.

Mental health and alcohol and other drug services must be integrated because of a higher rate of coexisting mental illness and alcohol or other drug dependency among LGBTI people.

TOWARDS CHANGE

We need communication among government, services and LGBTI communities to harness the expertise of LGBTI communities in the development, delivery and evaluation of initiatives, with targeted inclusion of particularly marginalised groups.

We must support collaboration among government agencies, mainstream mental health services and LGBTI organisations. We need targeted, tailored initiatives to complement inclusive mainstream initiatives.

We need specific training and support for government agencies, mainstream services, mental health services and community-managed organisations on LGBTI issues.

HEALTHY BODY AND MIND

The United Nations Convention on the Rights of Persons with Disabilities states that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability".

Unfortunately, for people living with mental illness, especially severe mental illness, this equality – which includes the right to good mental health, physical health and wellbeing, the same access to timely and quality health care and the other supports and services critical to a contributing life – is largely a dream.

People living with mental illness experience higher rates of poor long-term physical health than the rest of the population and for people with psychotic illnesses, the rates are startlingly higher. This is particularly the case with heart disease and diabetes.

Conversely, people whose physical health is poor are more likely to develop depression, anxiety and other common mental health issues.

Conditions such as chronic pain, asthma, severe headaches or migraines, arthritis, epilepsy, kidney disease and stroke are all experienced by people with psychosis at higher rates than the general population. Concerning levels of hepatitis, HIV, deficiency anaemia, Parkinson's disease, injury and poor dental health have also been highlighted among people with mental illness.

CARING FOR BODY AND MIND

It's clear that a holistic approach is needed to ensure adequate, equitable and appropriate care and support of our mental health and our physical health. We must be cared for as more than the sum of our parts or, indeed, our conditions.

In that context we also need to pay attention to the particular needs of Aboriginal people, those from culturally and linguistically diverse backgrounds, those living in rural and remote communities, people who are lesbian, gay, bisexual, transgender and intersex as well as taking into account associated issues such as disability or drug and alcohol misuse.

TOWARDS CHANGE

WE NEED

- **active engagement of all relevant portfolios across governments, noting the importance of a rehabilitation and recovery framework**

- **active engagement and participation of all levels of health care and across all specialities, particularly in primary health care**

- **health professionals to consider and communicate the impact of treatment, including on physical health, and actively manage that treatment in partnership with the individual.**

TOWARDS CHANGE

WE NEED

- to strengthen the workforce and capacity of general practice, community health services, specialist health services, the community-managed sector and allied health disciplines

- partnerships to enhance connections with the chronic disease prevention sector

- to adopt a recovery-oriented approach to medication where it is seen as one tool among many that a consumer may choose

- the risks of long-term use of medications to be monitored and to research and maximise the use of non-pharmacological strategies

- we must engage consumers and their families and carers in promoting positive lifestyle choices and developing appropriate care

- to build physical health into the recovery journey so that mental health consumers have easy access to physical health assessments. Funding should support integrated delivery of services.

We also need specific health interventions in relation to smoking, nutrition and physical activity. These interventions should include

- promoting ideas such as smoking reduction and using existing peer-to-peer support services to promote healthy lifestyles

- informing and training specialist clinical mental health services about nutrition

- improving access to dietitians in community health and, in that sector, prioritising people with mental illness

- providing specialist mental health services with information and training on the benefits of physical activity and motivational techniques

- evidence-based physical activity programs for people living with serious mental illness, including those in bed-based clinical rehabilitation services

- working with key groups such as local government and sport and recreation organisations to expand service models to include people living with a serious mental illness.

HEART OR CIRCULATORY CONDITIONS:

16% general population

27% among people with PSYCHOSIS

6% general population have DIABETES

21% people with PSYCHOSIS have DIABETES

HALF of people with psychosis have METABOLIC SYNDROME

1/3 are at risk of a **CARDIOVASCULAR EVENT** in **five years**

MAIA

Maia with her mother, Michele

Maia and her girlfriends from high school often get together for afternoon tea. Sometimes it's a party. Last time the theme was pink so Maia put a pink rinse in her hair and went with her twin sister Ariella. Maia enjoys listening to books on her iPod and likes receiving a hand massage from her young carers, who take her shopping or to the park.

It's a good life, says her mother, Michele. Maia uses a wheelchair because of her cerebral palsy and has a mild intellectual disability. She's valued in her community and adored in her family, which includes her father and younger brother.

Usually a happy, engaging person with a mischievous sense of humour and an enthusiastic take on life, in her early 20s things changed suddenly during two prolonged episodes of delirium, which revealed entrenched prejudices in the health system.

> **" It's a disability blindness. People see one disability and they don't see anything else ... It's an error of thinking, and it can be a fatal error of thinking."**
>
> *Michele*

"The first time it was completely out of the blue," says Michele. "She didn't know her own name and she didn't recognise family members. She was saying things that were really distressing." Maia was also screaming, obviously in pain.

Michele struggled to convince the hospital how unusual this behaviour was. "Instantly we came up against an attitude of, 'Isn't she always like that?'" Michele recalls.

She found it "profoundly insulting" that Maia's whole lifestyle, personality and network of relationships were disbelieved, and her daughter's distress disregarded amid the low expectations the doctors and nurses had for someone with a disability.

Conflict with the treating team resulted. The hospital identified and treated some physical problems to discharge Maia, despite her continuing psychological distress and confusion. "I said, 'You can't just send her home like this'," says Michele. "They told us to put her in a nursing home. We were scandalised by that … They were devaluing her out of existence."

Michele, herself a doctor, found a specialist clinic that looks holistically at mental health and other needs of people with an intellectual disability. Though not a panacea it provided a strong starting point to identify the physical problems behind much of Maia's distress.

Michele wants knowledge about disabilities clearly embedded within medical and nursing curriculums. She believes that without her professional experience, she might never have been able to navigate a health system that insists on viewing people through their principal diagnosis.

"I work in a public mental health service and when [clients] are physically unwell and they go into hospital they get the same nonsense," Michele says. "It's a disability blindness. People see one disability and they don't see anything else. If it was Maia's twin sister, people would go to the ends of the earth to help her, as they should. It's an error of thinking, and it can be a fatal error of thinking."

INTELLECTUAL DISABILITY

There are more than 125,000 people in NSW with intellectual disability and up to 40% of them also live with mental illness. This is a huge number of people needing a combination of supports that our system largely does not provide.

Specific genetic conditions associated with intellectual disability can increase the risk of mental illness, as can developmental brain abnormalities, and certain medications and their side effects. Those of us with intellectual disability also risk more physical health conditions which in turn increase the risk for mental illness.

If we have an intellectual disability it usually affects our coping skills and our ability to choose and do things for ourselves. This just creates more stress, making us even more vulnerable.

Distressingly, those of us with an intellectual disability experience higher rates of physical and sexual abuse and this too serves only to magnify vulnerability to mental illness.

Our risk of mental illness also increases because our social networks are restricted and we have fewer opportunities to engage in a range of life choices. Other social factors that have an impact are poverty, a higher likelihood of contact with the criminal justice system, negative experiences during schooling, and financial and emotional strain within the family.

If we have milder intellectual disability and good communication skills we are usually able to describe what we are experiencing. But for people with more severe intellectual disability or communication difficulties, mental illness may be interpreted by others as problem behaviours.

EXPERTISE, INTEGRATION AND ACCESS

There are pockets of expertise in NSW which support the physical and mental health needs of people with intellectual disability, but they are scarce and not integrated with mainstream services, so access is limited.

People fall through the gaps between services, with neither the health nor disability sectors taking full responsibility, nor having the right skills to deal with the complexity of the situation. This is further aggravated by the lack of adequate resources.

The NSW Ombudsman has found hospital rehabilitation units are, in effect, becoming long-stay units for people with an intellectual disability. This results from a culture among agencies, the lack of a model of care that specifically addresses the needs of people with both mental illness and intellectual disability, and the lack of appropriate step-down community support to provide transitional care between hospital and home.

Informal care from overworked families forms the backbone of the support people with intellectual disability receive. Inadequate access to services and skilled clinicians adds significantly to the burden on carers, diminishing not only their quality of life but that of the person they care for.

Australian research following a group of children and adolescents with intellectual disability for four years showed

10% of those with **schizophrenia received intervention**

Whereas **35%** of the general population has access to mental health supports in one year

BARRIERS TO BEST PRACTICE

WE DON'T HAVE

- **enough data on the prevalence of mental illness in people with intellectual disability**

- **enough data on the interaction between disability and mental health services**

- **enough training and confidence among mental health professionals**

- **a good understanding among carers, disability and mental health workers of what mental illness look like in people with intellectual disability**

- **coherent mental health service models for people with intellectual disability or sufficient funding to operate them**

- **co-ordination between community-based and clinical services and**

- **an inclusive approach to people with intellectual disability in mental health policy.**

People from a range of backgrounds such as culturally and linguistically diverse communities or people who are lesbian, gay, bisexual, transgender or intersex need special consideration. But Aboriginal Australians with an intellectual disability require a particular focus. They have a significantly higher rate of disability compared with non-Aboriginal people, they often suffer multiple disadvantages and they are over-represented in the criminal justice system. Many mainstream services are not perceived as culturally appropriate or accessible.

TOWARDS CHANGE

WE MUST

- include people with intellectual disability in all mental health reform initiatives

- provide better access to prevention and timely intervention for mental illness where professionals are able to identify co-ordinated and effective care and referral pathways for treatment

- engage in direct mental health service provision within the disability sector

- ensure equitable access to skilled treatment

- establish a pool of specialists in intellectual disability mental health with specialised services supporting mainstream services in providing care

- support collaboration among agencies at local, state and national levels

- have workforce education development and training in intellectual disability mental health for staff across sectors

- develop training for mental health professional groups, including curriculum at undergraduate and postgraduate levels and placement options in intellectual disability mental health

- alert tertiary education institutions to future workforce needs in intellectual disability mental health. Consideration needs to be given to the ongoing training of GPs, including in relation to health care co-ordination

- link data among mental health services, disability services, Medicare, the NDIS and other relevant agencies

- have more and better research.

Monica, left, Rohan and Leisa

TRAVELLING TOGETHER

THE POWER OF PEER WORKERS

The nurses at Lismore Hospital's acute mental health unit thought the woman working alongside them looked familiar.

"Several have come up over the time I've been working there, and said, 'Weren't you that person who used to sit out there on that seat and never say anything?' recounts Leisa, a peer worker at the hospital. "I said, 'Yes, that was me.' They couldn't believe it was the same person."

The development within mental health systems of a peer workforce, in which people who have experienced mental illness are employed to support people in distress, is backed by strong research evidence.

But in a country town, becoming a peer worker often means embracing as colleagues the people who used to lock your door and dispense your medication.

Leisa, who previously had not worked for 23 years, is happy to model what peer work is about. "The staff who work in mental health units rarely get the opportunity to witness people with mental illness being well."

Leisa is a graduate of the Lived Experience Project*, begun in 2011 – the first large-scale project in NSW to support people with a lived experience of mental illness and recovery to achieve a qualification and transition to employment as peer workers. It involves undergoing prevocational training, before studying for a Certificate IV in Community Services Work, and being mentored by a mental health worker to help smooth the transition back into the workforce.

Rohan, also a graduate, now works in the Personal Helpers and Mentors program via the Lismore branch of counselling agency Interrelate.

> " All the literature suggests people become more well. In fact you'll have the most reliable, punctual, engaged staff member you could hope for. "
>
> *Gabrielle Le Bon, social worker*

His role is a new one but has been well supported by his managers and colleagues. "If I want advice and help I'm comfortable asking for it," Rohan says. "At the same time I don't feel like I have to run everything past someone… I've discovered I'm actually really good at relating to people and using my lived experience as a form of expertise. It's the first real role I've had where I feel capable and confident and that's definitely had a positive effect on me."

Monica is using her peer work skills in the mental health and homelessness sector, after being unable to work for more than a decade. She says: "I was under the misguided impression that I needed to be fully recovered to be employable. I felt stuck. I desperately wanted to move forward but I feared that disclosing my illness would minimise my chances because there is a reluctance to employ people with mental health issues. This was an amazing opportunity. I suddenly realised that my lived experience of mental ill health was a desirable skill."

Social worker Gabrielle Le Bon worked in partnership with a range of agencies to develop the Lived Experience Project through the Northern Rivers Social Development Council.

The project was created in response to an identified shortage of skills in the mental health sector, a high incidence of mental illness and a higher than average rate of unemployment in the Northern Rivers region of NSW.

The bigger challenge was educating potential employers and getting them on board. Over time, employers have embraced the unique value of peer workers and the number of paid positions continues to grow. ◼

A MATTER OF JUSTICE

People living with mental illness are not only significantly over-represented in the justice system in NSW, they are also over-represented as victims of crime.

They are over-represented in the system not because having a mental illness makes you behave in a criminal way, but because of the complex interaction between mental illness and a variety of factors such as disrupted family backgrounds, family violence, abuse, use of drugs and alcohol, and unstable housing.

The vast majority, almost three-quarters, of people in the justice system are supervised in the community on either probation or parole. Probationers and parolees with mental health or drug and alcohol issues are substantially more likely to return to prison within a year of release compared with people without those issues.

The reasons for this are also complex. According to a review, people with mental health issues:

- can have functional impairments, such as memory difficulties, that make adhering to community-based sentence conditions difficult

- end up having to abide by more conditions than those without mental health or drug and alcohol issues because, for example, they might be subject to a community treatment order which involves medication and regular visits to health staff

- are monitored and controlled more closely and this means infractions are more likely to be observed and acted upon.

People in NSW with a mental health disorder are

3 to 9 times

MORE LIKELY TO BE IN PRISON

than their non-disabled counterparts in the general population

---

Young people in NSW with mental health disorders and/or cognitive impairment are at least

6 times

MORE LIKELY TO BE IN PRISON

than young people without disability in the general population

---

Up to **65%** of people living with mental illness **REOFFEND WITHIN TWO YEARS OF RELEASE FROM PRISON**

INADEQUATE AND UNACCEPTABLE

Access to services that recognise a complex mix of needs is limited. Not much progress has been made in addressing combinations of issues, such as mental health and drug and alcohol issues, faced by people on remand, people on short sentences, or the much larger population of people on community-based sentences.

Poor planning, inadequate identification and referral, lack of commitment from – and integration with – psychiatric services, inadequate resources, and a lack of suitable accommodation have made it difficult to keep people already arrested out of the system and to prevent them reoffending.

It is unacceptable that people living with mental illness often end up in custody because we don't have appropriate settings that cater for a range of interacting needs, such as mental health, intellectual disability and drug and alcohol issues.

- Elements of mental health support such as care co-ordination are often not available.

- The skills and experience of custodial staff regarding mental health interventions are severely limited.

- There is a lack of acute health care access for people at times of crisis.

- A majority of services are available only in Sydney, with limited access to appropriate health care in rural and regional correctional facilities.

A criminal response to a health matter is no response and does nothing to address the two-pronged stigma people suffer on return to the community: of having offended and of living with mental illness.
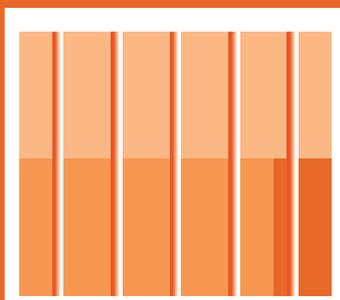
10,000 people in corrective justice system

7,700 with mental health condition

including

- **900** psychotic disorder
- **800** intellectual disability
- **4,900** brain injury

The justice system story is further complicated for groups with particular needs, for example:

- Women have higher rates of mental illness and suicidal thoughts than male inmates. They also tend to cycle in and out of custody more often than men, though on shorter sentences.

- Each year, 3% of children and young people aged 10-17 will come to the attention of the police. Those in contact with the juvenile justice system are vulnerable and disadvantaged. It's estimated about 70% of them are living with mental illness.

- Aboriginal people are already over-represented in the criminal justice system. This is compounded by the fact that many of them are also living with mental illness and have poorer physical health than the general population. Aboriginal women have demonstrated the highest rate of social and emotional wellbeing issues of any group of inmates.

- Forensic patients are those people who have been found unfit to be tried or not guilty by reason of mental illness. These consumers are frequently placed in environments, including correctional settings, that do not adequately address their mental health, physical health, or the factors that led them to commit crime. There is an added burden for those patients with intellectual, cognitive and other disabilities.

TOWARDS CHANGE

- We need a multifaceted approach to the identification and support of people with mental illness throughout the justice system.

- We need early intervention. Improvement will come from strengthening the connections between the social, health, education and justice sectors, and working with families and communities.

- Resources should be directed towards community mental health services, and early intervention programs that support people living with mental illness before their interactions with the corrections system.

- We need targeted and culturally valid health care services and programs.

- We should continue to support programs that up-skill front-line staff, such as the NSW Police staff training program, about mental health and wellbeing issues. This includes training for corrections staff in mental health and wellbeing issues including trauma-informed recovery practice.

- We must divert more people with cognitive and mental health issues out of the criminal justice system and into services that meet their needs and may also be effective in reducing reoffending.

- We need improved support for people moving between the justice system and the community.

- We need more work to ensure people receive appropriate levels of care that address underlying issues that may trigger them to reoffend. For example, we must support collaborative work between NSW Health, Housing NSW, Corrective Services NSW and Juvenile Justice to ensure adequate housing for people released from custody.

- We need more research about the intersection of mental illness, disability and the criminal justice system.

SPECIAL CONSIDERATIONS

Probationers and parolees frequently have complex mental health or intellectual disability and drug and alcohol issues. Mainstream services addressing these needs traditionally operate independently of each other. Care and support is often unco-ordinated.

Mental health cannot be separated from the experience of multiple disabilities, alcohol and drug use, and social disadvantage among Aboriginal people and communities.

This, along with the added stigma of a person's criminal history – regardless of the type of offence – can leave service teams misunderstanding needs or feeling ill equipped to meet a person's needs.

Three most common mental health issues in the prison population are

DEPRESSION, ANXIETY AND DRUG DEPENDENCE

47% of men being treated for mental health issues

54% of women being treated for mental health issues

21% of the prison population has attempted suicide **(27% women and 19% men)**

15% of the prison population has self-harmed

CIRCLE SENTENCING

We need to acknowledge, as part of the mix, the value of alternative cultural approaches, such as Circle Sentencing in Aboriginal communities. This takes the sentencing process out of its traditional court setting and into the community. Community members and the magistrate sit in a circle to discuss the offence and the offender, the background and effects of the offence, to develop a sentence that is tailored to the offender and those affected.
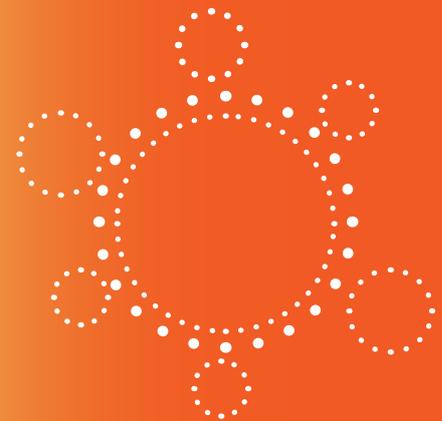
DRUGS AND ALCOHOL

The relationship between mental illness and drug and alcohol use is complex. This is because each exacerbates the other.

Almost three-quarters of those of us using mental health services also have drug and alcohol issues and 90% of those of us in drug and alcohol misuse treatment settings are also living with mental illness.

Findings about treatment outcomes tend to be mixed. This is a particular concern for young Australians because mental health problems and drug and alcohol problems loom large among health issues for those aged 16-24. Most people will never seek face-to-face care and support.

We can't ignore the fact that of all the years of life lost to disability, a high proporation is attributable to mental illness and drug and alcohol misuse.

The average life expectancy for those of us living with both mental illness and a drug or alcohol problem is 25 to 30 years shorter than for people in general.

It is important to recognise the added complexity of dealing with these issues if we are Aboriginal; from culturally and linguistically diverse backgrounds; living in rural or remote communities; lesbian, gay, bisexual, transgender and intersex people; or living with disability. Tailored approaches are required for these groups.

In the longer term, mental illness and drug and alcohol misuse are themselves associated with increased rates of heart disease and cancer. Along with respiratory disease, these are the leading causes of death for people with a history of mental health treatment.

AVERAGE LIFE EXPECTANCY of PEOPLE WITH MENTAL ILLNESS combined with drug or alcohol use

LIFE EXPECTANCY

General public

Mental Illness and drug and alcohol misuse

life lost: 25-30 YRS

25-30 years **SHORTER** than for people in general

We must see a shift in focus from beds to community to reinforce the idea of self-agency, where people have access to the right supports and services to manage well in the community.

POSITIVE CHANGE WILL REQUIRE

- a statewide approach and more funding for training and education and the establishment of a network of workers with a special interest in how drugs and alcohol interact with mental health

- more and better research and evaluation

- a common language across sectors

- ensuring programs don't rely on a single person so they can continue to operate even if that staff member is no longer there

- expert multidisciplinary teams in settings nearby to clients

- supporting alternative approaches such as eHealth initiatives which are emerging as a key force

- training for police and youth liaison officers

- ongoing training to address attitudes towards drug users for GPs and corrective, youth and housing agencies.

ACCESS & QUALITY

The health system tends to operate as a series of silos which makes access to quality, timely and integrated interventions difficult and inadequate. This is particularly so for people living with multiple, interacting issues.

A person's drug or alcohol misuse can be a criterion for exclusion from access to mental health services.

TOWARDS CHANGE

Any system should support the integration and delivery of evidence-based care to address the significant unmet need for people living with mental illness and drug and alcohol problems. But a one-size-fits-all approach is neither suitable nor sustainable.

Best practice comes from services whose guidelines for dealing with interacting conditions are integrated into routine practice. This also means having clear policies and procedures regarding such conditions.

We must see a shift in focus from beds to community to reinforce the idea of self-agency, where people have access to the right supports and services to manage well in the community.

When consumers go from home – the community – to a detox or rehabilitation setting, there are many protective factors and structures in place. When they go back into the community, many of these are removed and a lack of adequate follow-up leaves people at greater risk of relapse and overdose.

Families and carers of consumers must be taken into account to enhance access to

care pathways. It is often families or others who facilitate entry to services and this is usually at a time of crisis.

Consumers are often required to tell their stories or history over and over again, which can lead to treatment fatigue. This reinforces the need for a collaborative, shared-care approach by services.

Prevalence of smoking in people with

ANXIETY DISORDERS

22% smokers

11% never smoked

AFFECTIVE DISORDERS

12% smokers

5% never smoked

WHAT WE NEED

The reform directions presented in this document represent broad principles, and aspirations for a new approach to mental health and wellbeing in NSW.

They represent a fundamental shift – to a future in which a person, family or community sits at the heart of our thinking, services, delivery systems and planning.

That in turn presents enormous challenges to government and community-sector agencies charged with delivering not only health care but also social services, education, housing and the many other services that are critical in the lives of people who experience mental illness.

To make these changes effectively, we will need to incrementally transform the structures we have in place to deliver services – our buildings, workforce, information technology and budgets – reconfiguring them over time so that they can fulfil their primary function of supporting the things that people really need.

This section presents some initial ideas about the changes that will be required to create capable, flexible and responsive infrastructure to take us forward into a new generation of mental health reform. These will evolve, as new evidence emerges to support particular programs and approaches, as new technological developments create opportunities to do things smarter and faster, and as changing national approaches remodel the NSW mental health funding landscape.

INFORMATION IS POWER

We have barely begun to tap the potential of data collection and analysis as a means of improving our services, by giving us real-time feedback not only on the technical performance of systems of support but – crucially – on the experience of people who use them, and on whether their mental health and wellbeing improve as a consequence.

The cost of technology is falling rapidly, vastly expanding our options as we consider how to use information systems to support mental health. For example, hand-held devices that can quickly record key details at the point of contact between a service and a consumer are now becoming cheap enough to be widely deployed to mental health

workers who travel to people's homes. That may reduce the burden of paperwork and increase the chance that the system will hold an accurate and up-to-date record of the person's care and concerns, leading to better quality care and treatment in future.

The continuing development of secure, internet-based technologies for data sharing and data linkage presents new possibilities for collaboration among government, the community sector, consumers, carers, families and clinicians, giving them access to information that can improve planning and help determine the best support for individuals.

Information systems can improve continuity of care between clinical

care and community services and community, family and peer supports for people living with an illness in the community. With effective information sharing, there is less chance of the person living in the community inadvertently losing touch with the service system and the carers, clinicians and other people in their community such as friends and relatives who can assist with recovery.

But first, people who experience mental illness must have the assurance that their privacy will be respected, and that information about them will be available only to the people and agencies that really need to know it, because they are directly involved in supporting them.

TOWARDS CHANGE

- **We should support the rapid deployment of information systems in community mental health services and community-managed support agencies.**

- **We must always ensure people's privacy and the integrity of the records kept about them, but we should nevertheless support information sharing among agencies and service providers when this has the potential to improve care and support and has the person's consent.**

- **We should investigate the potential of real-time feedback systems, which would improve responsiveness and accountability by allowing both consumers and clinicians to record their perspectives, and to document evidence of immediate action in accordance with people's needs.**

- **Services need to be accountable for the quality of support they offer; they should be expected to contribute to standardised data collections in which their practices and results can be compared with others and benchmarked.**

- **Meaningful reports derived from routine data collections should be published regularly, where they can be viewed by people who use services and the community more generally.**

TOWARDS CHANGE

- Thirty years ago the Richmond report called for the closure of long-stay psychiatric institutions. We must bring that promise to fulfilment and close the remaining psychiatric institutions in NSW, redeploying the investment to community-based services.

- We should plan for services to acquire or rent premises in areas where people would go in the course of their ordinary lives – in town centres, close to shops or community facilities such as libraries – and accessible by public transport.

- We should support the development of agreed design principles for mental health facilities of all sizes and scales, based on advice from people who experience mental illness, families and carers, health care architects and interior designers.

- In more acute settings we should explore the potential of different floorplans and technologies to keep people safe without overt forms of security.

BRICKS AND MORTAR

The environment in which care and support are offered is crucially important. Building design sets expectations about what will happen there; it may comfort and reassure, or it may make people feel devalued and fearful. Building location may make the difference between being able to continue work or education, and having to suspend normal life to seek care.

The evidence shows people who experience mental illness benefit from environments where families and friends feel welcomed, where they have control over their immediate environment such as lighting, and where there is artwork and windows with a view of nature. It shows also that staff experience greater job satisfaction when the built environment is more sympathetic.

We want people to be able to find support close to home, in settings that are friendly, readily accessible and that do not restrict or stigmatise them. Hospitals are and will remain essential in the most severe crisis, but the research evidence tells us we can redefine what makes a severe crisis; even when acutely unwell most people can be better supported at home or in a home-like setting.

This move from hospitals to the community requires us to rethink our current and future investment in places where we offer support. Any up front costs will be offset in the longer term by the therapeutic benefits to people who use services.

PUTTING SKILLS TO WORK

By far the most valuable resources we hold in mental health are the skills, knowledge, energy and goodwill of the hugely diverse range of peer workers and other professionals who support people who live with mental illness.

But we still face many serious structural challenges in maintaining and developing a workforce that will carry us through the next decade, providing the diversity of support we need.

The gap we already have between demand and supply for specialist mental health staff is likely to widen in the near future as the ageing workforce retires in larger numbers and fewer people enter mental health professions. The effect will be felt unevenly; rural areas are likely to be hardest hit.

Others will leave to pursue different challenges, or in frustration with their roles or the way services are organised in a sector that can be immensely personally rewarding but also exposes workers to distress, trauma and burnout.

The avoidable loss of mental health workers is expensive in terms of recruitment, temporary replacement and training costs. Less tangible costs include reductions in morale, organisational memory and increased pressure on remaining staff.

Our existing systems emphasise the employment of people with particular professional backgrounds in particular roles. Sometimes, for no good reason, this reduces our ability to respond to local circumstances using a wider diversity of professional skills.

TOWARDS CHANGE

- Peer workers offer hope and understanding as well as knowledge and support to people who experience mental illness, and research shows they can be highly effective in supporting people's recovery. We must develop strategies to train and support a larger number of peer workers and integrate them as respected colleagues in mental health teams.

- Social workers, youth workers, Aboriginal mental health workers – and many others – have key roles to play as we move towards recovery-oriented mental health support and away from a strictly medical view of mental illness. We must ensure their contribution is adequately developed, rewarded and used in practice.

- All mental health professionals, including psychiatrists, psychologists and mental health nurses, are expected to be in increasingly short supply in the decade to come. We must develop robust projections about workforce need and advocate accordingly for adequate training places.

- We need to provide training for existing mental health workers to increase their understanding and skills in recovery-oriented practice and trauma-informed care, recognising that even highly skilled and experienced professionals may not have confidence in these domains.

MONEY

We know that when it comes to spending in our public health system, mental health comes a very poor second to physical health. 14% of the impact of all illnesses can be attributed to mental illness, but NSW Health spends only 8% of its budget on supporting people with mental illness. This means they do not have the same access to the high quality of care as those with physical illness.

We know that funds allocated for mental health care are not always spent on mental health care.

Hospital and health system budgets operate in such a way that money intended for mental health can be diverted to support more visible, politically sensitive issues such as emergency department waiting times or elective surgery waiting lists.

Compounding these problems, funds that are notionally allocated to community mental health may be spent in acute mental health settings, in a state which already relies too heavily on in-patient care.

Persistent under-funding leaches away the capacity of mental health services to respond to people's needs in a timely and appropriate way.

Additional funding comes from the Commonwealth Government, via Medicare and a range of other schemes including *headspace* centres and the Personal Helpers and Mentors program. But these funding sources frequently do not align well with state spending priorities, meaning a person with mental health needs can fall through the gap between the two systems.

TOWARDS CHANGE

- We need to introduce transparent systems within the NSW public health system for protecting and spending allocated mental health funds on mental health services and activities, with priority to services within the community.

- As activity-based funding becomes the dominant model for financing public hospital services, we must ensure payments are structured so that they do not perversely reward local health districts for keeping people in hospital, when they could be better supported in the community.

- As we ask community-managed service providers to take on an increasing proportion of mental health support, we need to ensure that their income is reliable enough to let them plan and develop the programs they offer, to the benefit of the consumers.

- We must carefully monitor the effects of Commonwealth programs, including the National Disability Insurance Scheme, to ensure that if NSW residents do not meet eligibility criteria they are still supported in accordance with their needs.

- Community-managed organisations that wish to operate in the NDIS enviironment will need to adapt their business model to accommodate a system in which consumers choose from a range of available services.

THE JOURNEYS

WHAT WE DID

The Mental Health Commission of NSW was created in 2012 to ensure that reforms to mental health support reflected the needs, wishes and hopes of people who experience mental illness, and their families and carers.

In addition, the Commission always takes into account the special issues that affect Aboriginal people and communities, those living in regional, rural and remote parts of the state, people whose mental illness is accompanied by drug and alcohol use, and those who come into contact with the justice system.

As the Commission approached the task of developing a draft Strategic Plan for Mental Health in NSW it wanted to be sure that everyone in the community had an opportunity for their views to be heard. It developed an innovative series of face-to-face and electronic consultations involving more than 2,000 people. This has allowed us to collect the broadest, most representative range of views from the community, mental health workforce and policy specialists who have contributed vast personal and professional experience.

THE JOURNEYS

The following section summarises the work done through these consultations, which were conducted around the concept of Journeys. The eight Journeys are based on typical experiences of mental health and mental illness across the life course. They reflect the fact that mental illness has a trajectory with different phases. Recognition, intervention and support at the right time can alter this path. They were designed to promote thinking about people – not about services, systems or funding.

In August 2013, more than 100 people came together in Sydney for a day-long workshop to refine the Journey concept. They included people with a lived experience of mental illness, carers, community-managed service providers and representatives of government agencies.

These people, from diverse backgrounds and professional disciplines, then broke out into separate groups according to interest and expertise to discuss individual Journeys in more detail – becoming the core of Journey teams which met on subsequent occasions. They looked for connections in different and traditionally separate functions, in order to find new solutions. They were joined in online collaboration spaces by members of the community, who commented directly on their work in progress.

The Commission

- built an understanding of the issues and opportunities within each Journey

- developed person-centred understandings about the successes and difficulties of our present systems of support, to identify where in each Journey we can make differences that matter

- turned these opportunities into prioritised actions, mindful of capacity, limited resources and the complexity of fundamental change.

The Commission also visited rural communities to test with them how the Journeys resonated in regions with high rates of mental illness and social disadvantage.

The result is the chapters that follow: inclusive, authentic portraits of how our present system of mental health supports applies in practice to people at various stages in their lives, and ideas for how it could be made better. The full suite of original Journey papers developed by the working groups is available online.

The ideas that emerged through the Journeys consultation are further embodied in the Towards Change sections of this report that address the needs of particular groups in the community.

The Commission is confident that the directions for reform contained in this Report truly represent a community consensus, and a mandate for real change that will benefit people who live with mental illness.

The next part of this Report takes us into those journeys.

NSW

People who signed online for the Strategic Plan project
1000

People who attended consultations, workshops, forums
2100

Consumers and carers involved in consultations
880

WHERE THE MENTAL HEALTH COMMISSION HAS TRAVELLED

Albury | Wagga Wagga | Narrandera | Leeton | Griffith | Dareton | Broken Hill | Wilcannia Walgett | Lightning Ridge | Moree | Dubbo | Wellington | Mudgee | Orange | Katoomba Penrith | Blacktown | Sydney | Wollongong | Nowra | Queanbeyan | Goulburn | Gosford Newcastle | Tamworth | Inverell | Armidale | Kempsey | Coffs Harbour | Lismore | Ballina

Ninan, left, and Sarah

READY TO LAUNCH
ON TRACK FOR LIFELONG WELLBEING

Alison Hemsley wants the students who live at Kooloobong Village to aim high, but she doesn't mean only academically.

Soon to be the largest of the University of Wollongong's residences, Kooloobong Village is the first in the world to adopt the principles of positive psychology in a student community. "It's not only about feeling good. It's also about functioning well," says Ms Hemsley, its student residence manager.

That can be about developing the stamina to withstand the stresses of a difficult, years-long course. "They may not have had that experience of endurance, and patience," says Ms Hemsley. "It's a precious skill, to work towards something for a period of time."

She believes a focus on wellbeing in early adulthood can lay the foundations for strong relationships and good decisions all through life, and that the move to uni presents a perfect opportunity to establish positive habits.

In the first semester of 2014 Kooloobong Village was already housing its full contingent of 553 mainly first-year students. Half are Australian, many of them from country NSW, 10% from the US, and the others from just about

everywhere else – 44 nations are represented.

On arrival at Kooloobong Village students are asked to complete a positive wellbeing survey. It asks them how strongly they agree or disagree with statements such as "I am optimistic about my future" and "I know what gives meaning to my life".

The survey orients students to the priorities of Kooloobong Village, before more detailed self-evaluations that help people identify their weaknesses and strengths. These tools – all optional – may prompt students to reflect deeply on their study plans, and that may be uncomfortable particularly for those whose cultures highly value education and professional status as a means of supporting an extended family.

"It's asking, 'is what you're studying bringing out your strengths?'" Ms Hemsley says. "Some students really struggle with that."

Kooloobong Village offers group learning in wellbeing techniques such as meditation and mindfulness. In its communal spaces, activities such as movie nights, cultural celebrations and cooking classes are organised by trained, paid part-time student leaders.

Students can take their concerns about themselves or others to the leaders, who are trained in suicide prevention, first aid, mental health first aid and positive psychology. They include Ninan, in his fifth year of engineering study, who says he "used to be a bit of a hermit" but Kooloobong Village helped him to discover he is extremely gregarious, a discovery that has recast his career ideas.

Sarah, at the start of her second year, has recognised that her "modest and quiet" persona was only part of the picture. She has gained confidence and derives great satisfaction from having made a happy transition from her high school in country NSW.

> **"**All students living in residence are in some way positively affected by living with others.**"**
>
> *Alison Hemsley, student residence manager*

BUILDING COMMUNITY RESILIENCE AND WELLBEING
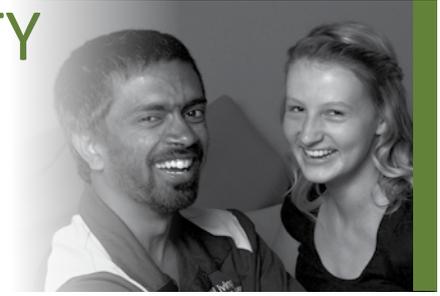
PROMOTING COMMUNITY RESILIENCE AND WELLBEING IS THE KEY

Mental health is a basic human right.

And yet by 2020 depression is expected to be the second biggest burden of disease around the world after heart disease. That's why we know we have to promote resilience, wellbeing and good mental health. If our whole community is well and resilient, we as individuals are more likely to meet our own life challenges successfully.

Social and emotional wellbeing means being able to enjoy life, to cope with stress and sadness, to fulfil goals and potential and to feel connected to others. But it isn't only these things.

Stable and safe accommodation or housing, meaningful employment, educational opportunities and positive social connections are particularly important to those of us already facing mental health challenges but they also help vulnerable people not to fall into mental ill health in the first place.

Just as physical health is not merely the absence of disease, mental health is not merely the absence of mental illness.

Improved community-wide understanding can only help reduce stigma and discrimination, as will prevention and early intervention in the community and shifting care and support away from hospitals.

Promoting mental health and wellbeing helps reduce risky behaviours such as alcohol and drug misuse – including tobacco – and social and economic problems such as dropping out of school, crime, absenteeism from work, and the rates and severity of physical and mental illness.

WHO IS ON THIS JOURNEY?

We are all on this journey together – at least, we should be.

The journey can progress smoothly only if responsibility for mental health and wellbeing goes beyond health service providers to include governments at all levels, non-government – or community-managed – agencies, employers, teachers, police, community leaders and the wider community itself.

Families and carers, including young carers, are on this journey too and they play a significant role. Their physical and mental health and wellbeing are often compromised and this isn't acknowledged enough.

Almost half (45%) of Australians will be affected by a mental illness at some point in their lives, so the human and social costs are immense.

Among the groups particularly at risk of experiencing mental illness are:

- Aboriginal people
- Culturally and linguistically diverse groups (CALD)
- Lesbian, gay, bisexual, transgender and intersex (LGBTI)
- People in regional, rural or remote areas
- People in or leaving the criminal justice system
- People whose mental illness is complicated by drug and alcohol use, chronic illness or a disability
- Families and carers of people with mental illness, including young carers
- Adult survivors of sexual and other abuse
- Children and young people in the care and protection system, including in foster care
- Forgotten Australians: children, including child migrants placed in institutional care or care outside a home setting during the 20th century.

WHY HAS THE JOURNEY BEEN SO TOUGH?

NSW's hospital-based system has undermined a holistic, person-centred approach to

- **care**

- **self-agency**

- **mental health promotion**

- **mental illness prevention**

- **early intervention when mental illness occurs.**

Services are fragmented and people typically have to go to a range of providers to get the help they require, when what they really need is to be able to go to a single one.

We also use language that perpetuates misunderstanding of what the term mental health means.

While the community can readily accept efforts to reduce or treat physical illnesses such as heart disease and diabetes, this isn't the case for mental health care and support because these are less well understood. This is particularly the case for community-based care.

All these things make it harder to promote better mental health and wellbeing in general.

THE RESEARCH TELLS US…

Focusing on mental health can foster:

higher educational achievement

improved relationships

safer & healthier
- families
- schools
- workplaces
- communities

personal dignity

things that support good mental health are:

social inclusion

opportunity for self-determination and control of one's life

meaningful employment, education, income and housing

The evidence suggests the same things protect against harmful drug and alcohol use, and reduce suicide.

being involved in a variety of activitites

having a valued social position

physical and psychological security

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Self-belief
Wellbeing
Support
Choice
Resilience
Information
Family
Self-agency
Community
Friendship
Dignity
Connection
Information
Early intervention
Empowerment

HOW WE CAN MAKE THIS JOURNEY BETTER

We need to shift our focus from illness to wellness and from despair to hope and recovery.

We need to encourage self-agency – when people draw on their own strengths and the resources of their families and friends – because this supports communities as well as individuals.

Self-agency is more than self-care. It's about being able to access the information and tools to care for yourself, make choices and have control over what you do.

The message is one of equal access to support services, self-belief, empowerment and being mentally well.

We need to build a skilled peer workforce at all levels of the mental health system and this means a commitment to capacity building and training. People who have travelled, or who are travelling, the mental health recovery journey must have the capacity and opportunity to take up senior roles, where their profound insights can help to inform and transform policy.

Services that support families and carers and promote their mental health and wellbeing should be an integral part of the approach, not just an add-on.

Any future system must support whole communities to maintain good mental health and wellbeing and to be resilient when faced with challenges in life. This must include the specific needs of diverse groups.

> " Mental health is defined as a state of wellbeing in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community. "
>
> *World Health Organisation*

WE CAN GET THERE

TELL THE WHOLE MENTAL HEALTH AND WELLBEING STORY

Mental wellbeing, strength and resilience come through social and economic participation. We all need to be included socially in our communities and to have meaningful employment and education opportunities, and stable and safe accommodation and housing.

WE'LL DO BETTER IF COMMUNITY LEADERS AND AGENCIES WORK TOGETHER

We need to build capacity and support for mental health and wellbeing in the community through education, training and programs proved to make a difference. We need community leaders to lead, implement and champion change – with tailored strategies or programs – and we must make sure information is shared across sectors.

NETWORKS OF PEOPLE ARE KEY TO MENTAL HEALTH AND WELLBEING

Let's engage with carers, families, colleagues and friends, and not only when people are at risk or experiencing mental health problems. We all benefit when everyone has good mental health and wellbeing and the resilience to maintain them.

WE'RE MORE LIKELY TO GET THERE WITH FEWER ROADBLOCKS

If we are truly person-centred, we'll know what's available in all communities so that we can guide people to the right information, with easy access if and when they need it.

DOING FOR OURSELVES WILL ENSURE LONG-TERM WELLBEING AND RESILIENCE

One size doesn't fit all. We'll all do better in terms of deciding and managing what's right for us if flexibility, self-agency and supportive care planning and delivery underpin everything.

LET'S THINK OUTSIDE THE SQUARE WHEN WE TALK ABOUT PEERS

A peer can be someone in a formal support role, or a friend, a workmate, or someone in a social or sporting club. We should value and let people who can and want to help do just that, especially if they are on the same journey of maintaining mental health and wellbeing or recovering from mental illness.

LET'S IMPROVE ACCESS TO SERVICES BY ACKNOWLEDGING PEOPLE'S CULTURE

We must ensure programs and solutions are welcoming to people regardless of their race, gender, sexuality, age or circumstances, and to their families and communities. If we don't, people won't use them.

THE EARLY YEARS
WHERE RESILIENCE BEGINS

The latest group of children arriving at school from Bellambi Point Community Preschool surprised and delighted their Kindergarten teacher by being the best prepared of any cohort in memory.

Bellambi, north of Wollongong, is an area of concentrated disadvantage, with high unemployment and social problems; at one stage 85% of the children at the preschool had some form of diagnosed communication difficulty.

Bill Feld, the director of Big Fat Smile, the organisation operating the preschool, attributes the change to Bellambi's participation in a pilot program within Early Start, an initiative at the University of Wollongong.

The children and teachers have access to innovative learning technologies and closer bonds have been forged between the preschool and parents, supporting the extension of preschool learning into the children's homes. When parents spend time in the centre, it gives staff the opportunity to model positive interactions with children and offer strategies for use at home.

Fathers in particular now spend more time at the centre, sitting with their children as they group items, solve puzzles and play musical notes on a responsive, visually appealing console or smart table.

For their group time, the children gather round an interactive whiteboard – a bit like a television set – with programming that increasingly will come not only from the internet but via a network linking an eventual 38 Early Start engagement centres, all in rural and regional areas.

Teachers share with parents links for online materials related to books they have read to the children, providing powerful continuity between the preschool and home, where many of the parents struggle with literacy.

The centres are a key element of the $44 million Early Start project – Australia's first large-scale response to evidence that early learning is critical not only to educational success but to ongoing mental health and wellbeing, healthy relationships, and the ability to live steadily in the community.

The project, funded by the Commonwealth Government with significant contributions from the Abbott Foundation and the University of Wollongong, will also support early childhood teacher training, interdisciplinary research and build a children's discovery space.

Professor Paul Chandler, the Early Start executive director, describes it as a social transformation project. "A large number of mental health issues have had their genesis in the very early years of life.

"If you want a highly educated and socially intact and healthy country, then investment in early years of life is critical to that," he says.

> **"**We're really changing society's view that early childhood [learning] is babysitting. It's not. It is where the real learning happens.**"**
>
> *Paul Chandler,*
> *executive director, Early Start*

2 THE BEST START

WHAT IS THE BEST START?

The best start in life is a healthy infant or child growing up in a healthy family. Our community needs families that can provide the social, emotional and cognitive support children need.

A focus on mental health and wellbeing, from promotion, prevention and early intervention through to more intensive support, can contribute to ensuring children have the best start.

If children's social, emotional and behavioural development falls behind in the early years, they may struggle in primary school. This pattern is then likely to continue in high school. Issues faced by adults, such as mental illness, chronic health problems, unemployment and offending, can have their beginnings in difficulties experienced during early childhood.

Recent analysis shows NSW has relatively low rates of developmental vulnerability among younger children compared with other Australian states and the ACT, but there's plenty more work to be done.

There are still real differences in vulnerability between children from low and high socioeconomic backgrounds and the inequalities are larger still for Aboriginal children and children whose parents speak English as their second language.

We now understand better how mental health and wellbeing contribute to strong and happy lives for families and, conversely, how family mental health and drug and alcohol issues create a lifelong risk of poor health, social exclusion and poverty.

'CHLOE'

Chloe is a 15-year-old Aboriginal girl who is pregnant. Chloe wants to keep her baby even though the pregnancy was unplanned.

She has no mental health diagnosis but has issues of alcohol and cannabis abuse as well as possible mood instability.

Her partner is 17 and is known to juvenile justice authorities. He has strong peer associations that include drug and alcohol misuse.

Chloe's family background includes domestic violence and overcrowding but her aunties and her sister are sources of strength for her.

WHO IS ON THIS JOURNEY?

The best start really begins before conception, with parents who are happy, healthy and ready for the challenges of welcoming a baby.

Postnatal depression is well known, but for new mothers the risk lies in the continuation or recurrence of mental illness that precedes their pregnancy, as well as drug and alcohol misuse. For some this overlaps with family environments of violence, abuse and trauma.

Young mothers and fathers are particularly at risk, given that the most vulnerable time for developing mental illness is between the ages of 18 and 24. This group has the highest prevalence of mental illness among all age groups.

These disorders are also commonly associated with drug and alcohol issues, especially in younger males.

Young parenthood tends to be associated with a disadvantaged background, having been exposed to abuse as a child, living in a dysfunctional family, being in an unhappy partner relationship and high levels of financial stress.

WHY HAS THE JOURNEY BEEN SO TOUGH?

It's difficult for our more specialised services – such as child mental health or care and protection – to respond adequately to the needs of vulnerable families for early intervention because their workload is dominated by urgent or crisis support.

Mental health problems in new mothers sometimes follow pregnancies marked by smoking and alcohol use, little or no antenatal care, foetal complications and higher need for hospital services.

While most mothers don't drink alcohol while pregnant, many do, especially if their pregnancy was unplanned.

There are greater risks for mental illness or distress in the weeks and months after giving birth because of hormonal changes, increased stress, sleeplessness and renegotiation of family roles and relationships.

Mental illness can affect the relationship between the mother and her infant, preventing her and the wider family developing a strong emotional attachment to the child, and affecting their ability to provide adequate care. This can mean delayed social and emotional development or significant behavioural problems for the infant.

Mental health issues of fathers are also commonly under-recognised with many, particularly younger fathers, unable to identify their needs and not seeking help or engaging with appropriate services.

Many services identify and support the transition to parenthood for mothers but fail to engage with or accommodate fathers.

Children of parents who misuse alcohol are more exposed to the risk of maltreatment, have greater risk of mental health problems, learning difficulties, behaviour problems and physical illnesses. They are also more exposed to the risk of dying prematurely.

None of these problems is a simple, direct or inevitable consequence of mental illness. Their likelihood depends on the severity and duration of mental illness and its impact on a family's social circumstances, combined with the presence or absence of other supports.

THE RESEARCH TELLS US…

During pregnancy
15-20% of women are affected by **mental health or addiction issues**

Although there has been a strong decline in recent years, an estimated **35%** of women drink during pregnancy

35%

about **20%** of women experience a mental health issue within the first year after the birth of their baby

yet many women go undiagnosed and untreated

10% of children under five have emotional or behavioural problems
Prevalence is higher for kids living in poverty or high-risk environments

Behavioural and emotional issues can include
- DEFIANCE
- IMPULSIVITY
- FEARFULNESS
- PHYSICAL AGGRESSION
- EXTENDED SADNESS
- SOCIAL WITHDRAWAL
- ATTACHMENT ISSUES

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Support for families

Culturally appropriate

Parenthood training

Support for young mothers

Education

Prevention

Early intervention

Access to services

Support for young fathers

Support for parents

Integrated services

Self-care tools

HOW WE CAN MAKE THIS JOURNEY BETTER

Investing in the best start to life has lifelong benefits.

We need an informed and aligned approach that includes families, carers, a wide range of health professionals, community-based organisations, social services and early childhood educational support, with mental health and wellbeing promoted as part of each role and function.

We need a system that links the development of family strengths, close-to-home early interventions and personalised support through shared planning and co-ordination that includes harnessing valuable but limited specialist child mental health service skills and capacity.

That system must address complex issues at a family level. Mental health and drug and alcohol issues will be part of the mix but alongside the social support services provided by a range of agencies.

If the most vulnerable children are to get the best start, we will have to address stigma, bring together mental health services and those focused on behavioural issues, and integrate social and mental health services.

In particular we must continue to develop early childhood health services that meet the needs of Aboriginal families for culturally safe and appropriate support.

> "
>
> The strongest influence on children's development is the quality of the parenting they receive, and the nature of their home learning environments. These have effects on many areas of development, including self-esteem, academic achievement, cognitive development and behaviour. Optimising parent-child relationships and home learning environments are important goals for early intervention.
>
> "

Benevolent Society

WE CAN GET THERE

IT'S NEVER TOO EARLY TO PROMOTE MENTAL HEALTH

Prevention and early intervention from before conception, readiness for parenthood programs, and reducing the rate of unintended pregnancies have the potential to improve many things for parents and infants, including mental health and wellbeing.

WE'LL GIVE OUR BABY THE BEST START IF WE'RE HEALTHY, HAPPY AND PREPARED

Effective parent-child relationships and home learning environments give children the best chance to develop good self-esteem, achieve academic success, and be physically and mentally healthy.

AS PARENTS WE NEED COMMUNITY-BASED MENTAL HEALTH SUPPORT

If community-based services get better at supporting parents, including when they are in an acute phase, they probably won't have to go to a hospital emergency department in the first place.

IF WE CAN BOND WITH OUR BABY, WE'LL ALL DO BETTER IN LIFE

Social and emotional bonding between mother, father and infant is widely recognised as the foundation for lifelong psychological wellbeing and cognitive development.

SUPPORTING OUR CHILDREN'S MENTAL HEALTH IS GOOD FOR SOCIETY

The early childhood years are when behavioural and emotional difficulties can emerge and where early intervention works, and is cost-effective. But less than one-third of children with mental health difficulties currently receive any professional support.

WE'RE AFRAID TO ASK FOR HELP BECAUSE WE DON'T WANT TO LOSE OUR KIDS

We must address the needs of vulnerable families with mental health or drug and alcohol issues, who are typically identified through child care and protection services, the justice system or after acute episodes of mental illness. Many won't seek help for fear of losing their children.

3 TROUBLED KIDS

WHAT MAKES A TROUBLED KID?

Most kids thrive through childhood with support from parents, family and community. But for some, through no fault of their own, this isn't the case.

They may be kids who have been in negative environments, from conception through the critical stages of early brain development, or who have been victims of trauma, violence, abuse or neglect.

They may be kids whose parents, for a variety of reasons including drug and alcohol abuse or mental illness, struggle in that role.

They may have complex mixes of developmental, relationship, behavioural, trauma and mental health issues.

They are likely to be challenging and disruptive in early education and school, the truants, the 'difficult' kids.

They are the children diagnosed with a conduct problem or anti-social behaviour that reflects the complexity of their home and family environments as much as anything medical.

They are at greater risk of struggling at school, and later of unemployment, poverty, severe mental illness and alcohol misuse and criminal offending.

Children exposed to extreme poverty or disruption – sometimes through immigration – from their cultural, family and community supports are particularly at risk.

A difficult future for these children is not inevitable, but the critical time for doing something about it is in childhood.

WHO IS ON THIS JOURNEY?

Of the 1 million or so school-aged children in NSW, about 100,000 will have mental health problems such as anxiety and depression. One in 10 preschool children (aged 3 to 5) show significant mental health problems, including poor emotional, behavioural and social skills and the rate of mental health problems among children aged 4 to 16 years is about 14%.

Almost a quarter of children live in a family with a parent who has mental illness.

Many are capable parents or have partners or close social supports who help share the load in raising children, but the impact of a parent's psychological distress can still be high.

It can have direct effects on child development and indirect ones through poverty, social isolation and stigma.

Severe and persistent parental mental illness contributes to child emotional and behavioural disturbances and can materially increase the risk of subsequent mental illness.

A substantial number of Australian children live in households where adults routinely misuse alcohol and other drugs and this is often combined with mental illness. These families face very complex issues with drug and alcohol misuse contributing to poverty, domestic violence and relationship breakdown.

Nearly two-thirds of families reported to Community Services have at least one biological parent with a history of either drug or alcohol misuse.

Children and young people with complex mixes of trauma, mental health problems and antisocial behaviour can do a significant amount of harm to themselves and others.

Behavioural issues, particularly those that begin in early childhood, are among the strongest predictors of serious health and social problems in adulthood.

WHY HAS THE JOURNEY BEEN SO TOUGH?

As a society we tend to isolate troubled kids, seeing them as the responsibility and problem of our special education services or care and protection agencies and services. They are, in effect, excluded from a wider spectrum of support and services.

Overall availability of interventions and services that could make a difference to children is low and biased towards crisis support, especially where there is a combination of mental health, drug and alcohol and child safety issues.

Spending on child and adolescent mental health services is a relatively small proportion of total spending on mental health despite offering protection against difficulties later in life and being generally good value for money.

We need a co-ordinated and mutually reinforcing approach from parents, teachers, health professionals and other key adults in the life of a child on this journey. Without it we can't respond effectively.

But we do not have enough highly skilled, well-trained professionals to deliver services, and the ones we do have are not evenly distributed across the state.

THE RESEARCH TELLS US...

FAMILY RELATIONSHIP STRESS

ABUSE, TRAUMA

IMPACT OF STIGMA

Between 21% and 23% of children live in a household where at least one parent is experiencing a mental illness

Children living in disadvantaged families **are more than 3 times** more likely than those in well-off families to suffer from mental health disorders

UNSAFE ENVIRONMENTS

1 in 10 preschool children (aged 3 to 5) show **mental health problems**

About **1 in 4** school children are bullied every few weeks or more

It is estimated that the **45% of children** who have mild or moderate conduct problems **go on to commit half of all crime**

PEER BULLYING

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Early intervention

Intensive and individualised programs

Recovery

Access to services

Hope Peer support

Coordinated approach

Highly skilled professionals

Specialist services

Keeping families together

Support for families

'DANNY'

Ten-year-old Danny is a bright, articulate child to those who know him. He has asthma, which limits his participation in activities.

His mother was abused as a child, has a history of serious mental illness and experiences poor physical health. She lives with Danny and his sister, five-year-old Amy, in a public housing unit in metropolitan Sydney.

Their father is absent and they are not well connected to their extended family. Danny likes playing computer games but has limited peer relationships or social networks.

Danny has patchy school attendance. He is seen as under-performing, as developing oppositional behaviour and there are queries about whether he also has learning difficulties.

HOW WE CAN MAKE THIS JOURNEY BETTER

The children and young people who find themselves on this pathway need more intensive, specialist and individualised services to redirect antisocial or other detrimental behaviour.

We need service systems and partnerships that are integrated and comprehensive across different settings so that it's as easy as possible for parents, carers and children to find their way to the help they need and have a right to.

Investment in school-based programs and support for vulnerable families need to be matched with investment in early mental health and drug and alcohol misuse responses for parents, as well as integrated mental health support for the children.

I CAN GET THERE

I'LL GET ON THE RIGHT TRACK IF I'M SUPPORTED WHEN I START SCHOOL

School-based mental health promotion, prevention and early intervention approaches using social and emotional learning methods will have a positive impact on me.

I'LL STAY ON TRACK IF I GET HELP EARLY WHEN I'M HAVING DIFFICULTIES

Early intervention works. We need the skills, understanding and models of care that promote access to this kind of support for me.

MY FAMILY HAS A LOT OF PROBLEMS AND WE NEED HELP WITH ALL OF THEM

The system needs better, more integrated ways of engaging with families such as mine where mental health issues are complicated by drug and alcohol misuse, violence or abuse.

I NEED GOOD SUPPORT FOR MY SERIOUS MENTAL HEALTH AND BEHAVIOUR ISSUES

Children like me who have a combination of behavioural and mental health issues that generate antisocial behaviour, exposure to the justice system and reliance on care and protection services, need intensive support.

THINGS WILL BE BETTER IF MY WHOLE FAMILY GETS SUPPORT

My needs and the needs of my wider family are easily overlooked in a mental health system oriented to individuals.

Amber, left, and Kale

GROWING UP STRONG
A WHOLE COMMUNITY NURTURED

When Margaret Mulcahy arrived at Coonamble High School at the start of 2013, she was confronted by drains and toilets that were not working, furniture that was scuffed and broken and a library that was under resourced and chaotic.

"People had no sense of identification as a whole community," says the veteran educator and former senior administrator in the Department of Education. The poverty and low expectations that hung over the Coonamble community were mirrored in the school buildings.

She set about making changes. First she appointed a head teacher for wellbeing, knowing that to have meaningful education for her 210 students – more than 60% of whom were Aboriginal – their individual and collective wellbeing had to be addressed.

Every morning, students meet with their year group and dedicated staff members who greet them, check on their wellbeing, ensure they are equipped for the day and have had breakfast. Weekly wellbeing lessons augment those general messages with discussions about problems students may encounter, and strategies to deal with them.

"This strong and planned focus isn't traditionally something you find in all schools, but I wanted that here," says Ms Mulcahy, the executive principal.

"A very large number of our kids have mental health issues …" says Ms Mulcahy. "There are high levels of depression and anxiety, and big issues such as violence, domestic violence and drug use impact many of them."

> " It's about giving them a challenge and saying, 'Don't give up'. We need them to believe in themselves. "
>
> *Margaret Mulcahy, executive principal*

Given the wider traumas of the town, situated two hours north of Dubbo, she says it's not surprising. "There's been a history of suicide … and there is a heightened awareness because of the drought."

She has a lot of scope to act in her students' interests because Coonamble is one

of 15 Connected Communities schools established in 2013 in disadvantaged towns in rural and regional NSW. The principals have authority to work across government departments and with external agencies.

Ms Mulcahy has brokered an arrangement with the community-managed child and family services agency UnitingCare Burnside at Dubbo. It sends a counsellor and trainee counsellor to the school one day a fortnight to support students with more serious social or mental health needs. Families can also use the service, which supplements the school's part-time counsellor.

Ms Mulcahy works closely with the Coonamble Family Wellbeing Project, run by the Commonwealth-funded Western NSW Medicare Local. And she is working with the local Aboriginal Medical Service in the hope of establishing an on-site wellbeing centre.

Ultimately, Ms Mulcahy would like the school to become a hub for students' health and wellbeing services.

Attendance at Coonamble High School is slowly improving and HSC successes in 2013 included one first-in-state result.

4 HEALTHY TRANSITIONS

WHY ARE HEALTHY TRANSITIONS IMPORTANT?

For young people to be happy and contributing members of our community they must be able to move successfully through the different stages of their lives and cope with changes.

They will go through many transitions: from childhood to adolescence, from primary to high school, from adolescence to adulthood, from dependence to independence and from education to employment.

But our current health, education and employment systems aren't really geared to provide the support needed to make sure young people can complete their education, find and keep a job and become independent adults during a time of enormous personal adjustment.

Many are missing out on timely support appropriate to their age, struggling at school and then being excluded from work opportunities.

The implications are profound for them, for their families, the community and our economic future.

We simply can't afford to have huge numbers of young people not realising their potential because we don't support them.

We also need to acknowledge that the routes young people can take to become successful, happy adults don't necessarily go in a straight line.

Bumps are common along the way but they can become positive, strengthening life events.

'ANNA'

Anna is 15, lives in western Sydney and is part of a large Filipino family network.

English is their second language. Anna is a member of a religious youth group.

She has been failing at school and has been diagnosed with an eating disorder.

She uses Facebook a lot to keep in touch with friends and has also been part of a young carers group. Her counsellor there has been trying to encourage her parents to be more supportive.

Anna has frequently sought help from the school counselling/crisis support team.

WHO IS ON THIS JOURNEY?

As many as a quarter of young Australians feel disengaged and are at risk of missing out on living healthy, productive lives.

It's common for young people passing through different life stages to take risks and to experiment – with drugs, alcohol, sexuality and so on.

Issues to do with suicide and self-harm are also very significant for people in this age group.

The teens and early 20s are also the most common time for the onset of mental illness, with 75% manifesting before the age of 24. But there's also evidence that for 50% of people who experience mental illness, the first episode occurs before the age of 14.

One in four young Australians lives with a mental illness and one in three experiences moderate to high levels of psychological distress.

WHY HAS THE JOURNEY BEEN SO TOUGH?

The top three concerns for young people are school or study problems, coping with stress and body image.

These problems come together to put them under enormous stress and can have a negative effect on their mental health and self-esteem.

Only a relatively small number of young people with a mental illness get any care. The types of services available vary considerably from place to place.

There seem to be inequities for young people with particular problems, such as borderline personality disorder. It can be extremely difficult for them to find appropriate support.

Young parents can also find getting the right mental health care difficult.

Our system still often uses unhelpful and arbitrary age cut-offs, which have the effect of limiting access to care at this most important period.

A particular concern is the lack of environments and interventions appropriate to young people's developmental and social needs, meaning young people end up in adult psychiatric wards. This can exacerbate the distress and trauma they experience.

THE RESEARCH TELLS US…

1 in 4

Australians aged 16-24 are living with a mental disorder and one in three experiences moderate to high levels of psychological distress

YOUNG WOMEN About 1/3 — had a mental health disorder — **YOUNG MEN** About 1/4

Young women were more likely to have anxiety or affective disorders than young men

TOP 3 ISSUES OF CONCERN to young people were

school or study problems **38%**

coping with stress **37%**

body image **31%**

These problems cause enormous stress and adversely affect mental health and self-esteem

Mental illness in young men aged 12-25 alone has been estimated to cost the Australian economy **$3.27 billion** a year in lost productivity

Australia loses more than **9 million** working days per annum because of mental illness among young men alone

However, data measuring **YOUNG MEN'S ACCESS TO MENTAL HEALTH CARE** reveals that **only 13%** received any care for their mental illness

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Quality control

Family and carer participation

Early access

Easy access

Sustainable

Youth participation in planning

Peer workforce

Recovery focus

Hope

Effective partnerships

Promoting mental health

Best practice

'CODY'

Cody is 15 and lives at home in Broken Hill, part of an Aboriginal family. His dad is in jail.

Cody doesn't go to school regularly. His childhood development was affected by foetal alcohol syndrome. He uses drugs and alcohol frequently and has been involved with the police and juvenile justice, because he shoplifted alcohol.

His home circumstances have caused concern to child protection services. Cody sometimes attends the Aboriginal Medical Service for treatment for depression and drug and alcohol misuse. His girlfriend is pregnant.

HOW WE CAN MAKE THIS JOURNEY BETTER

If we want our young people to develop resilience, the community needs to rethink how it views young people and how it engages with them.

Young people need public spaces and opportunities where they can feel included, valued and able to express themselves.

But how easy is it really for young people to find a place to enjoy themselves? The term 'youth' tends to have a negative connotation and public and media images of young people are often unjustifiably linked to gangs and danger.

We need to involve young people in mental health support planning and the mental health workforce.

There is already growing awareness of mental illness among young people so we need to build on these foundations, working with groups that have specialist expertise.

Online services need to be boosted. A larger role could be played by e-mental health technologies to allow discreet 24/7 access to care for young people.

Young people's mental health must be part of the agenda for educational institutions, as a key point of intervention for promotion of good mental health and wellbeing, as well as for prevention of mental illness and early recognition and response when someone is experiencing mental distress.

I CAN GET THERE

LET ME CHOOSE THE SUPPORT I NEED WHEN AND WHERE I NEED IT

Adult solutions won't work for me. If you think not enough kids like me are getting support then listen to us about what support we'd choose at school, at home, socially or at work and go from there.

EVERYTHING OLD SHOULDN'T BE NEW AGAIN, ESPECIALLY WITH EARLY INTERVENTION

You already understand how early intervention works best for the different problems I'm experiencing, so please make sure you design your support services to take that into account.

I'D LIKE EASY ACCESS TO ONE-STOP-SHOP YOUTH-FRIENDLY SERVICES

I'll get the support I need if it's delivered in a way I can relate to, including online, and if I can access it from a variety of places, not just through the health system.

I'M DEALING WITH SEVERAL PROBLEMS AT A TIME SO I NEED SUPPORT FOR ALL OF ME

My family and I have a lot of different problems, like drugs, alcohol and domestic violence, and things won't get better for us if services are scattered and don't talk to each other.

I NEED SPECIALIST SUPPORT NOW BECAUSE I'M DEVELOPING SERIOUS MENTAL ILLNESS

I keep hearing that early intervention works but I won't get the help I need if the system continues to operate along historical age limits and categories. Early intervention needs to be tailored for different types of mental health issues.

MARK'S STORY

Life is better now for Mark. **In 2008 he used the $1,400 he received from the Commonwealth Government's economic stimulus package to buy an eight-track recording studio and some cameras. At home at his unit in Katoomba in the Blue Mountains, he writes songs – upbeat pop and jazz.**

He sings, plays guitar and creates videos, which he loads to YouTube. His music occupies him intensely for many hours on most days. "It saved me heartache," Mark says simply.

Heartache has been a constant for him. In his teens he was diagnosed with bipolar disorder and has received medical treatment ever since. He has struggled with relationships. After a marriage break-up nearly two decades ago, he moved to the Blue Mountains to be near his young daughter, to whom he remains close.

"The time from 1997 to 2000 I spent not having anyone or anything," Mark says. "I used to cry a lot. It's miserable."

Mark still lives in the same rented unit as he did then, but now is supported under the NSW Government's Housing and Accommodation Support Initiative (HASI) program by workers from Aftercare, one of several organisations that deliver the program.

They accompany him shopping – Mark prefers not to drive – and often to medical appointments. They go for coffee or visit sites such as the Minnehaha Falls or Wentworth Falls Lake.

> **"** It's just knowing someone will be there ... So many times I've felt a depression because there was nothing in the future. **"**
>
> *Mark*

More importantly, they offer just enough social contact to prevent Mark, who does not have friends he can visit, falling into devastating isolation – from which it can be a short step to becoming unwell.

"It's just that knowing someone will be there," he says. "So many times I've felt a depression because there was nothing in the future."

From time to time, the Aftercare staff accompany Mark on a bigger trip – a day once at Bronte beach, another time to a football match. These activities create lasting memories for Mark, and sometimes inspire his songwriting.

The continuing contact has helped him "feel part of the community. I want to make a contribution". Now he greets tourists and assists them if he can – something he could never have considered in the past when his episodes of depression were so isolating and debilitating.

Mark says appropriate housing, and support to live in it, are essential for people who struggle long term with mental health problems. In an ideal world he would like to see residents in public housing developments better selected for their compatibility with one another – for example the establishment of unit blocks where people, like himself, who avoid alcohol could live away from the sometimes disruptive influence of those who drink.

But that is a side issue. Things are better than they have been in years for the father and musician, who now has things to do and company when he needs it. "People in general are pretty good," he says.

TOWARDS A BETTER LIFE

WHAT MAKES A BETTER LIFE?

Living a better life is a meaningful goal for all of us, whatever our circumstances and experiences. But if you suffer from severe mental illness, a better life can seem out of reach.

It's not about economic productivity. It's about not being stigmatised, socially isolated and lonely. It's about having friends, someone to love, something to do, something to be part of and something to look forward to.

We need to find new ways to promote social inclusion, meaningful participation and genuine community-based care for people with severe mental illness so that they can choose what's right for them to create the better life they want and have a right to.

WHO IS ON THIS JOURNEY?

About 3% of Australian adults live with severe mental illness. About half of these have a psychotic illness or bipolar disorder. The rest are mainly living with severe depression or anxiety disorders.

People on this journey often experience difficult conditions, such as physical illness or drug and alcohol issues, alongside their mental illness and this makes their situation more complex.

Homelessness looms large because we're not as successful as other OECD countries in getting people with mental illness into work.

For some groups, access to mental health care is unacceptably poor, as in the case of some Aboriginal communities where the incidence of mental illness is higher than in the general community.

Many people, especially in rural and regional areas, have a long wait for services or don't get any treatment because the right mix of services isn't available.

There is also a significant impact on friends and loved ones who are carers and provide support. Their own health and welfare, as well as their employment and social participation, are often compromised. The diversity of people's lived experience of mental illness and services challenges us to make sure those services are integrated across agencies and sectors, individually tuned and designed to stick with the consumer and their families so they don't fall through the cracks over time.

'RALPH'

Ralph is a homeless, unemployed man with severe and persistent mental illness. He attends a clozapine clinic.

He has a range of conditions that affect him at the same time so he experiences involuntary treatment from time to time. Last year he was admitted to hospital three times.

While Ralph has been referred to community mental health – and some non-government – organisations, nobody has checked if he is attending these services or if he has had any help with his housing needs.

'SALLY'

Sally is 43 years old and has bouts of depression followed by periods when she is quite well and able to lead a normal life.

She hasn't had frequent contact with mental health services but she has been prescribed medication by her GP and has received a mental health plan which has never been reviewed.

As a side effect of her medication and mental state she is very overweight and her physical health is poor. She's able to hold down a job but her colleagues avoid her and she has few friends. Her family relationships are strained.

She does not receive regular mental health care when she is unwell.

It's a sad reality that if Sally had attempted suicide, lived in a different postcode, or if she had children or other dependants, things would be different.

WHY HAS THE JOURNEY BEEN SO TOUGH?

We still focus on tangible, more easily measured issues such as dollars spent and bed numbers rather than on actual outcomes for consumers.

Despite a notional shift away from the idea of institutional care, there are still nearly 900 funded beds in stand-alone psychiatric facilities.

These account for about 20% of the state's mental health budget. More broadly, most of our mental health budget goes into hospital-based, crisis-driven care.

This is despite findings that nearly half the people occupying acute mental health beds in Australia could be treated effectively in other settings if alternative services were available.

Genuine, community-based mental health care hasn't materialised. We spend less on non-government mental health services than any other state or territory.

The unintended but negative consequences of relying too heavily on acute hospital-based mental health care are that consumers:

- **lose hope and confidence**

- **become isolated from community supports**

- **lose functional capacity, such as housing, and**

- **are more likely to be stigmatised.**

THE RESEARCH TELLS US...

SCHIZOPHRENIA most common form of psychotic illness

affecting 56% of males

with a psychotic disorder

33% of females

47% schitzophrenia

63% of males AND 42% of females with a psychotic disorder ASSESSED AS ABUSING OR DEPENDENT ON ILLICIT DRUGS

mean age of onset
MEN: 23 YRS
WOMEN: 24 YRS

1 in 10 males and 1 in 4 females with psychotic illness are married or living in a defacto relationship

GOVERNMENT PENSIONS MAIN INCOME SOURCE FOR 85.0% of people with a psychotic disorder

58% of males AND 39% of females with a psychotic disorder ASSESSED AS ABUSING OR DEPENDENT ON ALCOHOL

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Culturally appropriate

Partnership

Choice

Recovery   Empowerment

Person centred

Timely assessment

Peer support

Access to services

'TOM'

Tom is 32, single and has a Chinese father and Irish mother. He's lived in Australia since he was eight years old. He had started university with some ambition but dropped out after the first couple of years.

He recently broke up with his girlfriend after a relationship that lasted seven months. His relationships with his family have deteriorated and he regularly lashes out at them.

Tom is unhappy, unemployed, sleeps a lot and has few friends. He drinks heavily and uses drugs often. He recently got into trouble with the police for driving without a licence and possessing a small amount of drugs.

He does have a mental health plan but it hasn't been reviewed nor has he been seen by any public mental health service.

> "
> Helping people to find the right combination of services, treatments and supports and eliminating discrimination by removing barriers to full participation in work, education and community life is the key to the promotion and adoption of a recovery-oriented culture within mental health services.
> "
>
> *National Framework for Recovery-Oriented Mental Health Servic*

HOW WE CAN MAKE THIS JOURNEY BETTER

Living a better life is a meaningful goal for all of us, whatever our circumstances and experiences. But if you suffer from severe mental illness, a better life can seem out of reach.

The focus has to be on supporting recovery, self-determination, enabling mental wellbeing, people's strengths and resilience as well as building networks of support.

Mental health must be a partnership between people with lived experience and their people-to-people networks together with the support of a full range of voluntary, community, social and health services.

And consumers must have 24-hour access to important services.

The partnership depends on shared consultation and planning among consumers, families and carers, and providers and practitioners.

Mental health care systems need to balance a duty of care to provide protection and a duty to human rights and empowerment.

I CAN GET THERE

I CAN CHOOSE WHAT'S BEST FOR ME NOW

Even though I experience episodic or recurrent severe mental illness, I won't need to go to an over-burdened hospital emergency department if I am assessed and given advice quickly and if the links to intermediate levels of support are better.

SUPPORT ME WHEN I NEED IT MOST SO I CAN BE SAFE

If community-based services get better at helping me when I'm in an acute phase, I probably won't have to go to a hospital emergency department.

WORK TOGETHER SO I CAN BE ACTIVE, CAPABLE AND HOPEFUL

I don't need to stay in hospital for a long time but I get stuck there because I don't have a decent place to live. So if the community and agencies work and plan together I'll be able to leave hospital, focus on my wellness and recovery and make a better life for myself.

I CAN STAY IN MY COMMUNITY WITH A LITTLE HELP

Even though my mental health needs are long term and severe, the truth is that many people like me don't really need to be in a secure institution, or even benefit from it. So a good community-based situation would really enable me to achieve and live a better life.

WORK AS PART OF A TEAM SO MY HEALTH AND SOCIAL NEEDS CAN BE MET

I can participate and be happy in my community if my health and social needs are met but to get that happening, health, social and other services have to work as a team to make sure the right skills and resources are integrated and available right there in the community.

PEOPLE WHO'VE BEEN ON THIS JOURNEY BEFORE CAN REALLY HELP ME

I'm not the only person who knows what this journey is like so it would be incredibly helpful to work with people, my peers, who've also travelled this path and can share the wisdom that let them choose their better life.

THE WHOLE COMMUNITY BENEFITS FROM BEING SUPPORTIVE AND WORKING TO STAY HEALTHY

Supportive environments in communities, workplaces and social settings in general benefit everyone, not only people like me who have a mental illness, because wellbeing flows to the whole community and makes for a better life for us all.

Shiree Talbot

FREEDOM, HOPE, RENEWAL
SHARING SKILLS FOR A BETTER LIFE

Being in prison can very nearly break a young woman, says Shiree Talbot, but, in many ways, being released is just as challenging.

"You've come from a place where your every movement is monitored and controlled and where you have very little choice." Ms Talbot says that after leaving prison, there are issues of self-esteem, of feeling worthless, of being powerless.

Ms Talbot runs Beyond Barbed Wire, a mentoring program to help women leaving Wellington Correctional Centre, in western NSW, to make a confident transition back into their communities.

The program, which began in 2013 and is delivered by Barnardos, supports women, and their parenting, for the long-term benefit of their children. They are mostly Aboriginal, overwhelmingly young and usually serving short sentences for relatively minor offences.

Female mentors are recruited from western NSW and a wide variety of backgrounds, ages and interests. They support a woman to move back into her own life at a time when she may be feeling deeply demoralised, and back into the lives of her children who may be anxious and insecure after having temporarily lost her.

> "
> **The research is showing us that if we continue to let these women fall through the gaps, their children are 50% more likely than their peers to end up in contact with the criminal justice system themselves.**
> "
>
> *Shiree Talbot*
> *co-ordinator, Beyond Barbed Wire*

"These are women who have had things done to or for them so many times before. It's about empowering the woman to be the best she can possibly be, and just having someone to walk beside her on the journey she decides to take."

The focus is to encourage the woman, who is usually in severe financial hardship, out of her home. "It's things like going to the swimming pool or spending an afternoon at the park doing art and craft," says Ms Talbot, herself an Aboriginal woman who has spent time in jail separated from her four children.

Their conversations are confidential, though mentors must signal any serious concerns about the woman's children. Barnardos covers small costs, such as a coffee or a milkshake. Licensed premises are the only prohibition.

The mentors, she says, relish the opportunity to use their skills and strengths to help meet the needs of disadvantaged families in their community. They undertake a training program, specially tailored and delivered through Forbes TAFE, and get together every four weeks to debrief and share ideas.

Despite its early promise, Ms Talbot emphasises Beyond Barbed Wire is not a panacea for women who are living in traumatic situations and need intensive professional support.

She urges new approaches to women who offend – whose incarceration rates compared with those of men are disproportionately high and still rising – for the sake of current and future generations.

6 BREAKING THE CYCLE

WHAT DO WE MEAN BY BREAKING THE CYCLE?

The idea of breaking the cycle isn't limited to one type of person or one age group living one kind of mental health experience.

It's about finding ways to remove barriers that stop any of us stepping off a path we're stuck on that keeps compounding the risks we face. It's also about making sure we can get onto a new path that lets us have hope and get what we need to build a better life.

Focusing on breaking the cycle gives us the opportunity to create integrated responses across community, mental health and social services and the justice system in ways that address the causes of the difficulties people experience.

Prevention and early intervention are important but so is finding ways for people already well down a difficult path to get off it and live successfully in the community.

WHO IS ON THIS JOURNEY?

Most people struggling to break the cycle have a background of deep social disadvantage, poverty, unstable parental relationships, and drug and alcohol misuse. This can start at the beginnings of life, for example with the impact of foetal alcohol syndrome.

Combinations of mental health and drug and alcohol issues plus antisocial or criminal behaviour are common features in the lives of children, young people and adults stuck on this path.

These issues often complicate and compound one another. Mental illness or drug or alcohol problems may increase the likelihood of offending and being apprehended, while offending behaviour diminishes positive social connections or access to services that could address the mental health or drug and alcohol issues.

Families are often direct victims of offending behaviour, for example, domestic violence. They can also suffer from the disruption and instability caused by the imprisonment of a parent, leading to insecure housing or homelessness.

Almost half of all NSW inmates are parents of a child younger than 16 and about 18% had a parent in prison during their childhood.

For a small but important cohort of children, the risk of future offending can be identified early as they are at-risk children known to social sector agencies.

It's important to note that people with mental illness are disproportionately represented in the criminal justice system even though having a mental illness doesn't mean you will offend.

'ROY'

Roy is a man in his early 20s whose behaviour began troubling his parents in his late teens. After completing high school he had the same job for a few years and seemed to be doing OK.

But he started missing work and was cautioned by his employer about his poor performance. He began drinking heavily and was three times charged with driving under the influence of alcohol, risking the loss of his licence and job.

Roy's parents encouraged him to see the family GP to get help for his drinking. Roy declined. He was often argumentative and volatile with his parents, which made them concerned for his and their safety. They considered asking him to leave the house if he didn't change his behaviour.

He came to police attention again after hitting a stranger in the city in an unprovoked attack. He claimed the stranger had been saying bad things about him and was part of a conspiracy to ruin his life.

While in remand, a mental health assessment led to a diagnosis of paranoid schizophrenia and Roy was transferred to a prison hospital. His heavy alcohol use seemed to be a form of self-medication. Roy responded quickly to antipsychotic medication but there was concern he wouldn't continue his medication or engage with services once back in the community.

WHY HAS THE JOURNEY BEEN SO TOUGH?

The different, sometimes incompatible, philosophies of the health and justice systems, as well as the paucity of services bridging the two, make this a particularly tough journey.

While there's been some progress in establishing diversion pathways for adults and in providing mental health services – including for treatment of severe mental illness for people on long prison sentences – there are significant gaps in addressing mental health issues among people on shorter sentences, people on remand, or the much larger population of people on community-based sentences.

Breaking the cycle is more complicated for people with entrenched or unresolved issues, such as unemployment or drug and alcohol misuse.

Illicit drug and high-risk alcohol use are the most important predictors of prosecution and imprisonment.

For those who end up in the justice system, there are other barriers to a successful re-entry to the community.

For example, prisoners – whose health tends to be worse than that of the general population – may not have access to appropriate medications, whether for physical or mental illness. There's no continuity once they are back in the community.

Further, a pattern of offending and imprisonment can continue into the next generation because services may find it difficult to respond appropriately to children who have been involved with parents in criminal behaviour.

THE RESEARCH TELLS US…

50% & **67%**
OF MEN   OF WOMEN
are UNEMPLOYED in the 6mths before incarceration,
with 30% of men & 44% of women unemployed for 5 years or more

63% OF MEN **40%** OF WOMEN
were drinking alcohol at hazardous/harmful levels in the year before prison

60% & **37%**
OF WOMEN   OF MEN
in NSW prisons were **EMOTIONALLY, PSYCHOLOGICALLY or SEXUALLY ABUSED** before the age of **16**

Nearly **1/3** of adult male inmates were placed in out-of-home care before **the age of 16**

ALMOST HALF OF ALL INMATES are also a parent of a child under 16 years of age

18% OF INMATES had at least one parent in prison during their childhood

1 in 4 young Indigenous males aged 10-19 are processed through the criminal courts every year

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Breaking-the-cycle programs · **Best practice** · **Mental health support** · Support for drug and alcohol issues · **Housing** · **Employment** · **Prevention** · Early intervention · **Personal responsibility** · Continuity of health benefits

HOW WE CAN MAKE THIS JOURNEY BETTER

We need co-ordinated and continuous health care from first point of contact with the criminal justice system through to successful reintegration into the community.

We must also address community-based stigma and attitudes to ex-offenders with mental health issues.

If we tackle early the complex mixes of trauma, depression, anxiety, developmental delay, cognitive or learning difficulties, intellectual disability and conduct disorder, we're more likely to increase success in living, education and work and reducing the lifetime risk of offending.

With stronger connections among the social, health, education and justice sectors, and working with families and communities we could improve assessment and interventions for vulnerable young people.

Better access to mental health support will not by itself reduce antisocial behaviour and offending. We need a population-based mental health and drug and alcohol approach to help people gain skills and resources to keep their lives on track.

But we also need the justice system to embed ideas and practices that not only hold offenders to account but build a sense of personal responsibility, reduce the risk of harm or reoffending, and address and change antisocial behaviour.

'MATTHEW'

Matthew is an Aboriginal man in his mid-20s who was born with foetal alcohol syndrome to very young parents. His mother became pregnant at 15 and she and Matthew's father struggled with parenthood. His first contact with police was when his mother was the victim of domestic violence perpetrated by his father. She had taken out several apprehended violence orders against his father.

They lived in a house – with up to 10 relatives at a time – with his mother's extended family. Alcohol misuse and violence brought the family into frequent contact with police and the criminal justice system. Matthew's life was marked by disadvantage and unstable relationships.

Matthew started drinking at the age of eight. His school attendance was patchy and he fell behind in reading and writing. He was repeatedly brought to the attention of child protection services by police and teachers as he was frequently malnourished and had injuries from physical abuse. At times he was placed in out-of-home care.

He began offending and using drugs at 14 and had frequent contact with the juvenile justice system. He did not complete his school certificate.

Matthew enjoyed and was very good at sport and, in his early teens, was identified as having promise. But his unstable lifestyle meant this promise was never realised. Mental health difficulties were diagnosed at 18 when he was screened while on remand.

When he is in the community, he finds it difficult to maintain a support base because he does not have stable housing. He oscillates between being homeless and staying with family members.

I CAN GET THERE

IF MY PROBLEMS ARE TACKLED EARLY THEY WON'T GET OUT OF HAND

Children and young people like me who are dealing with lots of issues need help as early as possible. Like me, Aboriginal children and young people, and families and children of prisoners and offenders on community sentences, need special support.

YOU NEED TO KNOW MY WHOLE STORY TO UNDERSTAND MY BEHAVIOUR

If I'm going to be diverted from criminal behaviour then programs must be consistent and take into account not only my mental health and any drug or alcohol issues, but also the values, attitudes and thinking I grew up with.

IF I BREAK THE CYCLE WHILE IN CUSTODY I'M LESS LIKELY TO OFFEND AGAIN

If I can access programs that help me to break the cycle, as well as the mental health and cognitive care I need during short or community-based sentences, I'll be able to get off and stay off the path of offending before I get into really serious trouble.

MY ANTISOCIAL BEHAVIOUR BEGAN ONLY AFTER I BECAME MENTALLY ILL

I'm not in the majority but people like me whose antisocial behaviour resulted from mental illness or from high-risk drug or alcohol use need diversion and treatment within our custodial or community sentences.

JUST BECAUSE I'M IN JAIL DOESN'T MEAN I SHOULDN'T GET GOOD SUPPORT

We should have adequate access to mental health support and treatment of drug and alcohol problems, even if those being supported are in jail like I am.

WHEN I LEAVE JAIL I NEED TO MOVE INTO THE COMMUNITY WITHOUT STIGMA

So that I can move back into a stable community setting, the path that takes me there should meet my individual needs but should also address stigma and community attitudes to ex-offenders with mental health issues.

PAT'S STORY

Last summer was great for Pat. He stood upright for the first time on a surfboard and he has dropped more than 70 kilograms in weight.

It feels like sudden liberty, says the 31-year-old chef and barista.

In his late teens Pat was diagnosed with schizophrenia, preceded by a year of heavy drug use. "In the beginning when I was unwell I was just below 70 kilos and at the height of the weight gain I was 169," Pat says.

Heavily medicated, he put on 26 kilos in the first couple of months. "I did not even notice," says Pat, who recalls being completely preoccupied with trying to re-establish a sense of reality.

In addition to antipsychotic medication, Pat was taking antidepressants – though he did not acknowledge he was depressed. He used to eat for comfort: "Chips, chocolate, lollies … family-sized packs every day. It was a release, eating that sort of stuff."

There were serious health consequences. He was diagnosed with sleep apnoea, a weight-related condition that results in frequent waking, severely disrupting sleep quality.

Throughout his long journey, the psychiatrists who have cared for his mental health have rarely asked him about his weight or other physical side effects of his illness and its treatment. Pat thinks that is reasonable because people who are struggling with severe mental health issues may not be receptive to lifestyle advice.

His parents and siblings have given him exceptional support. His younger brother had a gym and paid for a personal trainer. Another brother encouraged him to take up surfing. "I did hear or read that surfing's really good for schizophrenia because of the endorphins you get," he says.

The weight loss began with a reduction in the dose of the clozapine he still takes, and his improving physical health is supporting his mental wellbeing in an upward spiral. The lowered drug dose "gives you more energy so you're not needing to sleep as much, so you can start being more active because you don't feel so lethargic," Pat says.

Pat moved on recently after 12 years at Cornucopia, the coffee shop on the campus of the old Gladesville psychiatric hospital in Sydney which is staffed by people recovering from mental illness. "It was a long time and a good time," he says. "They made you feel part of the community."

He is working in a new role, pursuing his interest in photography and is considering taking a course in managing a small business.

There is no big mystery to turning his health around. "It was mainly just stopping the foods I was eating," Pat says. "You have cravings and you just have to deny them. It's like giving up anything. It's a habit. Just stop the habit."

> " Now that I've been getting out there and doing stuff, looking back it was like going to jail. It was like a 10-year sentence. "
>
> *Pat*

7 BODY AND SOUL

THE MIND AND BODY CONNECTION

The concept of wellness of mind and body is ancient. We know people who suffer the combination of mental and physical illness fare worse than people with one or the other.

A person living with schizophrenia or bipolar disorder who also has diabetes has a higher risk of dying than a person with diabetes alone.

It's a vicious circle. People with physical illness are more likely to experience mental illness, especially anxiety and depression, and those with mental illness are more likely to develop physical illness.

The physical health issues of mental health consumers are often ignored, or risk factors such as smoking and obesity accepted as normal. Conversely, a dominant physical illness can mask a mental health problem.

The consequences are significant, not only for people, their families and carers but also for the health system which bears huge extra costs when physical and mental illness go hand in hand.

Mental health underlies about a quarter of GP visits so we must find better ways to support medical professionals to recognise and respond to overlapping needs.

WHO IS ON THIS JOURNEY?

More than a quarter of people with diabetes also suffer from mental illness, mainly anxiety and depression.

Research also shows a significant percentage of people living with schizophrenia are likely to suffer serious physical illness and this rises for people taking medications such as clozapine.

However, the norm is that the person with diabetes is treated for that, and the related mental health issues are treated separately or not at all.

Similarly, a person's schizophrenia diagnosis dominates their interactions with the health system even if they are overweight, have high blood pressure or diabetes, heart or circulatory conditions, or other risk factors.

Labels mask a much more complex human being and we need to help health professionals see beyond the dominant diagnosis if we are to provide truly holistic care.

People receive different responses and levels of service depending on whether they are seen for a physical health problem or a mental health problem, even if they suffer from both. The story is worse for those with mental health issues.

'PETER'

Peter is 45 years old. He has schizophrenia and heart problems that are exacerbated by the medications he takes for his schizophrenia. He is a smoker, overweight and has never managed to build the confidence and focus needed to develop a more healthy diet and exercise habits. He lives with his mother. He has medicines, variously prescribed by his GP, cardiologist and psychiatrist. While a care plan was developed a number of years ago, it has never been reviewed, despite numerous changes to his medications. Apart from being told about possible side effects, no one has talked to him about the range of medicines he is taking and how they can be best managed.

PETER'S FIRST CRISIS

Three years ago Peter started to feel severe pains in his chest. He was finding it hard to breathe and began feeling very faint.

Luckily his mother was at home and called an ambulance, which arrived within 20 minutes. The paramedics stabilised Peter and within the hour he was in the emergency department. He was triaged immediately, seen by the specialist who, after a short period of observation, admitted Peter to the cardiac ward.

All this occurred within three hours of feeling the chest pain.

Peter was discharged a week later with a clear care plan, including specialist follow-up. His discharge process included an appointment, the following day, with his GP.

PETER'S SECOND CRISIS

Last year, after a few days of feeling unwell, Peter became increasingly psychotic. As his behaviour got worse, his mother became more concerned for his health and safety so rang emergency services.

She was put through to the ambulance service which said it couldn't help, and suggested she ring Peter's GP or, if he got violent, the police. Peter was not violent, but his behaviour was increasingly distressing and he began to talk about ending his life.

His mother tried his GP but was put through to the after-hours service which said it couldn't help but suggested she call the local hospital. This also proved to be of little help. After talking to several people she was told no one from the mental health team was on duty, suggesting she call the regional hospital.

Peter's mother was now trying desperately to ensure he didn't leave the house as she was concerned she wouldn't be able to stop him killing himself. She finally managed to get hold of someone in the mental health crisis team at the regional hospital, who told her someone could come to see Peter some days later.

By midnight his mother was becoming very tired, a little scared and fearful for Peter's safety as talk of killing himself got more intense. She finally decided to take him to the emergency department. With the help of neighbours and a combination of encouraging words and physical restraint, she was able to get Peter into a car.

One of the neighbours drove them and they arrived at the emergency department at 2am where, after a considerable struggle, Peter was sedated. He was kept under sedation until late next morning when he was visited by a psychiatrist who admitted Peter to the psychiatric ward.

Peter was discharged a week later. He was back on his medication and seemingly stable.
No appointment was made with his GP.
No care plan was discussed.

WHY HAS THE JOURNEY BEEN SO TOUGH?

Holistic care requires effective co-ordination of physical and mental health services. But there are no incentives for service providers to link up and no consequences if they don't.

Progress has been slow or non-existent. Connections between hospitals and services in primary and community settings are poor or simply not there.

Vulnerable and unwell patients are often discharged into a vacuum with no care team set up to support them back in the community. It's often up to patients themselves to create the wrap-around services often talked about and needed if physical and mental health needs are to be properly met.

While some are lucky enough to connect with a carer who can help create links, most have to create their own and many just can't.

There is an overwhelming sense of disconnection between health services and the holistic needs of patients with physical and mental health concerns.

THE RESEARCH TELLS US...

More than **1/4** **OF PEOPLE WITH DIABETES** will also be experiencing **MENTAL ILLNESS** especially anxiety and depression

Almost **27%** of Australians with **PSYCHOTIC ILLNESS** experience heart or circulatory conditions compared with **16.3%** of the general population

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Partnerships

Community care teams

Autonomy

Holistic

Self-management

Lived experience

Stability

Hope

Capability

Co-ordination

HOW WE CAN MAKE THIS JOURNEY BETTER

We need to create a health services culture where mental and physical health needs are seen together because for too long the medical profession has treated the mind and body separately.

We must use the best evidence-based practice to manage both aspects effectively.

We can't expect every medical professional in the health and mental health system to have all the necessary skills. We can, however, certainly expect partnerships to be formed, and the multiple disciplines and expertise to be wrapped around the person and co-ordinated for the best possible care and support. We need a culture of integration and respect between general practitioners and hospital specialist services.

Acknowledging the interplay between physical and mental health means the system of mental health becomes more clearly a partnership between people who experience mental illness, their networks of friends, loved ones and carers, and support available from a full range of voluntary, community, social and health services.

We can create an expectation that people will participate actively and effectively in the design of their own care.

'PETA'

Peta is in her early 50s, has diabetes and her kidney function is deteriorating. She'll probably need renal replacement therapy within five years. She's on an unemployment benefit. Despite being active in her youth she's now severely overweight, smokes and does little exercise.

Peta found out about her diabetes in her late 30s during a routine visit to her GP. She was shocked. She was told there was no cure and that she had to see a specialist to organise appropriate treatment. Peta didn't really understand all the information she was given. She left with the only message that she would have this for the rest of her life.

Peta saw the specialist, was put on medication and at times did feel better. However, fatigue, swollen ankles and chronic back pain got worse over time and she started to become less sociable, spending more time away from friends.

Two years after her diagnosis she cut down her work because of stress. This made life at home harder, and her depressed moods got worse and more frequent. Her GP gave her some medication but it had little effect and, as her depression became worse, she wasn't able to stick to the medication and lifestyle program.

Over the next few years her visits to the GP and attendances at hospital increased. Three years ago she started to develop trouble breathing and was rushed to hospital three times. At no stage did anyone talk to her about depression. She was considered only as a patient who wasn't good at sticking to her diabetes program.

This made her feel more guilty and depressed, and made it even harder to do what she needed to do to look after her health. Peta now experiences at least four unplanned admissions to hospital every year. Her physical and mental health continues to deteriorate, yet no one has talked to her about her depression. She hasn't much hope that things will change and she hasn't the confidence or resilience to do much about it.

I CAN GET THERE

I NEED EASY ACCESS TO EARLY AND HOLISTIC ASSESSMENT

No matter what the health system might see as my primary diagnosis, I'll do better in the long run if the connections between my physical and mental health problems are acknowledged early and taken seriously.

WHEN THINGS ARE SERIOUS I NEED BETTER RESPONSES TO MY MENTAL AND PHYSICAL HEALTH ISSUES

People like me need a partnership between community, GPs and other primary carers and hospitals, so that they can respond properly if my physical or mental health worsens. The responses will be better if I am involved in the decision making every step of the way, together with my family and carers.

I NEED THE SYSTEM TO PASS ON ALL THE IMPORTANT INFORMATION

When people like me go back into the community, we need responsibility for our care to be transferred, not just a hospital discharge. If we are taking charge of our own care, that's still a transfer and the health system has a duty to ensure we have the right knowledge and skills to look after ourselves.

I NEED GENUINE COMMUNITY-BASED OPTIONS TO MANAGE MY ONGOING NEEDS

If I can access the right care and support or care services in the community, I might not take up a hospital bed unnecessarily or be afraid of being discharged from hospital before I'm really ready or able to cope because my bed is needed for someone worse off.

COMMUNITY-BASED CARE MUST RESPOND EFFECTIVELY TO ALL MY ISSUES

My care providers need to work in an integrated community-based system. Those people also need the skill and capability to care for both my mental and physical needs and to recognise when one might be masking the other. I want to look after myself but I need the right support and resources to do that.

I CAN MANAGE MY OWN LIFE, ESPECIALLY WITH SUPPORT FROM PEOPLE WHO'VE BEEN DOWN THIS ROAD

People like me will be better off generally if the mental health system puts in place supports such as self-management and peer support services that we know really work. Self-management lets me acknowledge the benefits I receive from pursuing my interests, my hobbies, my spirituality and any other healing approaches such as meditation or art.

I'LL DO BETTER IF THE WHOLE COMMUNITY RECOGNISES I'M A VALUABLE PERSON

I'm committed to learning how to manage my physical and mental health needs so I can thrive in the community. But it'll only work if everyone recognises that people like me have real lives, and that we're not just patients.

John Nadjarian
with a resident

ALL DUE RESPECT
OLDER PEOPLE GUIDING THEIR CARE

Sometimes a solution can be very simple. One man at the Linden unit, HammondCare's facility for people with both mental illness and dementia, is offered a teaspoon. He tends to gulp his food. With a smaller spoon he can still make his own choices about what and where to eat, but he is not at risk of choking.

The eight-bed unit at Hammondville is a 15-year joint venture with South Western Sydney Local Health District and a psychiatrist attends weekly. It accepts residents with a dual diagnosis of dementia and a mental illness and runs on a person-centred philosophy geared to interfere as little as possible with the residents' preferences.

"What we do in Linden for the first couple of weeks is basically leave people alone. We let them settle in, see what they like, what they don't like," says John Nadjarian, nurse manager for the special-care unit.

This contrasts with many aged-care facilities, which enforce strict rules about meal times, medication and personal hygiene.

He describes his approach for a former resident with an aversion to showers, which were not part of her cultural background. Her son would get her to have the occasional wash with a bowl of water and so, very occasionally, Mr Nadjarian would insist she showered so "at least I was able to

> **"**
>
> **It's been my experience through many years of nursing that you might as well fit in with the people because they're not going to fit in with you.**
>
> **"**
>
> *John Nadjarian, nurse manager*

get a quick look to make sure there was nothing happening with her skin integrity". It was "a fine line between offering her the right to be herself and me neglecting her".

The high needs of the unit's residents, which may include challenging physical or verbal behaviour, mean mainstream

aged-care facilities often refuse to accommodate them, says Mr Nadjarian. If they were not at Linden most would probably be admitted to hospital as involuntary mental health patients.

Catriona Lorang, the unit's psychologist, says that during 2013, nine out of the 17 residents had a previous history of mental health problems, before to the onset of dementia.

By reducing residents' exposure to things they find distressing, Linden's managers find previous challenging responses such as lashing out are often reduced. This allows them to safely reduce the number of psychotropic medications they prescribe, which in turn may increase people's ability to interact with others and enjoy their environment.

Mr Nadjarian says people with both dementia and mental illness are frequently neglected and misunderstood in a system that does not prioritise their needs.

He acknowledges that person-centred care for this group of people is costly but "it's better for the person" and "you do it because it's the right thing to do".

8 LIVING LONG AND STRONG

LOOKING FORWARD TO OLDER AGE

Getting older, wiser, freer and more able to cope with life's ups and downs should be something we can look forward to. But it's true that lots of changes occur as we age and some of those, such as retirement from work, changes in family life, social isolation and bereavement can have significant impacts on our physical and mental health.

We are in the midst of an unprecedented increase in the population aged 65 years and older. The fastest rate of growth is in people over 80. The steepest period of growth in the number and proportion of people aged over 65 will take place during the next 10 years.

And people's needs at 65 will be different at 75 and beyond.

From a positive perspective this offers the prospect of many more Australians living long and fruitful lives, a collective source of strength and capability.

Yet so far there hasn't really been a focus on the mental health needs of older people. Everyone in the community, whatever their age, benefits when we have the right kinds of supports in place to let people age well. We need to rethink how mental health contributes to people living full and successful lives for as long as possible.

> "
> **The thing that is needed is an understanding of older people without ageism. It's probably the most important thing to make recovery real.**
> "
>
> *Dr Rod McKay, psychiatrist Recovery into Practice forum, Sydney, 2013*

WHO IS ON THIS JOURNEY?

More people are joining this journey as the average age of our population increases.

The experience of mental illness changes as people get older and can be very damaging, especially if someone also has physical illnesses or dementia.

People with a mental illness are more likely than the general population to have another significant illness, such as cardiovascular disease.

The onset and severity of mental health problems, especially if drug and alcohol issues are also present, are likely to be compounded for people with underlying conditions such as a physical disability, brain injury, degenerative neurological illness or age-related cognitive impairment.

Though the prevalence of mental illness is markedly higher for people with a disability or impairment, they often have reduced access to support for mental health, and drug and alcohol issues.

People with pre-existing mental health problems who develop a terminal illness and need end-of-life care are possibly among the most under-represented and deprived populations in our society.

WHY HAS THE JOURNEY BEEN SO TOUGH?

With resources stretched to breaking point we can't seem to meet the needs of older people, focusing only on those with the most severe problems and often only once they are extremely unwell.

Our public hospital system often struggles to provide multidisciplinary care, comprehensive assessment, proper care planning, and follow-up monitoring and care. And people with mental health problems or illness may also have unmet social, housing, income and support needs.

Services often fail to engage with family and carers, so people's needs go unrecognised and unaddressed, particularly in rural and regional areas.

A heavy and sometimes intolerable burden falls on carers, affecting their own health.

People whose care and support have come through public mental health services may feel abandoned if responsibility for their care is handed over to residential aged care or other age-related services once they turn 65, or sometimes earlier. Therapeutic relationships established over many years can be forced to cease.

Our systems and services for people with disabilities tend to operate outside mainstream primary, community or hospital-based mental health support.

Having a disability or impairment often means reduced access to mental health or drug and alcohol misuse support. Availability and easy access to services for older people with mental illness are often lacking, and their complex needs are not being met by the mental health, general health, disability or aged-care sectors. For those over 85, who are at the highest risk of suicide, use of supports is even lower.

There is a paradoxical divide between mental health care and aged care which makes each the other's lowest priority. Services that should be seamless across settings are commonly perceived to be someone else's problem. Priorities don't align, opportunities for co-ordination are lost and bad care often follows.

There are also questions over the use of antipsychotic medications in residential care. While people with dementia can exhibit aggressive, violent or socially inappropriate behaviour, there is growing concern that antipsychotics are being overused or used inappropriately for behaviour control.

Many palliative care units don't have the facilities to ensure the safety of distressed patients or to manage difficult and challenging behaviours.

THE RESEARCH TELLS US...

Just OVER HALF
52% of all permanent aged-care residents had
symptoms of depression
about 87,000 people out of a population of 166,000

45% of people admitted
for the first time to residential aged care
from 2008 to 2012
also indicated symptoms of depression –
about 160,000 out of a population 235,000

In that period, the proportion of newly admitted residents
with symptoms increased by **21%**

WHAT'S IMPORTANT TO PEOPLE ON THIS JOURNEY?

Early intervention   Respect
          Recovery focus
Person-centred
          Care planning   Dignity
Multi-disciplinary   A full life
                    Resilience
Holistic   Hope

HOW WE CAN MAKE
THIS JOURNEY BETTER

We need to help people manage the impact of disability, including long-term disabilities, or the cumulative effects of ageing on cognitive or physical health.

A key element in improving services for older people with mental illness is keeping the social bonds of family, friends – and more formal supports – intact.

This is because the continuing nature of most disability and cognitive impairment, combined with relatively unsupported mental health issues, can lead to a loss of hope, a loss of capacity to participate in the community, and reduced physical health.

By addressing mental health issues – particularly the impact of depression – and integrating mental health support with physical health care, we can help people to be more resilient, live longer and feel better in themselves even if their health is declining.

Partnerships among mental health, palliative care and wider social services can make things better for people who experience mental distress or illness at the end of their lives.

We especially need appropriate mental health care for older Aboriginal people, who tell us they require services that build relationships with their communities, respond flexibly to them, and are culturally competent.

> "
> If we can ensure older people live healthier as well as longer lives … these extra years can be as productive as any others. The societies that adapt to this changing demographic can reap a sizeable 'longevity dividend' and will have a competitive advantage over those that don't.
> "
>
> *World Economic Forum 2012*

I CAN GET THERE

MY CARER IS MY MAINSTAY SO NEEDS AND DESERVES TO BE SUPPORTED TOO

Those who care for people like me need mental and physical health support, not only because they're vital to helping us age well but because they need to remain vital in their own lives. Early intervention will make sure there are regular and close connections between our families and carers and the services we use, including GPs, to monitor mental health and wellbeing and respond when necessary.

I'LL GET BETTER CARE AND SUPPORT IF SERVICES FIND NEW WAYS TO PARTNER UP

People like me need innovative partnerships that focus on the community while bringing together organisations responsible for mental health, physical health and social services.

THE AGEISM AND ELIGIBILITY BARRIERS BUILT INTO THE SYSTEM MEAN I CAN'T GET THE CARE I NEED

Concern for administrative efficiency rather than quality of care means my needs can't be met. Aged care needs support from mental health so that the right skills are available and I can get the right care.

I WANT TO LIVE WELL AT HOME FOR AS LONG AS I CAN

Mental health services need to provide integrated support for people like me to be independent at home but they also need to provide a seamless transition of that support into aged-care facilities when needed, and to be alert to any physical illnesses or impact of chronic illness or disability.

MY MENTAL HEALTH MUST BE A CORE CONCERN WHEN TREATING MY PHYSICAL PROBLEMS

Mental health treatment, care and support for people like me who also have chronic illness must be integrated, must actually work and must become the norm. The services must recognise and respond to depression, thoughts of suicide, and drug and alcohol misuse that can sit alongside the onset of dementia.

I'LL DO BETTER WITH A PROMPT RESPONSE TO MY ISSUES

It's no good assuming only certain age groups have certain problems and that nothing can be done because I'm elderly. People like me can stay resilient and capable if our problems are recognised early and the response is effective.

I WANT TO COMPLETE MY LIFE'S JOURNEY WITH DIGNITY

As I come to the end of my life, I deserve quality, holistic care and support for my mental and physical, including palliative, health needs. I am still a person. I have value.

IN CONCLUSION

ARE WE GETTING THERE?

We want mental health system change that makes a real and positive difference in people's lives. We want to see the evidence of high-quality, person-centred approaches to wellbeing and mental health support spread across the spectrum of activities and services – not only health but also social supports, housing, employment, education, justice and many others.

We need to know that the commitments we make to this kind of change can be monitored and measured, so that we can acknowledge, reinforce and reward positive progress. At the same time as scoping and designing reforms we must devise the measurements that will tell us whether these reforms are succeeding. This includes evaluating people's experiences and how they fare in the longer term on their recovery journey. A mix of quantitative and qualitative data will be required to give a comprehensive picture.

We are working against a backdrop of previous reform initiatives that have been energetically pursued but not fully realised, which in turn have engendered some scepticism and fatigue. As we work towards reform, we need to continue to build the consensus for change at the same time as implementing it. Robust measurements, that are tracked over time, publicly reported and relate to things we really care about, will help us achieve this.

Agencies, organisations and mental health workers will need additional skills in information management to support expanded data collection activities. Extension of existing data linkages between government agencies and the community-managed sector will be necessary to produce a meaningful, nuanced picture of the lives of people who experience mental illness, and their support needs across many domains of health and social services.

All monitoring work should be guided by the lived experience of people with a mental illness, their families and carers. We must design structured, evidence-based ways to evaluate the success of services in meeting their needs.

This means measuring not only to the quality the of services, but their capacity to support positive change more broadly. This includes how well they integrate with other services, whether they support local decision making, and their capacity to retain their quality and remain true to their principles and objectives as they grow.

The Commission's approach to measuring, monitoring and reporting will:

- **be guided by the lived experience of people with a mental illness, their families and carers**

- **support reform and drive positive changes in the mental health and wellbeing of the people of NSW, at both individual and community level**

- **support agencies to work collaboratively to improve mental health and wellbeing**

- **identify priorities for further research**

- **contribute to better informed public debate.**

A PERSONAL POINT OF VIEW

Consumer and carer experiences of care and support are not an optional extra. They should be central to our evaluations of services, and to the choices we make about the things we measure, monitor and report on.

NSW is already one of the first jurisdictions to have a framework for involving consumers in improving public adult mental health services. MH-CoPES (Mental Health Consumer Perceptions and Experiences of Services) questionnaires invite people to say what they liked as well as what needs improvement in the services they use. But response rates and use of the survey vary across the state.

The current questionnaire is being further developed as a national measure which will allow comparison with other states and territories.

The Commission is leading a project to develop new methods of data collection and reporting mechanisms, including the use of tablets, text messages and online surveys that allow people to offer real-time feedback in hospitals, clinics, the community and from home. It is hoped that by enabling people to contribute timely perspectives more easily, more people will participate and their collective insights will be more representative of the views of all consumers.

There is currently no continuing survey of the experiences of families and carers of people who live with mental illness. The NSW Carers (Recognition) Act 2010 provides impetus to look in more detail at carer experiences, and to use these to inform policy.

Consumer and carer input will also be essential in designing measures to evaluate the effectiveness of support and services. Those measures should not simply be derived from information that is already routinely collected. The measures should address things people tell us they care about, which may relate not only to health but also to social connectedness, ability to work or study, or any other aspect of the recovery journey.

TELLING EVERYONE

Information about the quality and performance of mental health support systems should not be a secret. Anyone in the community should be able to find timely data that can help inform their decisions as consumers, carers, professionals, sector managers or researchers. This should include data on the performance of individual services.

We should insist on regular public reporting of mental health data and statistics that are compatible with other data collections, support further analysis and interpretation, and are presented in ways that are accessible to all the community.
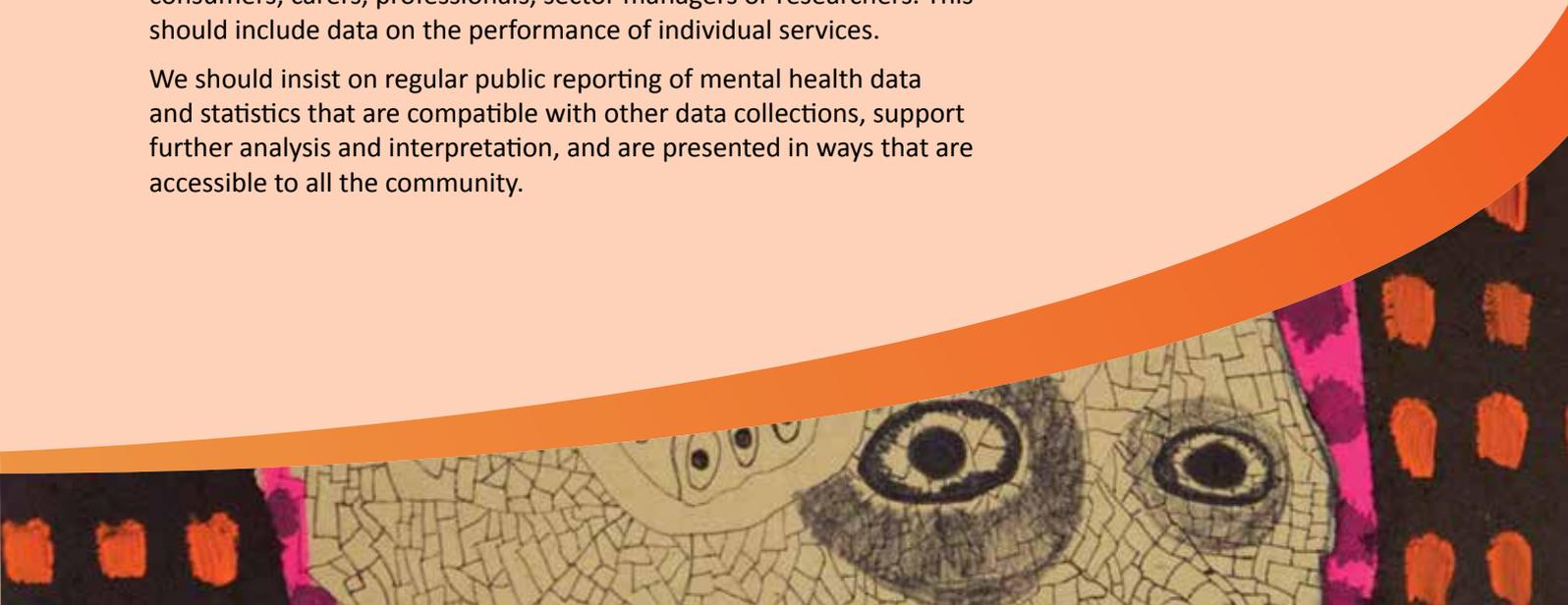
WHAT ARE WE MEASURING

The Commission will use and, where necessary, develop measures and indicators that address the actions and overarching reform focus of the Strategic Plan, as well as the mental health and wellbeing-related targets and actions set out in the State Health Plan and NSW 2021.

The Commission supports the following monitoring initiatives and will align its activities with them.

- **The national targets and indicators for mental health reform endorsed by the Council of Australian Governments Expert Reference Group, which address six foundation areas:**

    - More people with poor mental health will have better physical health and will live longer

    - More people have good mental health and wellbeing

    - More people with poor mental health will live a meaningful and contributing life

    - More people will have a positive experience of support, care and treatment

    - Fewer people will experience avoidable harm

    - Fewer people will experience stigma and discrimination.

- **The Mental Health Non-Government Organisation Establishments National Minimum Data Set, which is being developed in partnership with Australian Institute of Health and Welfare.**

    - In NSW, in 2011 the non-government sector accounted for 6% of state government spending on mental health, and it is expected community organisations will take on a growing role under reforms intended to minimise reliance on hospitals. It is essential in this environment that we can measure how well both small and large community organisations perform in supporting people and their recovery. The minimum data set is intended to support the collection of nationally consistent information on the activity of community managed organisations that provide mental health support, to better inform policy, practice and planning. It is scheduled for implementation in 2015-16.
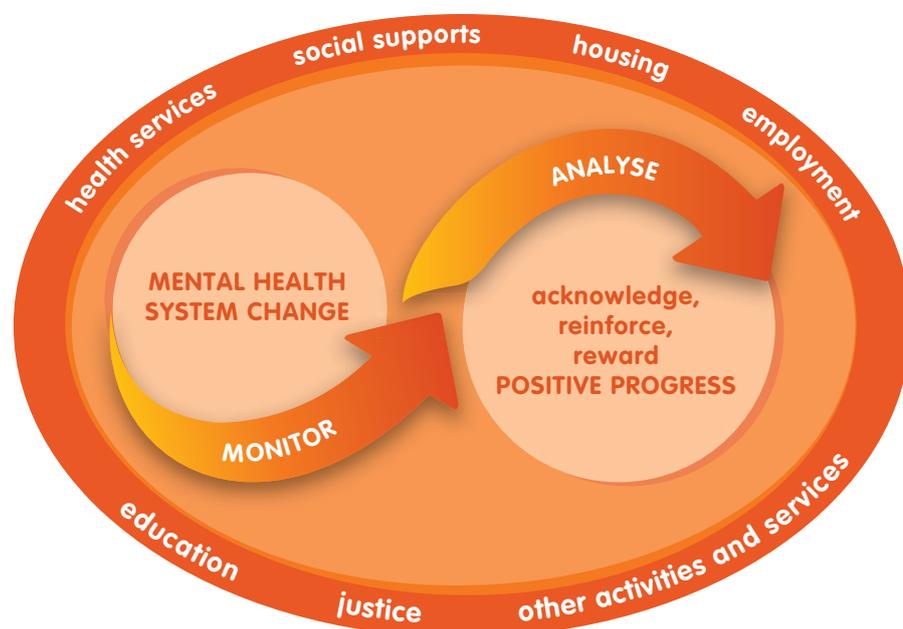
A LETTER FROM **BRADLEY FOXLEWIN**

People are not their symptoms. And yet the system has been dominated by the idea that mental illness is the inevitable outcome of a person's particular chemical make-up. This in turn has evoked chemical and diagnostic responses, almost exclusively.

While diagnosis and medications have a place in our kit, we also need other tools and strategies that position an idea of mental wellness around a person – a whole person with a history, a family (or not), living in a community.

The development of a strong, proud, peer workforce, thoroughly integrated into our mental health and social support systems, is the best way to support the creation of the tools we will need to bring about the enormous change required.

People with a lived experience of using mental health services, or of being directly subject to the Mental Health Act through involuntary treatment, are in an excellent position to provide a safe relational environment for others.

Peer workers can support decision making with the person but can also support clinicians seeking to enhance the decisions they make with the wisdom of lived experience. In both cases, the person's expertise – supported by the peer worker's experience – remains at the centre of decision making.

"It will require hard work … to make these changes happen … the hard but valuable work of recovery."

This provides greater agency and increases skills to pursue recovery, not only for the person but also for the system, which has much to learn from engaging people living with a mental illness.

People who engage with our mental health services are managing their lives as best they can. Most have experienced abuse as a child or at another age. Sadly, practices still exist in the mental health system that can revive the memory and experience of trauma for vulnerable people: seclusion is one, the gross overuse of mandatory community treatment orders another.

People whose lives are diminished by the effects of unresolved interpersonal trauma are often the same people who don't engage in the mental health system because they are frightened to do so.

People with mental health challenges also engage, or not, in services for families, justice and other areas of health. Supporting them effectively in the face of their previous traumatic experiences is a system-wide challenge. It requires tools that can effect change towards wellbeing in social, emotional, physical, cognitive and cultural realms, across all areas of service delivery.

It will require hard work – very hard work – to make these changes happen, but that is what we must ask people to do: the hard but valuable work of personal, interpersonal and system recovery.

Bradley Foxlewin

DEPUTY COMMISSIONER

ACKNOWLEDGEMENTS

The Commission would like to acknowledge and thank the more than 2,000 people who contributed to the development of the Strategic Plan for Mental Health in NSW, to which this Report is a companion.

In particular we wish to recognise the many people with a lived experience of mental illness, and their families and carers, who generously assisted us in the planning process and helped us to remain true to our central mission: to develop policies that promote and protect mental wellbeing, and support people who experience mental illness to live well in our community.

The Plan presents reform actions that have the potential to make a real difference in people's lives. But we also wished to honour the inspiring stories we heard during the Plan's development phase. In this Report we have attempted to portray those human experiences and to present mental health reform from the perspective of those who stand to benefit from it.

Many organisations and individuals also contributed professional knowledge and expertise. We would like to acknowledge particularly the members of the Commission's Community Advisory Council, whose energy, insight and diverse perspectives are reflected on every page of these documents, and Synergia Ltd who provided the Commission with valuable assistance in the development of the Plan. NSW Consumer Advisory Group - Mental Health (NSWCAG) and Mental Health Carers ARAFMI NSW (ARAFMI) reached out to their networks of consumers and carers on our behalf and encouraged people to contact and engage with us. We are truly grateful for their trust.

The following organisations and individuals assisted us in many different ways, from hosting discussions in country community halls to providing specialised technical advice.

Aboriginal Affairs NSW

Aboriginal Disability Network

Action Foundation for Mental Health

Aboriginal Health & Medical Research Council of NSW

ACON

Adults Surviving Child Abuse

Afford Employment

Aftercare

Ambulance Service of NSW

Anglicare Northern Inland

Anglicare NSW South, NSW West and ACT

Association of Psychologists in Developmental Disability Services

Auburn Diversity Services

Australian Association of Social Workers

Australian Drug Foundation

Australian Foundation for Disability

Australian Institute of Business Wellbeing

Australian Institute of Criminology

Australian Medicare Local Alliance

Australian Red Cross

Australian Psychological Society

Mr Eddie Bartnik, former WA Mental Health Commissioner

Beautiful Minds

Benelong's Haven

beyondblue

Billabong Clubhouse

Black Dog Institute

Blue Mountains Tenancy Advice and Advocacy Service

B Miles Supported Accommodation

Booroongen Djugun Aboriginal Corporation

Bourke Aboriginal Health Service

BoysTown

Bradfield Park Carers Program, Kirribilli

Brain and Mind Research Institute

Break Thru People Solutions

Broken Hill Youth Accommodation and Support Service

Butterfly Foundation for Eating Disorders

Canadian Mental Health Association

CanTeen

Carers Assist NSW

Carers NSW

Catholic Community Services NSW/ACT

Centacare New England North West

CentaCare Wilcannia – Forbes

Central Coast Local Health District

Centre for Rural and Remote Mental Health

Centre for Translational Neuro-Science and Mental Health

Centre of Research Excellence in Mental Health and Substance Use

Centre of Research Excellence in Suicide Prevention

Co.As.It. (Italian Association of Assistance)

Community Relations Commission for a Multicultural NSW

Community Restorative Centre

Community Solutions

Consumer Activity Network (Mental Health)

Council of Social Service of NSW (NCOSS)

CRANES Community Support Programs

Create Foundation

Crescendo Partners

Corrective Services NSW

Department of Developmental Disability Neuropsychiatry (3DN) – University of NSW

Department of Education and Communities

Department of Family and Community Services

Department of Police and Justice

Department of Premier and Cabinet

Disability Advocacy NSW

DiverseWerks

Drug and Alcohol Multicultural Education Centre

Durri Aboriginal Corporation Medical Service

Dubbo Aboriginal Land Council

Dubbo Koori Interagency Network

Professor Kathy Eagar, Director, Australian Health Services Research Institute Sydney Business School – University of Wollongong

Elizabeth Evatt Community Legal Centre

Ethnic Communities Council of NSW

Executive Evolution

Fairfield Migrant Resource Centre

Far West Local Health District

Far West Medicare Local

Federation of Ethnic Communities Council of Australia (FECCA)

Future Achievement Australia

Gamarada Indigenous Healing and Life Training

Gay and Lesbian Rights Lobby

General Practice NSW

GROW NSW

headspace

Healing Foundation

Health and Disability Commission New Zealand

Health Education and Training Institute

Mr Ravy Heng, Khmer Carers Support Group, Cabramatta

Hills Holroyd Migrant Resource Centre

Homeless Person's Legal Service

Homelessness NSW

Housing NSW

Hunter Institute of Mental Health

Hunter Medical Research Institute

Hunter Medicare Local

Hunter New England Local Health District

Hunter Valley Research Foundation

Illawarra Multicultural Forum

Illawarra Shoalhaven Local Health District

Immigrant Women's Health Service

Independent Community Living Australia

Indigenous Australians with Mental Health Disorders and Cognitive Disability in the Criminal Justice System Project – University of New South Wales

Inner West Tenants' Advice and Advocacy Service

Inner West Sydney Medicare Local

Interrelate

Jarrah House

JewishCare

Justice Health & Forensic Mental Health Network

Juvenile Justice NSW

Kamira Alcohol and Other Drug Treatment Services

Kangaroo Valley Carers Support Group

Kogarah Diagnostic Assessment Service

Lane Cove Council

Launchpad

Lebanese Muslim Service

Legal Aid

Life Without Barriers

Lifeline

Lifeline Foundation for Suicide Prevention

Lifeline Harbour to Hawkesbury

Liverpool Migrant Resource Centre

Lou's Place

Maari Ma Health Aboriginal Corporation

Macarthur Diversity Services Initiative

Macedonian Welfare Association

Manly Drug Education and Counselling Centre

Professor Maree Teesson and colleagues, Centre of Research Excellence in Mental Health and Substance Use, National Drug and Alcohol Research Centre – University of New South Wales

Marrin Weejali Aboriginal Corporation

Professor Bernadette McSherry – University of Melbourne

Mental Health Association NSW

Mental Health Carers ARAFMI NSW

Mental Health Coalition of South Australia

Mental Health Commission of Western Australia

Mental Health Coordinating Council

Mental Health Review Tribunal

Metro Migrant Resource Centre

Mid Mountains Neighbourhood Centre, Katoomba

Mid North Coast Local Health District

Milk Crate Theatre

MIND Australia

Mission Australia

Multicultural Communities Council of Illawarra

Multicultural Disability Advocacy Association of NSW

Multicultural Problem Gambling Service

Murrumbidgee Local Health District

Murrumbidgee Medicare Local

National Aboriginal and Torres Strait Islander Suicide Prevention Advisory Group

National Disability Services

National Drug and Alcohol Research Centre

National Mental Health Commission

National StandBy Response Service

Neami National

Nepean Blue Mountains Local Health District

Network of Alcohol and Other Drug Agencies

New England Medicare Local

New Horizons Enterprises

Northern NSW Local Health District

Northern Settlement Services

Northern Sydney Local Health District

Northern Sydney Medicare Local

NSW Agency for Clinical Innovation – NSW Intellectual Disability Network

NSW Attorney General's Department

NSW Audit Office

NSW Bureau of Crime Statistics and Research

NSW Commission for Children Youth and Families

NSW Consumer Advisory Group Mental Health

NSW Council for Intellectual Disability

NSW Education Program on Female Genital Mutilation

NSW Health

NSW Institute of Psychiatry

NSW Kids and Families

NSW Ministry of Health

NSW Ministry of Police

NSW Multicultural Health Communication Service

NSW Multicultural Health Services

NSW Ombudsman

NSW Police Force

NSW Public Guardian

NSW Public Service Commission

NSW Refugee Health Improvement Network

NSW Refugee Health Service

NSW Rural Fire Service

NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS)

NSW Treasury

Occupational Therapy Australia – NSW Division

Official Visitors Program

On Track Community Programs

Parents, Families, and Friends of Lesbians and Gays

Parramatta City Council

Partners in Culturally Appropriate Care NSW and ACT

People with Disability Australia

Pharmaceutical Society of Australia

Pioneer Clubhouse, Balgowlah

Polish Australian Welfare Organisation

Post and Antenatal Depression Association (PANDA)

Professional Association of Nurses in Developmental Disability Australia (PANDDA)

Psychotherapy and Counselling Federation of Australia

Public Schools NSW

Queensland Mental Health Commission

ReachOut.com by Inspire Foundation

Redfern and Waterloo Aboriginal Community

Mr David Richmond

RichmondPRA

Royal Australian College of General Practitioners

Samaritans

Sax Institute

Schizophrenia Fellowship NSW

Schizophrenia Research Institute

Serbian Welfare Association

Settlement Services International

Social Policy Research Centre – University of New South Wales

South Coast Portuguese Association

South Coast Private

South Eastern Sydney Local Health District

South Eastern Sydney Medicare Local

South London and Maudsley NHS Foundation Trust

South Western Sydney Local Health District

South Western Sydney Medicare Local

Southern NSW Local Health District

Southern NSW Medicare Local

St George Community Housing

St George Migrant Resource Centre

St Vincent de Paul Society

St Vincent's Health Network – St Vincent's & Mater Health Sydney

St Vincent's Hospital Sydney

Stepping Out

Suicide Prevention Australia

Sydney Gay and Lesbian Business Association

Sydney Local Health District

Sydney Multicultural Community Services

Sydney South Western Local Health District

Synergia

TAFE Western Sydney Institute

Ted Noffs Foundation

The Association of Independent Schools of NSW

The Benevolent Society

The Crossing

The Disability Trust

The Exodus Foundation

The Lyndon Community

The Marmalade Foundation

The Pinnacle Foundation

The Salvation Army

The Sydney Children's Hospitals Network

Transcultural Mental Health Centre

Triple Care Farm

Twenty10 incorporating the Gay and Lesbian Counselling Service of NSW

UnitingCare Mental Health

UnitingCare Unifam Counselling and Mediation

University of Sydney

University of Western Sydney

Wayside Chapel

Weave

WentWest

Wesley Mission

Western NSW Local Health District

Western NSW Medicare Local

Western Sydney Aboriginal Medical Service

Western Sydney Local Health District

Western Sydney Partners in Recovery Consortium

WHOS (We Help Ourselves)

Wingecarribee Family Support Services

Wise Group

Wollongong City Council

Women in Prison Advocacy Network

Women's Health NSW

Youth Action

YouthLink

REFERENCES

WHAT WE KNOW

Australian Bureau of Statistics (2012). Australian social trends March quarter 2012. cat. no. 4102.0. Canberra, Australian Bureau of Statistics.

Australian Bureau of Statistics (2012). Causes of death, Australia. cat. no. 3303.0. Canberra, Australian Bureau of Statistics.

Buhrich, N., T. Hodder and M. Teesson (2003). Down and Out in Sydney (V0l.2): Caring for homeless people who have a mental disorder. Sydney, Research Group in Mental Health and Homelessness.

Deloitte Access Economics (2007). Smoking and mental illness: Costs. Melbourne SANE Australia.

Indig, D., L. Topp, B. Ross, H. Mamoon, B. Border, S. Kumar and M. McNamara (2010). 2009 NSW inmate health survey: Key findings report. Sydney, Justice Health Sydney.

InforMH (2013). Clinical Information Benchmarking Report Engine v10 for Period ending December 2013 Kendall, P. C. and R. C. Kessler (2002). "The impact of childhood psychopathology interventions on subsequent substance abuse: policy implications, comments, and recommendations." Journal of Consulting and Clinical Psychology **70**(6): 1303.

Laursen, T. M., T. Munk-Olsen and M. Vestergaard (2012). "Life expectancy and cardiovascular mortality in persons with schizophrenia." Current opinion in psychiatry **25**(2): 83-88.

Lim, D., K. Sanderson and G. Andrews (2000). "Lost productivity among full-time workers with mental disorders." The journal of mental health policy and economics **3**(3): 139-146.

McDermott, S., J. Bruce, I. Oprea, K. R. Fisher and K. Muir (2011). Evaluation of the Mental Health, Housing and Accommodation Support Initiative (HASI): Second Report, Social Policy Research Centre, University of New South Wales.

Morgan, V. A., A. Waterreus, A. Jablensky, A. Mackinnon, J. J. McGrath, V. Carr, R. Bush, D. Castle, M. Cohen and C. Harvey (2012). "People living with psychotic illness in 2010: The second Australian national survey of psychosis." Australian and New Zealand Journal of Psychiatry **46**(8): 735-752.

National Mental Health Commission (2013). A Contributing Life: the 2013 National Report Card on Mental Health and Suicide Prevention. Sydney, National Mental Health Commission.

NSW Government (2014). NSW Health Budget 2013-14. Sydney, NSW Government.

Steering Committee for the Review of Government Service Provision (2014). Report on Government Services 2014. Vol. E: Health. Canberra, Productivity Commission.

Infographics
Australian Bureau of Statistics (2008). National survey of mental health and wellbeing: Summary of results 2007. cat. no. 4326.0. Canberra, Australian Bureau of Statistics.

Australian Bureau of Statistics (2012). Causes of death, Australia. cat. no. 3303.0. Canberra, Australian Bureau of Statistics.

Australian Institute of Health and Welfare (2012). Mental health services: In brief. cat. no. HSE 125. Canberra, Australian Institute of Health and Welfare.

Commonwealth Department of Health and Ageing (2013). National Mental Health Report 2013: Tracking progress of mental health reform in Australia 1993-2011. Canberra, Commonwealth of Australia.

THE REFORM STORY

Burdekin, B., D. Hall, M. Guilfoyle and National Inquiry Concerning the Human Rights of People with Mental Illness (1993). Human rights and mental illness: Report of the national inquiry into the human rights of people with mental illness. Canberra, Australian Government Publishing Service.

Human Rights and Equal Opportunity Commission (1989). Our Homeless Children: Report of the national inquiry into homeless children. Canberra, Australian Government Publishing Service.

New South Wales Parliament Legislative Council Select Committe on Mental Health (2002). Inquiry into mental health services in New South Wales. Parliamentary paper no. 368. Sydney, NSW Parliament.

Richmond, D. (1983). Inquiry into health services for the psychiatrically ill and developmentally disabled. Sydney, NSW Department of Health.
World Health Organisation (2013). Comprehensive mental health action plan 2013-2020, World Health Organisation.

ABORIGINAL WELLBEING

NSW Aboriginal Affairs (2013). OCHRE: Opportunity, Choice, Healing, Responsibility, Empowerment. Sydney, NSW Aboriginal Affairs.

NSW Ministry of Health (2012). NSW Aboriginal Health Plan 2013-2023. Sydney, NSW Ministry of Health.

Infographics
Australian Bureau of Statistics (2013). Estimates of Aboriginal and Torres Strait Islander Australians, June 2011. cat. no. 3238.0.55.001. Canberra, Australian Bureau of Statistics.

Australian Bureau of Statistics (2013). Life tables for Aboriginal and Torres Strait Islander Australians, 2010-2012. cat no. 3302.0.55.003. Canberra, Australian Bureau of Statistics.

Australian Bureau of Statistics (2013). Prisoners in Australia, 2013. cat. no. 4517.0. Canberra, Australian Bureau of Statistics.

Centre for Epidemiology and Evidence (2012). Psychological distress by Aboriginality, persons aged 16 years and over, NSW 2002 to 2011. Sydney, Health Statistics New South Wales.

Vos, T., B. Barker, S. Begg, L. Stanley and A. D. Lopez (2009). "Burden of disease and injury in Aboriginal and Torres Strait Islander Peoples: the Indigenous health gap." International Journal of Epidemiology **38**(2): 470-477.

BEYOND THE CITIES

Australian Bureau of Statistics (2010). Suicides. cat. no. 3309.0. Canberra, Australian Bureau of Statistics.

Hart, L. M., A. F. Jorm, L. G. Kanowski, C. M. Kelly and R. L. Langlands (2009). "Mental health first aid for Indigenous Australians: Using Delphi consensus studies to develop guidelines for culturally appropriate responses to mental health problems." BMC psychiatry **9**(1): 47.

Pirkis, J., M. Harris, W. Hall and M. Ftanou (2011). "Evaluation of the better access to psychiatrists, psychologists and general practitioners through the Medicare Benefits Schedule Initiative." Melbourne: Centre for Health Policy Programs and Economics, University of Melbourne.

Suicide Prevention Australia (2008). Position Statement: Responding to suicide in rural Australia. Sydney, Suicide Prevention Australia.

Infographics

National Rural Mental Health Alliance (2009). Fact sheet 18: Mental health in rural Australia National Rural Mental Health Alliance. Canberra.

A QUESTION OF DIVERSITY

Australian Bureau of Statistics (2012). Census of Population and Housing 2011. Basic Community Profile. cat. no. 2001.0. Canberra, Australian Bureau of Statistics.

Australian Bureau of Statistics (2012). Census of Population and Housing 2011. Expanded Community Profile. cat. no. 2005.0. Canberra, Australian Bureau of Statistics.

Coffey, G. J., I. Kaplan, R. C. Sampson and M. M. Tucci (2010). "The meaning and mental health consequences of long-term immigration detention for people seeking asylum." Social science & medicine **70**(12): 2070-2079.

Minas, H., R. Kakuma, L. S. Too, H. Vayani, S. Orapeleng, R. Prasad-Ildes, G. Turner, N. Procter and D. Oehm (2012). Mental health research and evaluation in multicultural Australia: Developing a culture of inclusion. Mental Health in Multicultural Australia. Centre for International Mental Health, Melbourne School of Population Health, University of Melbourne.

Infographics

DiverseWerks (2014). CALD research to assist with development of the draft Strategic Plan, Prepared for the Mental Health Commission of NSW.

SEXUALITY AND IDENTITY

Couch, M., M. Pitts, H. Mulcare, S. Croy and S. Patel (2007). Tranznation: A report on the health and wellbeing of transgender people in Australia and New Zealand. Melbourne, Australian Research Centre in Sex, Health & Society, La Trobe University.

Dyson, S., A. Mitchell, A. Smith, G. Dowsett, M. Pitts and L. Hillier (2003). Don't ask, don't tell: Hidden in the crowd: the need for documenting links between sexuality and suicidal behaviour among young people. Monograph Series Number 45. Melbourne, Australian Research Centre in Sex, Health and Society, La Trobe University.

Grierson, J., J. Power, M. Pitts, S. Croy, T. Clement, R. Thorpe and K. McDonald (2009). HIV futures six: Making positive lives count. La Trobe University, Australian Research Centre in Sex, Health and Society.

Leonard, W., M. Pitts, A. Mitchell, A. Lyons, A. Smith, S. Patel, M. Couch and A. Barrett (2012). Private Lives 2: The second national survey of the health and wellbeing of gay, lesbian, bisexual and transgender Australians. Mongraph Series Number 86. Melbourne, The Australian Research Centre in Sex, Health & Society, La Trobe University.

Pitts, M., A. Smith, A. Mitchell and S. Patel (2006). Private lives: A report on the health and wellbeing of GLTBI Australians. La Trobe University, Australian Research Centre in Sex, Health and Society.

Smith, A., C. E. Rissel, J. Richters, A. E. Grulich and R. O. Visser (2003). "Sex in Australia: sexual identity, sexual attraction and sexual experience among a representative sample of adults." Australian and New Zealand journal of public health **27**(2): 138-145.

Suicide Prevention Australia (2009). Position Statement: Suicide and self-harm among Gay, Lesbian, Bisexual and Transgender communities. Sydney, Suicide Prevention Australia.

Infographics

Hillier et al (2004). Drug-use patterns of heterosexual and non-heterosexual women: Data from the Women's Health Australia Study. Out in the antipodes: Australian & New Zealand perspectives on gay and lesbian issues in psychology. D. W. Riggs and G. A. Walker. Western Australia, Brightfire Press.

Hillier, L., T. Jones, M. Monagle, N. Overton, L. Gahan, J. Blackman and A. Mitchell (2010). Writing themselves in 3: The third national study on sexual health and wellbeing of same sex attracted and gender questioning young people. Melbourne, Australian Research Centre in Sex, Health and Society, La Trobe University.

Howard, J., A. Arcuri, P. Aggleton, A. Ball and P. Mane (2006). "Drug use among same-sex attracted young people." Sex, drugs and young people: International perspectives: 101-119.

HEALTHY BODY AND MIND

Australian Institute of Health and Welfare (2013). Diabetes and disability: Impairments, activity limitations, participation restrictions and comorbidities. cat. no. CVD 63. Canberra, Australian Institute of Health and Welfare.

Colquhoun, D. M., S. J. Bunker, D. M. Clarke, N. Glozier, D. L. Hare, I. B. Hickie, J. Tatoulis, D. R. Thompson, G. H. Tofler and A. Wilson (2013). "Screening, referral and treatment for depression in patients with coronary heart disease." Medical Journal of Australia **198**(9): 483-484.

Kisely, S., L.-H. Quek, J. Pais, R. Lalloo, N. W. Johnson and D. Lawrence (2011). "Advanced dental disease in people with severe mental illness: Systematic review and meta-analysis." The British Journal of Psychiatry **199**(3): 187-193.

National Mental Health Commission (2012). A Contributing Life: the 2012 National Report Card on Mental Health and Suicide Prevention. Sydney, National Mental Health Commission.

Infographics
Australian Bureau of Statistics (2008). National survey of mental health and wellbeing: Summary of results 2007. cat. no. 4326.0. Canberra, Australian Bureau of Statistics.

Morgan, V. A., A. Waterreus, A. Jablensky, A. Mackinnon, J. J. McGrath, V. Carr, R. Bush, D. Castle, M. Cohen and C. Harvey (2012). "People living with psychotic illness in 2010: The second Australian national survey of psychosis." Australian and New Zealand Journal of Psychiatry **46**(8): 735-752.

INTELLECTUAL DISABILITY

Australian Institute of Health and Welfare (2008). Disability in Australia: Intellectual disability. Canberra, Australian Institute of Health and Welfare. Bulletin no. 67.

Cooper, S., E. Smiley, J. Morrison, A. Williamson and L. Allan (2007). "Mental ill-health in adults with intellectual disabilities: prevalence and associated factors." British Journal of Psychiatry **190**: 27-35.

Howlett, S. and J. Trollor (2013). Clinical services planning for adults with an intellectual disability (ID) and co-occurring mental disorders. University of New South Wales, The Department of Developmental Disability Neuropsychiatry.

NSW Ombudsman (2012). Denial of rights: the need to improve accommodation and support for people with psychiatric disability. Sydney, NSW Ombudsman.

Infographics
Slade, T., A. Johnston, M. Teesson, H. Whiteford, P. Burgess, J. Pirkis and S. Saw (2009). The mental health of Australians 2: Report on the 2007 national survey of mental health and wellbeing. Canberra, Commonwealth of Australia.

Tonge, B. and S. Einfeld (2000). "The trajectory of psychiatric disorders in young people with intellectual disabilities." Australian and New Zealand Journal of Psychiatry **34**(1): 80-84.

A MATTER OF JUSTICE

Australian Institute of Health and Welfare (2012). Juvenile justice in Australia 2010-11. cat. no. JUV 10. Canberra, Australian Institute of Health and Welfare.

Baldry, E. and E. McEntyre (2011). "Prison bars are health barriers." O&G Magazine **13**(3): 53-54.

NSW Law Reform Commission (2012). People with cognitive and mental health impairments in the criminal justice system: Diversion. Sydney, NSW Law Reform Commission.

Skeem, J. L., S. Manchak and J. K. Peterson (2011). "Correctional policy for offenders with mental illness." Law and human behavior **35**(2): 110-126.

Infographics
Indig, D., L. Topp, B. Ross, H. Mamoon, B. Border, S. Kumar and M. McNamara (2010). 2009 NSW inmate health survey: Key findings report. Sydney, Justice Health Sydney.

McCausland, R., E. Baldry, S. Johnson and A. Cohen (2013). People with mental health disorders and cognitive impairment in the criminal justice system: Cost-benefit analysis of early support and diversion. Sydney, University of New South Wales and PwC.

DRUGS AND ALCOHOL

Australian Bureau of Statistics (2008). National survey of mental health and wellbeing: Summary of results 2007. cat. no. 4326.0. Canberra, Australian Bureau of Statistics.

Australian Institute of Health and Welfare (2012). Australia's health 2012. cat. no. AUS 156. Canberra, Australian Institute of Health and Welfare.

Deady, M., M. Teesson, K. Mills, F. Kay-Lambkin, A. Baker, A. Baillie, F. Shand, L. Manns, H. Christensen and P. Haber (2013). One person, diverse needs: Living with mental health and drug and alcohol difficulties. Sydney, National Health and Medical Research Council Centre of Research Excellence in Mental Health and Substance Use.

O'Connor, N., G. E. Hunt, M. O'Hara-Aarons, A. Hall, J. Snars, V. Storm and T. Lambert (2014). "The Sydney Mental Health Client Mortality Audit: What does it tell us and what are we to do?" Australasian Psychiatry: 1039856213519690.

Stenbacka, M., A. Leifman and A. Romelsjö (2010). "Mortality and cause of death among 1705 illicit drug users: A 37 year follow up." Drug and alcohol review **29**(1): 21-27.

Infographics

Australian Bureau of Statistics (2008). National survey of mental health and wellbeing: Summary of results 2007. cat. no. 4326.0. Canberra, Australian Bureau of Statistics.

Lawrence, D., C. Holman and A. Jablensky (2001). Preventable physical illness in people with mental illness. University of Western Australia, Centre for Health Services Research, Department of Public Health.

WHAT WE NEED

Australian Bureau of Statistics (2008). National survey of mental health and wellbeing: Summary of results 2007. cat. no. 4326.0. Canberra, Australian Bureau of Statistics.

Australian Institute of Health and Welfare (2012). Mental health services: In brief. cat. no. HSE 125. Canberra, Australian Institute of Health and Welfare.

Begg, S., T. Vos, B. Barker, C. Stevenson, L. Stanley and A. Lopez (2007). The burden of disease and injury in Australia 2003. cat. no. PHE 82. Canberra, Australian Institute of Health and Welfare.

NSW Government (2014). NSW Health Budget 2013-14. Sydney, NSW Government.

Richmond, D. (1983). Inquiry into health services for the psychiatrically ill and developmentally disabled. Sydney, NSW Department of Health.

JOURNEY 1 – BUILDING COMMUNITY RESILIENCE AND WELLBEING

Australian Bureau of Statistics (2008). National survey of mental health and wellbeing: Summary of results 2007. cat. no. 4326.0. Canberra, Australian Bureau of Statistics.

World Health Organisation (2001). The world health report 2001- Mental health: New understanding, new hope. Geneva, World Health Organization.

World Health Organisation (2014). Fact sheet 220: Mental health: Strengthening our response. Geneva, World Health Organization.

Infographics

Moodie, R. and R. Jenkins (2005). "I'm from the government and you want me to invest in mental health promotion. Well why should I?" Promotion & Education: 37-41.

Oades, L. (2013). Building Community Resilience and Wellbeing The University of Wollongong. Unpublished, Prepared for the Mental Health Commission of NSW.

World Health Organisation (2004). Promoting mental health: Concepts, emerging evidence, practice: Summary report. Geneva, World Health Organization.

JOURNEY 2 – THE BEST START

Australian Government (2013). A snapshot of early childhood development in Australia 2012: AEDI national report. Canberra, Australian Government.

Brinkman, S. A., A. Gialamas, A. Rahman, M. N. Mittinty, T. A. Gregory, S. Silburn, S. Goldfeld, S. R. Zubrick, V. Carr and M. Janus (2012). "Jurisdictional, socioeconomic and gender inequalities in child health and development: analysis of a national census of 5-year-olds in Australia." BMJ Open **2**(5).

Moore, T. and M. McDonald (2013). Acting Early, Changing Lives: How prevention and early action saves money and improves wellbeing. Prepared for the Benevolent Society. Melbourne, The Murdoch Children's Research Institute and The Royal Children's Hospital.

Infographics

Australian Institute of Health and Welfare (2012). Experience of perinatal depression: data from the 2010 Australian National Infant Feeding Survey. Information Paper. Canberra, Australian Institute of Health and Welfare.

Cameron, C., Davey, T., Kendall, E., Wilson, A. and R. McClure (2013). "Changes in alcohol consumption in preganant Australian women between 2007 and 2011". Medical Journal of Australia **199**(5): 355-357

Egger, H. L. and A. Angold (2006). "Common emotional and behavioral disorders in preschool children: presentation, nosology, and epidemiology." Journal of Child Psychology and Psychiatry **47**(3-4).

JOURNEY 3 – TROUBLED KIDS

NSW Department of Community Services (2007). A closer look: Recent trends in child protection reports to DoCS. Sydney, NSW Department of Community Services.

Sawyer, M., F. Arney, P. Baghurst, J. Clark, B. Graetz, R. Kosky, B. Nurcombe, G. Patton, M. Prior and B. Raphael (2000). Mental health of young people in Australia. Canberra, Commonwealth Department of Health and Aged Care.

Infographics

Australian Government (2013). A snapshot of early childhood development in Australia 2012: AEDI national report. Canberra, Australian Government.

Maybery, D. J., A. E. Reupert, K. Patrick, M. Goodyear and L. Crase (2009). "Prevalence of parental mental illness in Australian families." Psychiatric Bulletin **33**(1): 22-26.

Sainsbury Centre for Mental Health (2009). The chance of a lifetime, preventing early conduct problems and reducing crime, Sainsbury Centre for Mental Health.

Sawyer, M., F. Arney, P. Baghurst, J. Clark, B. Graetz, R. Kosky, B. Nurcombe, G. Patton, M. Prior and B. Raphael (2000). Mental health of young people in Australia. Canberra, Commonwealth Department of Health and Aged Care.

South Australian Department of Education and Children's Services (2006). Healthy Minds/Healthy Futures: Child Mental Health and Wellbeing Study. Predicting and Improving Mental Health Resilience in Early Childhood. Summary of Research Findings From 2005 for Educators.

JOURNEY 4 – HEALTHY TRANSITIONS

Australian Bureau of Statistics (2008). National survey of mental health and wellbeing: Summary of results 2007. cat. no. 4326.0. Canberra, Australian Bureau of Statistics.

Mission Australia (2013). Youth Survey 2013, Mission Australia.

National Centre for Vocational Education Research (2012). Doing well: helping young people achieve their potential. Adelaide, National Centre for Vocational Education Research.

Orygen Youth Health Research Centre (2011). Models of collaborative care for children and youth (0-25 Years): Final report. Victoria, Orygen Youth Health Research Centre.

Infographics
Inspire Foundation and Ernst & Young (2012). Counting the Cost: The impact of young men's mental health on the Australian economy. Sydney, Inspire Foundation and Ernst & Young.

Mission Australia (2013). Youth Survey 2013, Mission Australia.

Muir, K., K. Mullan, A. Powell, S. Flaxman, D. Thompson and M. Griffiths (2009). State of Australia's Young People: A report on the social, economic, health and family lives of young people. Report for Office of Youth, Social Policy Research Centre, University of New South Wales. Canberra, Commonwealth of Australia.

JOURNEY 5 – TOWARDS A BETTER LIFE

Australian Health Disaster Management Policy Committee (2009). Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009-2014. Canberra, Commonwealth of Australia.

Morgan, V. A., A. Waterreus, A. Jablensky, A. Mackinnon, J. J. McGrath, V. Carr, R. Bush, D. Castle, M. Cohen and C. Harvey (2012). "People living with psychotic illness in 2010: The second Australian national survey of psychosis." Australian and New Zealand Journal of Psychiatry **46**(8): 735-752.

Infographics
Australian Health Ministers' Advisory Council (2013). A national framework for recovery-oriented mental health services: Guide for practioners and providers. Canberra, Commonwealth of Australia.

Morgan, V. A., A. Waterreus, A. Jablensky, A. Mackinnon, J. J. McGrath, V. Carr, R. Bush, D. Castle, M. Cohen and C. Harvey (2012). "People living with psychotic illness in 2010: The second Australian national survey of psychosis." Australian and New Zealand Journal of Psychiatry **46**(8): 735-752.

JOURNEY 6 – BREAKING THE CYCLE

Weatherburn, D., L. Snowball and B. H. Hunter (2006). "Economic and Social Factors Underpinning Indigenous Contact with the Justice System: Results from the 2002 NATSISS Survey, The." BOCSAR NSW Crime and Justice Bulletins: 16.

Infographics
Butler, T. and L. Milner (2003). 2001 New South Wales inmate health survey. Sydney, Corrections Health Service.

Indig, D., L. Topp, B. Ross, H. Mamoon, B. Border, S. Kumar and M. McNamara (2010). 2009 NSW inmate health survey: Key findings report. Sydney, Justice Health Sydney.

Weatherburn, D., L. Snowball and B. H. Hunter (2006). "Economic and Social Factors Underpinning Indigenous Contact with the Justice System: Results from the 2002 NATSISS Survey, The." BOCSAR NSW Crime and Justice Bulletins: 16.

JOURNEY 7 – BODY AND SOUL

Mental Illness Fellowship of Australia (2011). The Physical Health of People Living with a Mental Illness – Literature Review, Programs Overview & Recommendations. Marleston, Mental Illness Fellowship of Australia Inc.

Parslow, R. A., V. Lewis and G. Marsh (2011). "The general practitioner's role in providing mental health services to Australians, 1997 and 2007: Findings from the national surveys of mental health and wellbeing—Research-In a decade of increasing access, did GPs take up the mantle?" Medical Journal of Australia **195**(4).

Vinogradova, Y., C. Coupland, J. Hippisley-Cox, S. Whyte and C. Penny (2010). "Effects of severe mental illness on survival of people with diabetes." The British Journal of Psychiatry **197**(4): 272-277.

Infographics
Morgan, V. A., A. Waterreus, A. Jablensky, A. Mackinnon, J. J. McGrath, V. Carr, R. Bush, D. Castle, M. Cohen and C. Harvey (2012). "People living with psychotic illness in 2010: The second Australian national survey of psychosis." Australian and New Zealand Journal of Psychiatry **46**(8): 735-752.

Kruse, J., N. Schmitz and W. Thefeld (2003). "On the Association Between Diabetes and Mental Disorders in a Community Sample Results from the German National Health Interview and Examination Survey." Diabetes Care **26**(6): 1841-1846.

JOURNEY 8 – LIVING LONG AND STRONG

Australian Bureau of Statistics (2010). Population by Age and Sex, Australian States and Territories, Jun 2010. cat. no. 3201.0. Canberra, Australian Bureau of Statistics.

Draper, B. and L.-F. Low (2010). "Psychiatric services for the "old" old." International Psychogeriatrics **22**(04): 582-588.

Morgan, V. A., A. Waterreus, A. Jablensky, A. Mackinnon, J. J. McGrath, V. Carr, R. Bush, D. Castle, M. Cohen and C. Harvey (2012). "People living with psychotic illness in 2010: The second Australian national survey of psychosis." Australian and New Zealand Journal of Psychiatry **46**(8): 735-752.

Infographics
Beard, J., S. Biggs, D. Bloom, L. Fried, P. Hogan, A. Kalache and S. Olshansky (2011). Global population ageing: Peril or promise. Geneva. World Economic Forum.

Australian Institute of Health and Welfare (2013). Depression in residential aged care 2008–2012. cat no. AGE 73. Canberra, Australian Institute of Health and Welfare.

ARE WE GETTING THERE?

Australian Institute of Health and Welfare (2011). Mental health services in Australia: Expenditure on specialised mental health services. Canberra, Australian Institute of Health and Welfare.

Australian Institute of Health and Welfare (2014). Mental health establishments NMDS 2011-12. Canberra, Australian Institute of Health and Welfare.

Expert Reference Group to COAG Working Group on Mental Health Reform (2013). National targets and indicators for mental health reform. Sydney, National Mental Health Commission.