

A Contributing Life: the 2012 National Report Card

on Mental Health and Suicide Prevention



Australian Government
National Mental Health Commission

Acknowledgements

Firstly, we acknowledge those people with a lived experience of mental health issues, their families, friends and other supporters who provided input into the process to develop this first Report Card, along with the many people from different organisations and the general public with an interest in mental health and suicide prevention.

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attended our Roundtable discussions and above all gave generously of their time – whether it was to speak of their personal experiences, their achievements, and to share their data or insights. Without their input it would not have been possible to produce the Report Card.

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About us

This is the first annual Report Card of the National Mental Health Commission.

The Commissioners are: Mr Peter Bicknell, Ms Jackie Crowe, Professor Pat Dudgeon, Professor Allan Fels AO, Professor Ian Hickie AM, Mr Rob Knowles AO, Ms Robyn Kruk AM (ex-officio Commissioner), Ms Janet Meagher AM, Ms Sam Mostyn and Professor Ian Webster AO.

Our vision All people in Australia achieve the best possible mental health and wellbeing.

About this Report Card

This Report Card is accompanied by a technical document which provides more detail on the data it contains. It can be downloaded from our website www.mentalhealthcommission.gov.au. Requests and enquiries concerning reproduction and rights should be directed to the Director of Policy, Strategy and Projects PO Box 1463, Royal Exchange, Sydney NSW 2000. This publication is the first of an annual series of Report Cards. A complete list of the Commission's publications is available from our website.

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A number of electronic fact sheets along with a short summary of this publication are available on our website. Please note that there is the potential for minor revisions of data in this report; refer to the online version for the most up-to-date version.

The quotes on the inside cover come from people around Australia who participated in a qualitative research study commissioned in 2012 by the National Mental Health Commission. The purpose of the study was to take a snapshot of Australian community awareness and attitudes to mental health and suicide. The study will be published in 2013.



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A message from the Chair, Professor Allan Fels AO



I am very pleased to present to the Prime Minister
A Contributing Life: the 2012 National Report Card on Mental Health and Suicide Prevention.

This is the first report of its kind, and begins our job as a Commission in reporting each year on how Australians are faring in their mental health and on the things that aid recovery and help make people's lives better. Achieving good mental health for Australia will be a far bigger task than making improvements only in the health system. To improve lives we will need to go further.

Mental health is everyone's business

It is not about 'us' and 'them', it's about everyone. We will all be profoundly affected at some stage in our lives by mental health – either directly, in our family or circles of friends, or at work. That is why we need to highlight and report on the things that matter to all our lives – where we live, what we do, our friendships and community and what we need to help us live a full and contributing life.

We knew that it would be a challenging year when we started just 11 months ago. We take very seriously the hopes everyone has for the Commission. We have always tried to be honest about what this first report can and cannot be, but we are ambitious for the future. The 2012 Report Card helps move towards this ambition.

A contributing life

At our first meeting we made a commitment that we will always have people at the heart of what we do. Commissioner Janet Meagher puts it very simply when she says that people with mental health problems want the same thing as everyone else. Even the most disadvantaged should be able to lead a *contributing life*. This can mean many things. It can mean a fulfilling life enriched with close connections to family and friends, good health and wellbeing to allow those connections to be enjoyed,

having something to do each day that provides meaning and purpose – whether it be a job, supporting others or volunteering, and a home to live in, free from financial stress and uncertainty.

At the Commission we believe that everyone has a right to lead a contributing life. All of us, not just governments, can play a part in enabling those living with and recovering from mental health difficulties to achieve the life they want.

Every family has an experience to share

We know that mental ill health will profoundly affect every Australian at some point, through the experience of family, friends or work colleagues.

We know that people want to help but they don't always know where to start, either at home, with friends, in the community or at work. They struggle to know how to talk about it and they worry that intervening will make things worse. We're not taught how to help, and information on what to do isn't nearly as well-known as it should be. It used to be like this for other illnesses, for example cancer,

but times have changed and attitudes and behaviours have moved on. It's now mental health's time.

Australians do want to talk about mental health and suicide and they want to know what is best to do, that there is someone to talk to and somewhere to go for help, whether it's for personal reasons, family, fairness and social justice or broader economic and social reasons.

How a Report Card can help drive improvement

The Commission wants to drive continuous improvement. But to do so we need the support of, and authority from, governments and the community. We value our independence and we will use this to push for change.

We want to put a national spotlight on people experiencing mental health difficulties and their families and supporters; on what they need, the challenges they face and what needs to be done to assist their recovery. We have heard loud and clear that there is more to people's lives than the services they use; they are of course important, but we look not just at the number of

services, but also their range, availability, accessibility and quality.

In this first Report Card we can't immediately address every issue that people have asked us to. Nor can the Commission or the Report Card change things overnight. It's impossible to spotlight all the various service gaps or look into all the very real issues faced by many different groups of people such as citizens of Culturally and Linguistically Diverse (CALD) backgrounds, people with eating disorders, veterans, refugees, people with intellectual disability and those living with borderline personality disorders.

At the same time we can't do justice to all the overwhelming good work of people in mental health support services and elsewhere, and the very positive initiatives that are happening across Australia every day.

We've had to make some hard choices about what we cover this year. But we have been delighted with the amount of information and assistance that people have offered and provided. It will not go to waste.

Our first Report Card takes a big picture view and sets the scene for later reports.

It has helped us to shape our priorities and to work out where we can best add value. Future reports may well look quite different.

What will not change is our belief in the need for clear and well communicated messages about what works from evidence, research and from the perspective of those with lived experience of mental health difficulties and those supporting them. This evidence and experience also needs to demonstrate good value for the taxes we pay.

People working in mental health are very good at talking to each other in their own language. We have tried to make this a Report Card that any Australian can pick up and read. Addressing mental health as a wider issue will also help to improve wellbeing across our communities, right across Australia.

Letting the data do the talking

We have avoided the trap of calling for new data, letting the existing information tell the story. We have sought the advice and input of those with lived experience, their families and supporters, government, private and non-government service providers, industry leaders and academics. We know that there are, however, important data gaps that do need to be addressed and we have identified some of these.

We have also not moved directly into so-called 'league tables' that are often used to compare the performance of States and Territories and normally provoke an argument about who is the best and who is the worst. This misses the point. However, the Commission believes that the more meaningful focus in the longer term needs to be at the local level with strong support from the community and all government leaders.

We will also not waver from our view that governments need to agree and report on a small number of meaningful national indicators and ambitious but achievable targets. These need to concentrate and link up effort in all of the areas that help people to live contributing lives – housing, employment, education, family and social support, and physical health.

I would like to thank my fellow Commissioners for their commitment and contributions, and the Commission staff for their outstanding efforts, in developing this Report Card.

On behalf of the Commissioners I commend this Report Card to all governments and all Australians.

**Professor Allan Fels AO
Chair**

Our big picture view

The Commission's big picture case for change identifies what governments and communities must do and keep doing.

We have four priority areas for action.

We will not see real change unless the following four areas become part of everyday business.

We have also set out where action must start with our ten specific recommendations for 2012.

1 Mental health must be a high national priority for all governments and the community

Mental health must be the business of the Prime Minister, Premiers and Chief Ministers

Reform will wither on the vine without ongoing support and oversight by every government across Australia when they come together to discuss and agree on matters of national importance as the Council of Australian Governments (COAG). It is imperative that mental health continues to have the direct support of the Prime Minister and Premiers and Chief Ministers. Cross-government oversight is vital. Without links between housing, employment, education, health, family and child support, justice and corrections we will never give people the best chance of recovering and living contributing lives.

Mental health and wellbeing must not be pushed aside by other priorities or become a casualty because money is tight. In fact, money will be wasted if we take our eye off the ball. It's an investment now for all our futures.

We must get a proper understanding of the value of good mental health to drive reform

There is bipartisan support for increasing Australia's productivity and reducing unnecessary costs that result from mental health being dealt with ineffectively in the community, service systems and in the workplace.

There has been some work on the **cost** of mental illness. There is still much to be done to demonstrate the **value** of good mental health.

The Australian Government must ask the Productivity Commission to work in partnership with us to report on the economic and productivity impacts of mental ill health and suicide in Australia and the value of good mental health. This will provide an accurate and credible picture of the benefits from preventing mental illness and promoting mental health, and the productivity from increasing participation, promoting recovery oriented approaches and investing in properly evaluated services.

The value of good mental health to each person, the community and the wider population all affect the broader workings of our society.

Governments must meet their existing commitments

Commitments have already been made by all Australian Governments through COAG and the United Nations^{1,2,3,4,5} and the public expects them to be delivered. These include the following:

- increasing access and quality of services to meet gaps
- including people with a lived experience of mental health issues, families and supporters in planning, design and evaluating policy and services
- recognising the role that non-government organisations play, and
- not discharging people with mental illness from hospital or other facilities into homelessness.

It is not acceptable that it can take years to get agreement or simply to report progress on measures endorsed by all Australian Governments.

The mental health and wellbeing of Aboriginal and Torres Strait Islander peoples needs to be included as one of our national priorities

All governments have given a strong commitment in various COAG agreements to give Aboriginal and Torres Strait Islander peoples an equal chance to have a fully contributing life.⁶ We stand together with Aboriginal and Torres Strait Islander leaders to say we must overcome the compounding cycles of disadvantage and poor social conditions to improve resilience, physical and mental health.

In this Report Card we feature Aboriginal and Torres Strait Islander peoples' mental health and social and emotional wellbeing, and show the very powerful impact that families and communities can and do have.

2

We need to provide ‘a complete picture’ of what is happening and closely monitor and evaluate change

Behind every bit of data is a part of a person’s story.

It is often the only voice that a person has. People should not be treated as a series of different ‘body parts’ or file numbers depending on what type of clinician or agency they are seeing for assistance.

A lot of money and front line staff time is spent collecting information that remains hidden. There are over 75 national mental health indicators, but these focus too heavily on health services. It is currently almost impossible to get a good picture of whether support is effective. Data doesn’t always show the important work being carried out in the community or by private providers or the important role that families, support people and peer workers provide.

It doesn’t tell us if people’s lives are improving, whether they are being treated with respect, or whether we have got the balance right in where we spend money.

Data must be rationalised and the right data collected

This will free up valuable time and resources that could be used to **link data** held by disability services, coroners, police, ambulance services, housing and employment agencies, prisons, hospitals, community services and between government, private and non-government service providers.

Data from non-government organisations must be included in national minimum data sets so that we get a more rounded picture of service provision in Australia and can address problems when people move between services.

This is the only way we will reduce the chance of people falling between the cracks, or being invisible. Work has started on this but progress needs to speed up and implementation needs to be funded.

The Australian Government needs to commit to conducting reliable and regular national mental health population surveys to measure progress

We need measures such as the National Survey of Mental Health and Wellbeing and other surveys,⁷ to focus on people living and recovering from severe mental illness and the mental health of children and young people. **These need to occur on regular intervals of no less than five years, commencing no later than 2014.**

The surveys should not just focus on health services. They must focus on all of the aspects of a contributing life; they must tell us about localities or communities, such as rural and remote; CALD communities or Aboriginal and Torres Strait Islander peoples.

Future Report Cards will rely heavily on these surveys.

Governments must ensure that announced mental health funding is spent on mental health as promised

It is pleasing to note that governments across Australia have to date increased their expenditure on mental health related services. However, experience backed up by published audit findings⁸ confirm that publicly committed funds do not always stay in mental health services and are too often siphoned off at the end of the financial year to meet overspends in other service areas. The risk of this occurring will be heightened as budget pressures mount.

All governments must independently and transparently report each year on the actual expenditure on mental health prevention, community based, rehabilitation, recovery and acute care services and compare this with the announced expenditure. This way we will know that money committed to mental health is actually used in mental health, is used in the right areas and is not used to offset funding pressures or subsidise shortfalls in hospital or related budgets.

3

We need to agree on the best ways to encourage improvement and get better results

We must initially agree on what is good practice across all mental health and support services. This must be based on evidence. Services need to be effective, efficient, provide value and demonstrate improvement in the mental health and experiences of people using them and their families and support people.

This will make it possible to work out if money is being spent sensibly. We need a commitment to regularly reviewing whether existing services and practices and the way people do things are still the best ways. This must happen. Without this, success or failure is measured by how much money has been put into the system or how many beds are in the system. This currently makes it possible for anecdotal or unsubstantiated claims to be made that Australia has either the best or the worst mental health services. Based on what standard? Measured on what outcomes?

The Report Card identifies the six key areas that make a difference to a contributing life. This is not just about access to clinical services. It is not just about ‘technical efficiency’ or getting the price right. We need a system that is not just based on how much we do and how much it costs but one that looks at whether we are actually improving people’s lives in the most cost-effective way. We want the way in which we fund and we measure to drive change in the system. This will mean moving to more bundled models of care.

The Commission wants to engage with the mental health community to assist in reaching agreement on the appropriate models of care for all of these areas.

Australia is very good at identifying need. It is not so good at matching the services to meet that need. Agreement on appropriate models must be reached in the first instance. This will then allow existing service provision to be mapped against need. This will give us a baseline for national reporting and a sensible framework for future investment.

The new Activity Based Funding system should be designed to meet the needs of people with mental health difficulties regardless of whether services are provided in hospitals, in the community or elsewhere. Alternatives to hospitals must be a priority.

All governments have agreed to make sure that health dollars are well spent. They have agreed to introduce Activity Based Funding (ABF) and to identify a national ‘efficient price’ for all public hospital services as part of the COAG 2011 National Health Reform Agreement. This Agreement guarantees more funds for state and territory health services by making the Australian Government an equal funder for the growth in demand.

But ABF focuses only on hospitals and not the critical mental health activity that occurs in the community. There is a big risk that the sole focus and promise of more money for one-off hospital services will lead to activity being delivered back in hospitals, instead of in the community where we know in many cases it works better.

Governments have also agreed to keep people out of hospital when they don’t need to be there. This is highly important for mental health as the vast majority of services are provided in the community – we know that in 2009-10 there were more than 222,000 mental health related hospitalisations and more than 6.5 million public community mental health service contacts.⁹

The design and implementation of ABF must give as much priority to the appropriateness, effectiveness and quality of mental health outcomes for people as it does to the efficient cost of services.

The Independent Hospital Pricing Authority (IHPA), which develops the ‘national efficient price’ for public hospital services must have the authority to price an annual package of support that meets all of the health needs of people with mental health difficulties. If not, COAG will have got it wrong. We hope that COAG continues to drive improvement in mental health services and not push services back into hospitals. This will be more costly and less effective all round.

The National Disability Insurance Scheme must fully cover the psychosocial disability that results from mental illness

Mental health problems and associated physical health problems can be just as disabling as sensory, intellectual or physical disabilities. There must be no competition: disability is disability, whatever the cause.

All governments must commit to a National Disability Insurance Scheme that properly assesses and funds support for Australians living with a psychosocial disability arising from a mental health disorder. A psychosocial disability affects the extent to which a person can carry out day-to-day activities – it can affect their “ability to live independently, maintain friendships, maintain employment and to participate meaningfully in the community”.¹⁰

4

We need to analyse where the gaps and barriers are to achieving a contributing life and agree on Australia's direction

All governments must prioritise the development and implementation of a nationally agreed mental health service planning framework

It is impossible to know “are we there yet” unless we know where we want to get to, and whether we offer quality services that work. This must be from the perspective of the person and family, not just the clinician.

Unlike Canada and New Zealand, Australia has no nationally agreed picture of what a good mental health service framework should look like and how it should be properly resourced, nor of the role that families and support people should play in such services.

The framework should tell us what services people should get regardless of where they live, so there is the best use of resources to support people to gain the most improvement. It must give a clear picture of the appropriate coverage, levels and range of mental health services needed at a regional level along with the workforce mix needed to deliver it.

More and more non-government organisations in housing, community services, employment and health are supporting Australians living with mental health difficulties and their families. **A national service planning framework must over time move beyond beds and clinical services and include non-government/community services across all sectors, including peer and family workers.**

Governments must be brave enough to set goals and targets for improving mental health and reducing suicide and be judged by the community on their results

A priority for COAG is to agree on the right indicators and targets at the national level that will bind all governments to work co-operatively and drive results. These need to consider the five areas of a contributing life, and the experiences of people and their supporters who need or use services.

The Commission is hopeful that COAG will do this through the promised Ten Year Roadmap for National Mental Health Reform. If not, the Commission will move to identify appropriate targets based on a person-centred, whole of system approach.

COAG should give the Commission the role of monitoring progress against the Roadmap to assist in driving reform between government and other service providers. The Commission must be given access to the data needed to do this properly.

Nationally we need to see where the gaps are across the five areas of a contributing life, to see mental health as a co-ordinated and integrated system. This will provide the way ahead for how we approach mental health and physical health improvement, stable housing, workplace and community involvement, mental health and community workforce requirements, improved access to services and personal support for the person living with a mental health difficulty and their supporters, integrated care approaches and a continued reduction in suicide.

Building on these four planks, the Commission has made ten recommendations to achieve our vision for a contributing life for people with mental health difficulties, their families and supporters.

Our 2012 Report Card recommendations

Our recommendations have been developed based on the elements of a contributing life, and what we have heard from those who have contributed to our work. They go to the heart of where the Commission believes we need real action.

Recommendation 1

Nothing about us, without us – there must be a regular independent survey of people’s experiences of and access to all mental health services to drive real improvement.

The real test for mental health services and supports is whether they improve people’s lives. The best people to judge this are those with lived experiences and their families, friends and other supporters. This is the real report card for governments and communities. This needs to be hard wired into the way we judge success, and measured regularly.

Action: The National Mental Health Commission will undertake a regular national survey of people with mental health difficulties and their families and support people. The survey will consider access to services, as well as perceptions and experiences. This will build on and complement existing efforts and ensure that people always have a voice and remain at the centre of decision-making about all the services that impact on them.

Recommendation 2

Increase access to timely and appropriate mental health services and support from 6-8 per cent to 12 per cent of the Australian population.

If people need a service or support, they should get it when they need it. The COAG Reform Council has acknowledged that the proportion of people receiving “private and public mental health care services” (relative to the population) has remained constant.¹¹ In these areas we are not keeping pace with population growth – we know there are gaps. The area where services are increasing, however is in access to Medicare funded General Practitioner (GP) psychiatrist, psychologist and other health professionals for mental health needs.¹²

Agreement needs to be reached on the most appropriate ways to deliver more services and map existing services against what is required. This needs to be backed by evidence-based investments, including support for new strategies to reach those who currently do not use the existing primary, specialist or emergency health services but need help.

Action: All governments must agree and meet the target proposed in the Fourth National Mental Health Plan Measurement Strategy that 12 per cent of the population should be able to access mental health services in a year.¹³ There must be agreement to this indicator with an implementation plan and investment strategy to achieve this.

Recommendation 3

Reduce the use of involuntary practices and work to eliminate seclusion and restraint.

The experience of specific treatment practices without a patient's consent (or undertaken involuntarily) are of concern. Rates of involuntary admissions have remained stubbornly around 30 per cent of all mental health hospitalisations.⁹ We need to know why.

Many people have told us that high use of seclusion and restraint in mental health facilities are often an early sign of a system under pressure. They can deny people their rights. There is little evidence to support seclusion as an effective and positive clinical intervention to people when they are at their most vulnerable.

But the use of such practices is complex and can also be used with safety in mind.

Australia has ratified international agreements committing to human rights. All Governments in 2005 also ratified an agreement to reduce and where possible to eliminate seclusion and treat people in the least restrictive way.

But only four jurisdictions report their use of seclusion publicly.

One recent report shows that over 53 per cent of mental health patients who were secluded, in the surveyed hospitals, experienced seclusion for more than four hours and the number of mental health patients experiencing major complications while in seclusion had increased.¹⁴ We need to know if this is a more system wide problem.

Action: All jurisdictions must contribute to a national data collection to provide comparison across states and territories, with public reporting on all involuntary treatments, seclusions and restraints each year from 2013. This information should be reported at the service unit level.

Action: The National Mental Health Commission will call for evidence of best practice in reducing and eliminating seclusion and restraint and help identify good practice treatment approaches. We will do this in partnership with the Mental Health Commission of Canada and Australian partners, including the Safety and Quality Partnerships Subcommittee, Disability Discrimination Commissioner, Australian Human Rights Commission and interested state mental health commissions.

Recommendation 4

All governments must set targets and work together to reduce early death and improve the physical health of people with mental illness.

The poor physical health and early deaths of people with mental health difficulties is a serious national problem. The three big drivers of early death are suicide, cancer and heart disease. Mental illness tends to overshadow many physical health risks, most notably smoking rates. People with mental health difficulties also

have lower access to the health services they need, potentially contributing to premature death. Enduring mental illness has the same impact as other chronic diseases and needs to be dealt with in the same manner.

Action: Enduring mental illness must be given the status of a chronic disease to give it higher national focus and support.

Action: The physical health needs of people with mental health problems need to be given a higher priority in all areas of health. The initial focus must be on rapidly reducing cardiovascular disease by reducing risk factors such as smoking, poor diet and by increasing physical activity for people living with mental health problems.

Action: All government funded mental health related programs must also be measured on how they support people to achieve better physical health and longer lives. Priority should be given to the financing of multi-disciplinary primary care (through GPs and other primary health care organisations).

Action: All relevant services must give priority to tracking **both** the physical and mental health needs of those with enduring mental illness.

Recommendation 5

Include the mental health of Aboriginal and Torres Strait Islander peoples in 'Closing the Gap' targets to reduce early deaths and improve wellbeing.

We must combat the vicious cycles of disadvantage that exacerbate mental and physical health issues. Up to 15 per cent of the 10 year life expectancy gap compared to non-Indigenous Australians has been attributed to mental health conditions.¹⁵ Poor mental health contributes to suicide risk and high rates of smoking, alcohol and substance abuse and obesity that in turn progresses chronic disease: the biggest killer of Aboriginal and Torres Strait Islander peoples.

Action: Mental health must be included as an additional target in the COAG 'Closing the Gap' program. This must be done through the development and implementation of an Aboriginal and Torres Strait Islander Mental and Social and Emotional Wellbeing Plan to commence in 2013. This must also address the current work and future findings of the Aboriginal and Torres Strait Islander Suicide Prevention Advisory Group.

Action: Training and employment of Aboriginal and Torres Strait Islander peoples in mental health services must increase. There must also be better support for Aboriginal and Torres Strait Islander families. There must be regular reporting on progress.

Recommendation 6

There must be the same national commitment to safety and quality of care for mental health services as there is for general health services.

All Governments have made good progress in agreeing to mandatory standards for general health services. But national mental health safety and quality standards are only voluntary. This is despite suicides in hospitals being reported as “sentinel events” (an unanticipated outcome causing death or serious physical or psychological harm) and the poorer health status of people with mental ill health. The high risk of suicide within two weeks of discharge is also of major concern.¹⁶

Action: All governments must agree that there is the same emphasis on improving the quality of care and reducing adverse events in mental health services as applies to other physical health services. Governments must commit to implementing nationally agreed and mandatory service standards in mental health services as they have done for other health services. The National Mental Health Commission will work with the Australian Commission on Safety and Quality in Health Care (ACSQHC) to identify what it takes to get proper uptake of national mental health service standards and make them mandatory.

Recommendation 7

Invest in healthy families and communities to increase resilience and reduce the longer term need for crisis services.

What happens in the first three years of a child’s life will have a significant impact on whether they will go on to lead a contributing life. We back the expanded Medicare Healthy Kids Check¹⁷ for three year olds which will support families and children by reviewing emotional wellbeing and development as well as physical checks such as hearing. Mental health promotion and prevention must be an essential focus for families at risk.

But to invest in healthy families we need to go further. Grandparents, siblings or children may be the carers in some families and should not be overlooked. It’s critical that any investments in this area are sustainable, locally and culturally relevant and fit in with the community. They must be linked to the elements we have defined as essential for a contributing life.

Action: Increase enhanced and personalised support for parenting through culturally relevant forms of home-based visiting (ante-natal and in the first few years of life). These must be provided at a local or regional level. There must also be active follow-up where a family is under stress or experiencing tough financial or social difficulties.

Recommendation 8

Increase the levels of participation of people with mental health difficulties in employment in Australia to match best international levels.

What’s good for people with mental health difficulties is also good for the economy.

Despite our efforts Australia has a lower participation rate of people with mental ill health in the workforce when compared internationally. This is a matter for governments, business and communities. We need evidence to tell us what works for different workplaces, especially the significant number of small employers who employ almost half of all workers in the private non-financial sector. Policies and employment programs supporting people with mental health difficulties can’t be done in the same way as programs for someone with a physical disability. Although efforts are put into preparing people to get into the workforce, more work is required to assist people and their employers when they get there. We need better evidence to understand the link between health and employment outcomes, including the important role of employers, families and support people.

Action: The National Mental Health Commission will pull together a Taskforce, including industry, government and community leaders to actively promote effective employment support programs and workplace based programs that increase the participation in employment of people with mental health difficulties.

The Commission will partner with the Business Council of Australia (BCA), Council of Small Business of Australia (COSBOA), the Mental Health Council of Australia (MHCA), Comcare and other key industry and community groups (including beyondblue and SANE Australia) to call for evidence and work together to advance the adoption of good workplace practices in Australia. This should support workforce leaders to change the way mental health is dealt with so that workplaces are more capable of dealing with mental health matters in a manner that leads to the betterment of the workforce and the workplace. The Commission will report progress.

Action: Employment support programs, initiatives and benefits must be more flexible. They must recognise that mental illness comes and goes and what that means for people and their families. Programs must provide long-term support for the employee, families and support people and the employer, with appropriate incentives and milestones.

Recommendation 9

No one should be discharged from hospitals, custodial care, mental health or drug and alcohol related treatment services into homelessness. Access to stable and safe places to live must increase.

We have heard this from our consultations; enough reports have made this point¹⁸ – we now need action. Every opportunity must be taken to break the pathways into homelessness. Hospitals and prisons must take responsibility for assertive case management of people with mental ill health into a stable home. The two weeks after discharge can also be when people are most vulnerable to suicide.¹⁶ All governments have committed to implementing and reporting a COAG commitment of ‘no exits into homelessness’. This requires active follow up in the community using tenancy officers or outreach or peer workers.

Action: All governments must implement and report regularly on the existing COAG commitment of ‘no exits into homelessness’¹⁸ from statutory, custodial care and hospital, mental health and drug and alcohol services for those at risk of homelessness.

Action: Discharge planning must consider whether someone has a safe and stable place to live. Data must also be collected on housing status at point of discharge and reported on three months later, linked to the person’s discharge plan.

Action: Governments must commit to removing any structural discrimination barriers to people with mental health difficulties accessing social housing. Just as important is providing support to help vulnerable residents to settle in, adjust and remain in their homes.

Recommendation 10

Prevent and reduce suicides, and support those who attempt suicide through timely local responses and reporting.

Best estimates show that there are over 65,000 reported suicide attempts in Australia each year.¹⁹ Good work is underway but everyone agrees we can and need to do better.

When there’s a bushfire, flood or threat of outbreaks of infectious disease, Australia knows what to do and does it well. All levels of government and agencies, and the non-government organisations work together and everyone knows their job. We don’t have the same tracking, early warning and response systems for suicide risk, hotspots and clusters.

Action: Develop local, integrated and more timely suicide and at-risk reporting and responses. These should be co-ordinated, community based, culturally appropriate, early response systems and suicide prevention programs. They should promote community safety, reach the most vulnerable, and use up-to-date information from the ‘first responders’ such as Police officers, occupational health workers, ambulance officers and mental health workers.

Action: Programs with a proven track record (which are evidence-based) must be supported and implemented as a priority in regions and communities with the highest suicide or attempted suicide rates – action needs commitment and a humane approach.

Introduction

This first Report Card casts an independent eye over how we as a nation support the estimated 3.2 million Australians²⁰ each year who live with a mental health difficulty, their families and support people, and how we provide and co-ordinate the services they need.

In doing this, the Commission has taken a recovery perspective to its work – which reflects that a recovery journey of a person living with a mental health difficulty aims to achieve as fulfilling a life as possible, which is unique to each person. This is a wide-angle view beyond mental health to see the context of people's lived experiences and their hopes for leading a full and contributing life.

A Contributing Life

A Contributing Life is where people living with a mental health difficulty can expect the same rights, opportunities and health as those without a mental illness. Simply put,

this is about having a good home, meaningful activity, valued friendships, proper health care and opportunities for education and training, all without experiencing discrimination due to having a mental health difficulty.

Through publishing the Report Card the Commission aims to drive change, so that over time each person has the choices available to achieve a full and contributing life, improve their overall health and wellbeing, and live in communities that have better opportunities to build good mental health, strengthen resilience and work to prevent suicide.

This Report Card is holding up a mirror to mental health in Australia to see a reflection of what the current circumstances are for people living with a mental health difficulty, and to see what can make a change for the better.

The Commission wants to drive action, building on the groundswell of public concern and advocacy we have heard across Australia about improving services and support for people living with a mental health difficulty and for people at risk of suicide.

This is a...

human rights issue

because the rights of an individual who is living with a mental health difficulty are often set aside.

This is a...

community issue

where we must not lose sight of the fact that human contact and community support for people when they are not faring well is the foundation of community wellbeing.

This is a...

life and death issue

where people living with a severe and persistent mental illness have their life expectancy cut by up to 32 years;^{21,22} where they are more likely to die from cardiovascular or related metabolic disease;²³ where mental illness is experienced by over half of the people who lose their life through suicide.²⁴

Where we are today

Mental illnesses are a disorder of the mind, which typically develop in a person's life from mid-to-late adolescence.²⁵ Like other illnesses, mental illnesses can also develop as a person gets older and can vary in severity.

Mental illness is not uncommon in our community. It is experienced by nearly half of the Australian adult population at some point over their lifetime (45 per cent of the population²⁶) of whom 5.1 per cent will use alcohol excessively or have a drug addiction.²⁰

It is estimated that 7.3 million Australians aged 16 to 85 have a lived experience of a mental illness.²⁶

We know that one in five adults or 3.2 million Australians will experience a mental health difficulty in any year.²⁰ The most common mental illnesses are affective disorders which include depression and bipolar disorder,²⁰ anxiety disorders and substance use disorders.²⁰ People living with these illnesses make up the majority of all people who experience a mental illness.

Along with these frequently occurring mental illnesses, a smaller number of people, estimated at around 3 per cent of the adult population, will experience a severe mental illness such as schizophrenia or bipolar disorder (which are known as psychotic illnesses).¹

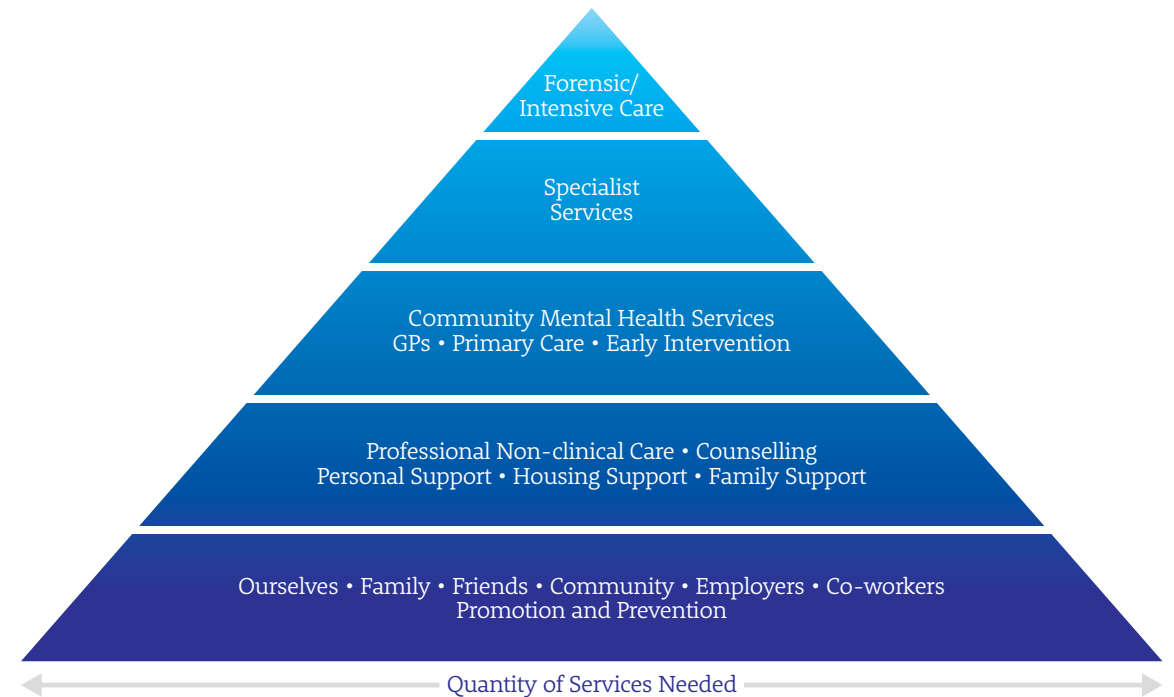
The majority of people living with mental illness can recover with appropriate treatment and support.²⁷ However, for about 20 per cent of people with schizophrenia where their illness is more persistent, it has a greater effect upon their ability to carry out activities in their daily lives and they need additional support.²⁸

We know that in our community, mental illnesses are the leading cause of the non-fatal disease burden. This means that of the total years of healthy life lost through illness and disease in Australia, 24 per

cent are lost through the effects of mental illness.²⁹ Anxiety and depression, alcohol abuse and personality disorders account for almost three-quarters of the total burden.²⁹ These figures, although not always included in accepted mental health definitions, have significant implications for community wellbeing. These figures show that mental illness is a chronic illness, with measurable impacts reducing the quality of a healthy life.

With almost one in two Australians experiencing a mental illness in their lifetime,²⁶ we will all have someone in our family, a work colleague or a friend who will experience a mental health difficulty, or experience some form of mental health condition ourselves. Just as that group of people is diverse, so too are the responses needed to support them.

When looking to an optimal mix of services, we see that family and friends, our local community, employers and co-workers are the foundation of support for each of us, but that we too are responsible for our own self-care. Support from our community, GPs and other professionals play a greater role in mental health and good health overall than specialist health services or the most highly specialised care.



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

The Commission strongly considers that wellbeing, prevention and effective interventions for a broad range of people are vital – and that we must continue a focus upon people living with a mental health difficulty and those at greatest risk. The Commission wants to explore how well we are working to support people achieving a contributing life and bring this into the light for all Australians to see.

The Commission has sought out indicators to measure

how effectively our combined investments in Government, private and non-government services are making a difference.

Some exist, many do not. Some are reported on, and some are not released to the public – or the Commission.

This is not good enough.

It is not good enough when we know that as a nation we spent over \$6.3 billion or \$287 per Australian on mental health-related services in 2009-2010.

This expenditure has seen an average annual increase of 4.5 per cent of spending per Australian between 2005-06 and 2009-10.³⁰ But there is little or no accountability as to what improvements we are getting for such a significant investment, whether it improves the health and wellbeing of people with a mental illness and provides them with the services they need.

Our international standing

Our investment in mental health as a nation is significant but we cannot track at a national level the outcomes of this investment, in a way that is meaningful to the community.

There were:

1,434

specialised mental health care facilities in Australia in 2009-10³⁰

31.1 million

prescriptions of mental health-related medicines dispensed by community pharmacies in 2010-2011³⁰

1.7 million

Australians (8 per cent of the population) who received public and/or private clinical mental health services in 2009-10³⁰

Service provision and access to treatment are important – but they are not the whole story.

At a national level, we don't measure whether we are providing effective, evidence-based mental health care, or the appropriate range of services to support a person in their recovery, such as helping people find and keep a good job or a home.

We do not collect routine information to measure how we support a person to have a contributing life, across the cultural, physical health, social, and community aspects of their lives.

We do not collect routine information on the experience of services and support systems from people who live with a mental health condition, their families or people who support them in their recovery.

We need to better understand why in any year only 35 per cent of the 3.2 million people who reported they had a mental health difficulty in the previous 12 months used mental health services.²⁰

These are the type of issues the Commission wants Australians to better understand.

The Organisation for Economic Co-operation and Development (OECD) reports that the costs of “mental health problems to society are substantial,”³¹ with costs in the range of 3-4 per cent of Gross Domestic Product in the European Union and an average of 9 per cent across OECD countries.

For Australia, the OECD reported that mental health costs were 6.5 per cent of all health care costs in 2000, which was not dissimilar to Japan (6.8 per cent in 1999) or the USA (7.5 per cent in 2003), but was less than half of the highest contributing country, the Netherlands, where in 2003 15.6 per cent of health care costs were attributed to mental health.³¹ However, the health systems of these countries differ and insights into the optimum level weren't made clear in the OECD report.

On other performance indicators, the OECD found that Australia had one of the highest rates of usage of antidepressant medications of 18 OECD countries reviewed – only Iceland had a higher rate.³¹ Australia also had some of the lowest rates of medication use for anxiety treatment and of hypnotics and sedatives.

Research undertaken on behalf of the Commission³² found that we cannot readily compare our overall performance with other countries. Work on international mental health benchmarking is only in its infancy, and where promising work is happening it focuses on health data rather than measures of the inclusion of people living with a mental health difficulty in community life.

Differences in how we define and count data between countries make even simple comparisons difficult, even in areas that might seem straightforward, such as suicide rates. There are few international comparators that Australia contributes to, so tracking how we rate in comparison to international performance is either hard to do in an overall sense, or is possible only on specific indicators – which by

themselves do not mirror the wider experience of mental health service delivery.

This observation about the consistency of international data and measurement has been found by the Commission to also be true of our national reporting. While we collect a lot of data, this often doesn't build the pictures that tell us whether efforts, money and services are improving people's lives. There are not many indicators – on service effectiveness, patient experience, or participation rates of people living with a mental health difficulty in education and employment – upon which all states and territories report.

What we've heard and the approach we're taking

The Commission believes that we all need to think differently about mental health, to see mental wellbeing as important to the individual person, their family, support people and community. To move away from seeing services as separate elements. To realise that the interconnections between services, the place of families and support people, health care providers, co-workers, teachers and friends, together are what improve mental health and health outcomes, wellbeing and a sense of a life well lived.

A whole-of-life approach is not a new idea. The first Australians, the Aboriginal and Torres Strait Islander peoples, consider that emotional health and wellbeing are intrinsic and equal parts of a person's good health and that of their community.

The Commission has taken this lead as the philosophy to sustain a contributing life.

In developing this first Report Card we have consulted across the nation; held roundtable discussions; received numerous submissions; visited services around Australia; held online surveys, including to find out what young people think is important; surveyed community attitudes to mental health and suicide; and spoken

with people who have a lived experience of mental health issues, whether personally or as families, friends and support people around the country.

The three straightforward messages we heard from the remote Aboriginal community of Ltyentye Apurte (Santa Teresa) ring true wherever we go – “Listen to us, involve us in decisions that affect us, support us to make our recovery successful.”

Consistent messages sent to the Commission are that we must see the whole-of-life impact of having a mental illness; that access to mental health care is important, but what is also needed is timely access to the right type of care and community support –

and a community to accept you; that having good overall health is a challenge when you are prescribed medications that together with higher smoking rates, poor diet and obesity, reduce your general health; that along with early intervention and prevention, there need to be services for all age groups.

This sets a challenge for the Commission, governments and the Australian people.

We should hold the nation accountable for improved outcomes from the significant expenditure on mental health made each year and also to improving our understanding, awareness and response as a community.

“Listen to us, involve us in decisions that affect us, support us to make our recovery successful.”

We do need investment in specialist mental health services, in supported accommodation, specialist vocational services and in suicide prevention. However, from a national perspective we cannot tell if they are achieving improvements in people's lives.

In building this Report Card we sought data to shed light on the outcomes that services make to people's lives to assess whether we are seeing continuous improvement. We looked for data based on evidence and experience; to understand what quality care is and how partnerships between services and support people improves outcomes; to consider suicide prevention and what effective strategies look like.

In this first year, we found that data on the number of times a service is delivered, such as a visit to a mental health specialist, was much

more widely available than information on whether the visit led to long-term improvement; and also that data on the experiences of care was severely lacking.

This 2012 Report Card has drawn upon a wide range of sources to construct a critical view including personal experiences, national data collections, private, not-for-profit and non-government sector data, evidence, evaluations and submissions made to the Commission. To support this, the Commission also engaged academic work to provide advice on current good practice and what research evidence and evaluations tell us.

We acknowledge openly that in this first Report Card we have not covered every part of the population and that many who are at high risk of mental health issues or experience

social exclusion will not find themselves in this first edition. To address this we are continuing to collaborate with leading partner organisations with an interest in mental health to find ways of working together on our common goals, including representatives of veterans' organisations, culturally and linguistically diverse people, the Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) community and young Australians, to name a few.

The 2012 Report Card is the first of a series where over time the level of reporting will be enhanced through improved availability and collection of data to support the Commission in its responsibilities to report on the breadth of services and system improvements needed for a contributing life.

The First National Report Card on Mental Health and Suicide Prevention

In this first Report Card, there is a feature on the emotional and social wellbeing of Aboriginal and Torres Strait Islander peoples, to give a direct voice to the Indigenous community. This is in addition to the inclusion of Aboriginal and Torres Strait Islander-specific population data, where available, in each chapter.

Future Report Cards will have a different feature to give both focus and voice to specific communities, issues and trends, but mental health and suicide prevention of Aboriginal and Torres Strait Islander peoples will be a continued interest.

Each chapter presents a different aspect of a contributing life, including personal experiences, data and information, assessment and commentary about how we are faring to see where we are improving, and where there is more to be done.

The Report Card will look to existing performance indicators related to the chapter areas to see how governments are performing against agreed national targets, because we need accountability and change that is felt in communities and impacts upon people's lives.

Within each chapter we focus on a 'spotlight issue'. This enables a range of specific issues to be considered in more depth in addition to the broad theme of the chapter. It will allow us to gather more specific information from

national surveys, evidence and experience-based information and studies, and use this to identify gaps in our knowledge base and learning on the issues of most concern. We will use this approach to drive continuous improvement and good practice.

In 2012 the Report Card chapters have the following focus issues:

Feature: Aboriginal and Torres Strait Islander peoples' mental health and wellbeing

Tells a story of social and emotional wellbeing within the Indigenous community, and what implications it has for how we approach service delivery in the future.

Ensuring effective support, care and treatment

Access to care and quality of care is essential, as is access to the right type of care, when needed and which provides treatments based on the best available evidence.

Preventing suicide

Effective interventions are timely in supporting people contemplating suicide, strengthening communities and working across emergency services, local community organisations and crisis services.

Thriving, not just surviving

The physical health of people with a mental health difficulty which is worse than the general community on just about every measure.

Something meaningful to do, something to look forward to

Participation in personally rewarding work, employment and community involvement breaks social exclusion, increases self-worth and supports economic independence.

Connections with family, friends, culture and community

Inclusive approaches to care for family and support people, where a triangle of care between the person living with a mental health difficulty, their family and support people and their clinicians are all part of the one team to support the person on their recovery pathway.

Feeling safe, stable and secure

Having a home is much more than just shelter, it provides a base to lead a contributing life and needs to be secure from threat of eviction and fear of homelessness.

The Report Card is also accompanied by a technical document on data quality, use of evidence and a summary of the consultation processes.

The Commission hopes this work will contribute to the improvement of the lives of all people living with a mental health difficulty – Aboriginal and Torres Strait Islander peoples, non-Indigenous Australians and new arrivals in our communities.



Feature: Aboriginal and Torres Strait Islander peoples

Overcoming cycles of disadvantage for a contributing life

Chris, New South Wales

I am a person of Aboriginal origin that happens to be diagnosed with bipolar disorder. I say that purposely because I am a person before any other labels. I am also a son, a brother, an uncle, a fiancé and a father.

I read in a magazine a list of the 10 most stressful things that could happen to a person in their lifetime. Ironically I read that just after I was diagnosed and all those things had happened to me in the short space of 12 months; my brother suicided and I was badly injured in a car accident which led to me losing my job and becoming homeless.

I got locked up in jail after a fight and two weeks before I was released my mother got hit by a car and was tragically killed. I was released from jail and had to find a job, transport, and housing and at that point my ex-girlfriend moved to Queensland with my eldest son and my heart broke.

Things were really bad; I had nowhere to go. I started to self-medicate with illicit drugs; and was hospitalised.

If only I knew then what I know now – that I have a mental illness. Hindsight is a wonderful thing and looking back I can see the periods of depression, mania and psychosis. My untreated illness was woven throughout my life, impacting my ability to cope. I needed help, but without treatment like others would get for other illnesses, I was lost.

When I was seven years old, my neighbour called me a “little black bastard”. I asked my mother why and she told me for the first time, that I had been adopted from an Aboriginal family.

In time I came to understand that I was a member of the Stolen Generations. Twelve years ago, I woke up with a strong sense that I needed to find my biological mother. Three months later, I found out she had died at the time that I experienced my strong pull to find her.

Since then I have been to my nation, met my family and started learning about the land and all its special and sacred offerings. I am exploring a whole new world of family and kinship. My knowledge of my illness, my extended families and me looking after myself all help me live a positive life.

My uncle said something to me that sums up the feeling: “welcome back son, we’ve been waiting for you”.

Jerara's journey

The story of the mental health and emotional and social wellbeing of Aboriginal and Torres Strait Islander peoples is as diverse as the journeys of different communities and generations. This feature chapter reflects this diversity through the fictional story of a young boy, Jerara. We share his journey from his early life to his adulthood.

It is only one story to provide an insight into the mental health challenges faced by some, although by no means all, Aboriginal and Torres Strait Islander peoples.

There is enormous diversity in contemporary Aboriginal and Torres Strait Islander life and mental health challenges vary accordingly. The relatively traditional lifestyles lived by a minority on remote homelands and islands provide an entirely different context for supporting wellbeing and a contributing life³³ to that of city lifestyles.

Contrary to public perception, almost a third of Aboriginal and Torres Strait Islander peoples live in cities.³⁴ There might be members of many different Aboriginal and Torres Strait Islander nations, and others living together in an urban setting compared to a remote area with one nation predominating.

Historical forces will shape Jerara's mental health before he is conceived. Many different cultural and language groups remain from pre-colonial times, as do holistic conceptions of mental health that have their origins in traditional patterns of living³⁵. 'Social and emotional wellbeing' is a positive state of physical, mental and spiritual health enjoyed by many Aboriginal and Torres Strait Islander peoples today that is connected to the strength of their cultures, country and ancestors, families and communities, however they may operate.³⁶

For Jerara, this might be a source of strength, resilience and healing throughout his life,³⁷ as it is for many Aboriginal and Torres Strait Islander peoples – the majority of whom report enjoying positive wellbeing.³⁸

The other force that will shape Jerara's mental health is the impact of colonisation and the assimilation policies that attempted to replace Aboriginal and Torres Strait Islander cultures with European ways.

Culture is experienced and expressed in different ways. Jerara, for example, might speak an Indigenous language and engage in Aboriginal cultural practice in different ways in remote or urban settings. This diversity in culture and the different ways it is experienced and expressed, all equally valid, is one of the great strengths of Aboriginal and Torres Strait Islander peoples.

There were approximately
669,700
Aboriginal and Torres Strait Islander peoples in Australia in 2011, comprising an estimated 3 per cent of the total population.³⁹

In 2006 about 32 per cent lived in major cities, 43 per cent in regional areas and 26 per cent in remote and very remote areas.⁴⁰

The population is relatively young with a median age of
21 years
compared to 37 years for the non-Indigenous population.³⁹

If Jerara is born into a community with a strong collective and cultural life which is centred on self-determination, he is more likely to enjoy better, life-long mental health. A positive cultural identity and Aboriginal spirituality will help Aboriginal children and young people to navigate being a member of a minority group in their own country;⁴¹ and provide meaning in the face of adversity.⁴²

Jerara might live in a remote setting, or he might live in a city and identify with the contemporary Aboriginal and Torres Strait Islander rights or arts movements.

While many cultures and communities are strong, almost all experience challenges. Some of these challenges might relate to languages, access to traditional lands, traditional law, governance and kinship structures.⁴³ Government programs that result in a 'takeover' from culturally based forms of community governance in remote communities, or from community controlled services in urban settings, only add to these challenges.⁴³

Among individuals in different settings, these challenges might be experienced as family violence,⁴⁴ lateral violence,⁴⁵ alcohol and drug use³⁴ or a pervasive sense of being out of control.⁴⁶ 'Malignant grief' has been observed in some communities: irresolvable, collective and cumulative grief that causes individuals and communities to cease functioning and causes death and suicide clusters in communities.⁴⁷

Inter-generational and trans-generational trauma among Stolen Generations survivors, their descendants and the almost four in 10 (38 per cent) of people whose families were affected by child-removal policies is well documented, and is associated with poverty,

substance abuse, incarceration and mental health conditions.⁴⁸ The unique challenges facing survivors further complicate the overall picture.³⁴

Into this world Jerara will be born. However, his personal journey begins before he is born.

Optimally, Jerara's mother would have been able to access culturally competent maternal health services (such as the Nurse Family Partnership Program⁴⁹) through Aboriginal Community Controlled Health Services in the first trimester, and gained from the multiple flow-on benefits – such as stopping smoking. She might have received advice on diet and made friends with other expectant mothers and broken a pattern of social isolation.

But Jerara might not have such an auspicious start. His mother might be socially isolated, living far from other community members, or even without a community.



Jerara's mother might be one of the **three in ten** Aboriginal and Torres Strait Islander peoples who report barriers to accessing health services.⁵⁰

As a result of not receiving anti-smoking messages, or as a way of coping with stress, she might have been one of the **fifty per cent** of Aboriginal and Torres Strait Islander mothers who smoke while pregnant.³⁸

Jerara might, in utero, share his mother's experience of family violence or her fears for her safety and her loss of control. Trauma and stress experienced by mothers during pregnancy has been associated with behavioural problems in young children.⁵¹ Further, Jerara's mother might be one of the **one in seven** women with post-natal depression,⁵² perhaps because she had little choice but to give birth away from her community supports and disconnected from her country.⁵²

Jerara might be one of the one in four who have experienced racism and discrimination and the associated health impacts.³⁴

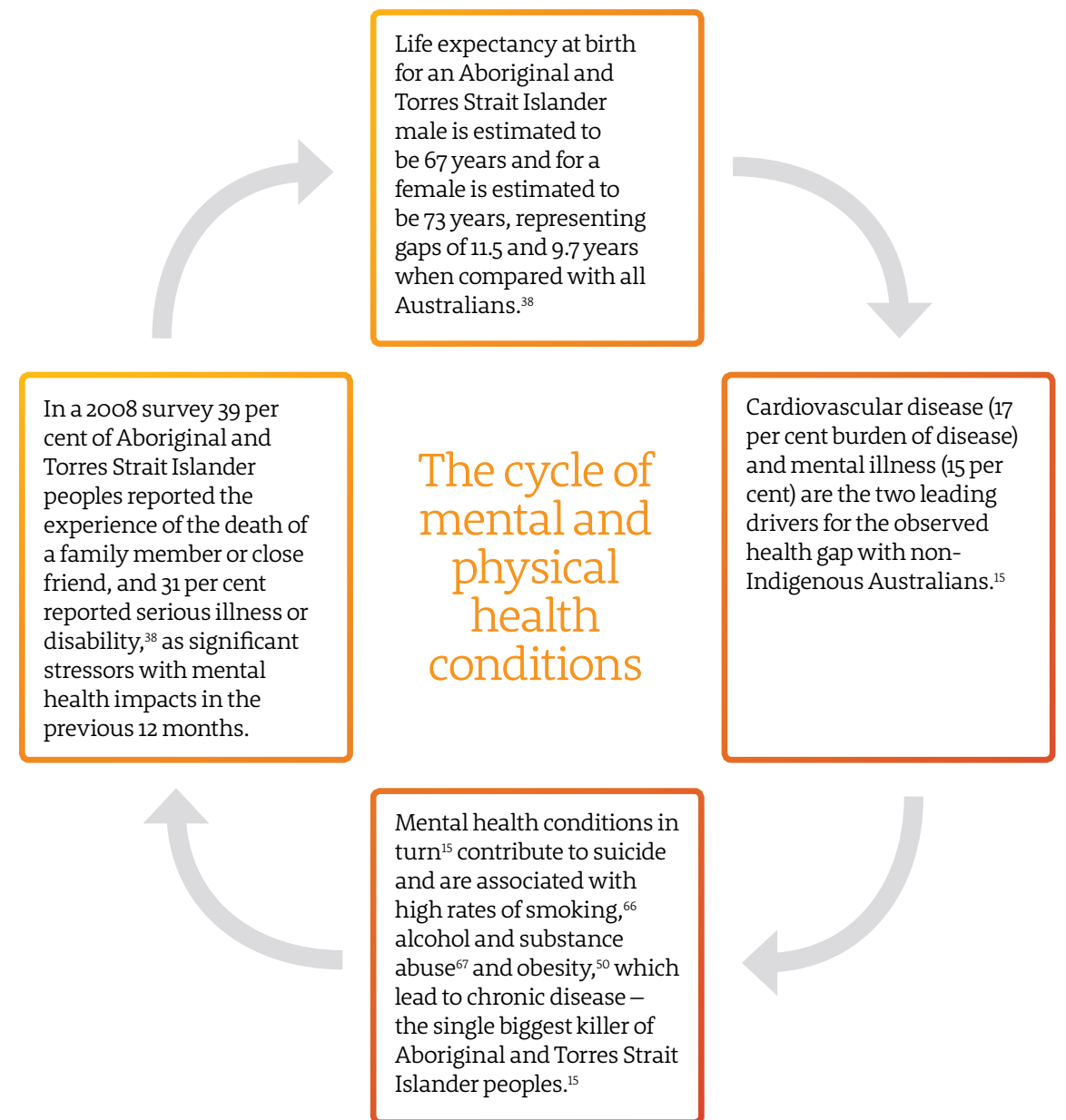
Equally important in determining adult mental health conditions,⁵³ there is a high likelihood that Jerara will be born into poverty in either a city or remote setting – a legacy of colonial dispossession, displacement and long-term social exclusion. As a child, Jerara is two and a half times more likely than a non-Indigenous child to be born into the lowest income group.³⁸ Poverty (at least as indicated by unemployment, lower education attainment and lower income)⁵⁰, and ill-health³⁴ is strongly associated with high rates of stressors and psychological distress.³⁴

Jerara has a one in two chance of living with a disability or long-term health condition, and if so, less access to health and other services.^{34,54} He might live in sub-standard or overcrowded housing that compounds these issues.

As Jerara grows, he has a one in two chance of being raised in a one-parent household,⁵⁰ often without an adult male role model to shape his cultural development. His mother and father might otherwise lack parenting skills because they are one of the one in twelve Aboriginal and Torres Strait Islander adults removed from their family as a child³⁴ and who have not been exposed to the influences of parents.

From an early age, trauma and stress might adversely affect Jerara's cognitive development.^{55,56} His capacity to exercise self-control – to delay self-gratification – might be compromised. Ensuring that every young Aboriginal and Torres Strait Islander child has access to quality and supportive day care programs and education is very important.

Prominent Aboriginal psychiatrist Professor Helen Milroy reports that it is not unusual for the Aboriginal children she sees as patients to have experienced many deaths in their immediate family networks (including by homicide, fatal illnesses and motor vehicle accidents) in addition to other traumatising incidents, such as sexual abuse,⁵⁷ in the 18-month period prior to their presentation.⁵⁸



There were at least
946
 Aboriginal and Torres Strait Islander suicides between 2001 and 2010: **twice the rate of other Australians.**⁶²

Professor Milroy reports that the impact of trauma on Aboriginal and Torres Strait Islander children and their families is a major undetected, underestimated and misunderstood determinant of mental health conditions in the Aboriginal and Torres Strait Islander adult population. Despite the existence of dedicated mental health professionals and teachers, there is a lack of resources across the system. In turn this can mean that early childhood services, primary school, high school, GP, child protection services, child mental health services and juvenile justice services⁵⁹ might fail to detect Jerara's distress or to intervene effectively.

Jerara might be placed in the 'too hard basket' because of his aggressive behaviour and low educational attainment, rather than this being understood as an expression of his distress.

A solution proposed by Professor Milroy is to ensure that schools and all services working with Aboriginal and Torres Strait Islander children are 'trauma-sensitive', and that clear clinical and culturally competent pathways are established to ensure traumatised Aboriginal and Torres Strait Islander children receive the treatment they need at an early age.⁵⁸

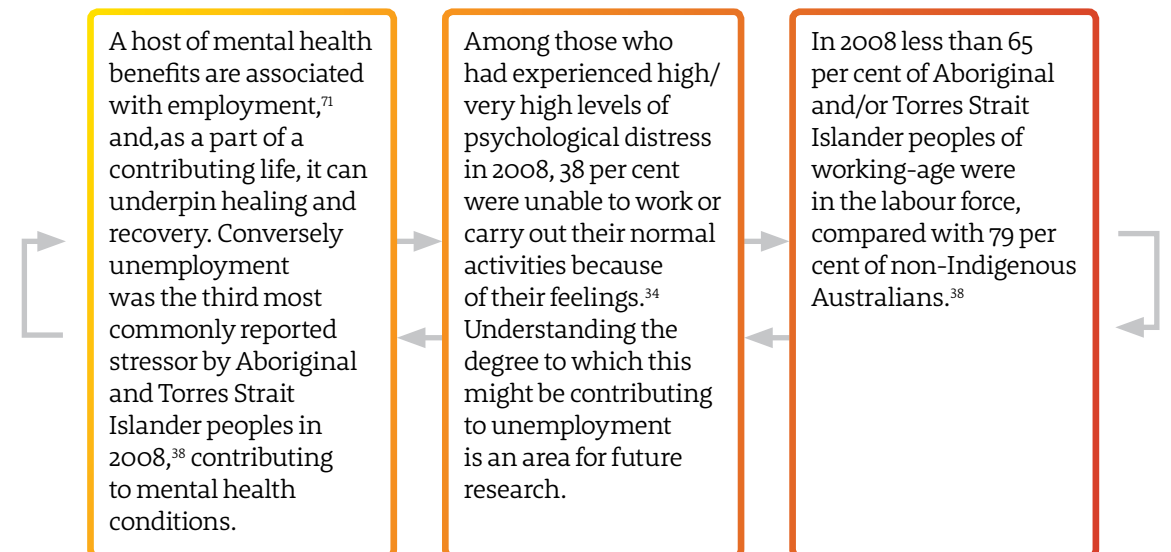
But experience shows that Jerara may well enter adult life with his trauma undetected and untreated – and he might now also have an alcohol and substance abuse problem.

Jerara might be re-traumatised all his adult life. High rates of life stressors are reported for Aboriginal and Torres Strait Islander peoples.³⁴ He might experience lower levels of employment,³⁴ education⁶⁰ and housing⁶¹.

The cycle of mental health conditions and imprisonment



The cycle of mental health conditions and unemployment



Studies show a strong association between strong culture and cultural participation with better wellbeing and physical health in Aboriginal and Torres Strait Islander peoples.^{63, 64}

Nearly one-third of Aboriginal and Torres Strait Islander peoples aged 15 and over reported high or very high levels of psychological distress in the previous four weeks:

2 1/2

times the rate reported by non-Indigenous Australians.³⁴

Aboriginal and Torres Strait Islander peoples use psychiatric disability services at

double

the rate of non-Indigenous Australians.⁹

Jerara might be gay or transgender, live as a 'sistergirl' and experience homophobia and transphobia from his own and the wider community. He might find himself in compounding cycles of poverty, aimlessness, trouble with the law, alcohol and substance abuse, isolation, trauma and mental health conditions – including, ultimately, psychosis.

At some point Jerara might seek professional help. He might feel confident navigating the 'mainstream' mental health services (GPs and community mental health services, for example) available in cities, but he might not.

In his vulnerable state he might not feel comfortable if there are no Aboriginal mental health professionals or other Aboriginal staff visible or available. Or he might receive a sub-standard service that is not culturally competent.

If his ancestors appear to him in his thoughts it might be taken as a symptom of psychosis when in fact it might be part of the healing process. Navigating services and programs which may not be culturally responsive might disadvantage Jerara throughout his life.

Jerara would be unlikely to encounter such problems in mental health and social and emotional wellbeing services designed and delivered by Aboriginal and Torres Strait Islander peoples and communities.

The Aboriginal Community Controlled Health Sector recommends that services be funded to offer an integrated social and emotional wellbeing program with Aboriginal Family Support Workers, alcohol and substance abuse workers, social workers and psychologists available.⁶⁵ These services are also better placed to offer traditional healing: cultural medicine for cultural wounds.

Mental health and social and emotional wellbeing services are an important support for living a contributing life, and Jerara might rely on them to begin his road to healing and recovery from mental health difficulties and addictions.

In time he might re-enter the workforce and begin healthy relationships. Just as a negative compounding cycle might have undermined Jerara's mental health in the first place, an equally compounding – but this time positive – cycle might support the contributing life that, in turn, underpins the good mental health that Jerara will enjoy for the rest of his life.

Jerara might also reclaim his culture as a significant part of his healing process. As an Aboriginal man in healing, participating in his culture might play a vital part of a contributing life.

Living with loss

Experience of bereavement and loss is a part of the lives of many Aboriginal and Torres Strait Islander peoples. Thirty-nine percent of Aboriginal and Torres Strait Islander peoples have reported they have experienced the death of a family member or close friend.³⁸ Among Aboriginal and Torres Strait communities there were 946 suicides between 2001 and 2010,⁶² a figure that is double the rate of non-Indigenous Australians. As a community, life expectancies are about 10 years less than those of other Australians.

What it means for Julie, Northern Territory

I am a single mother who is walking on a painful, lonely journey that is one of the most devastating of all human experiences – the loss of a child to suicide.

The death of a child is an enormous tragedy. What follows afterwards is the horrible despair and pain which is thought by many to exceed all other bereavement experiences. When we lose a child, we are robbed of the anticipated future together. When our child dies, it feels like a part of us dies with them.

It feels particularly frightening to a single parent, for there is no partner to bridge the gap of isolation. My parents were deceased, all my siblings lived interstate and although I had friends, many did not understand the loss of a child to suicide.

The isolation becomes real after a few weeks. Friends who were initially supportive drifted away, assuming someone else was checking on me. When I reached out to my family and friends, they were busy or not home, which made me feel

more rejected than ever.

Finding a support group was a lifesaver.

I knew they were available by phone 24/7, and willing to talk or listen. Just knowing that helped reduce my sense of isolation. They gave me hope. I also knew as a single parent I had to help myself, to help my surviving children.

The knowledge that I am strong enough to handle my job as a single parent is what gives me the courage I need to survive.

Sadly I also lost two other children, one who drowned and one to Sudden Infant Death Syndrome. But it was through the loss of my three children, that I was taught my life learning lessons and I have become who I am today. I believe with all my heart, despite what I have been through, I am now going to go through the best period of my life and it will be phenomenal! For me there is no sadness, only joy, as I walk this journey I know my children are walking in spirit with me.



While mental health and social and emotional wellbeing services are essential, they are not the whole story.

The majority

of Aboriginal and Torres Strait Islander peoples **reported feeling happy** (72 per cent), calm and peaceful (59 per cent) and full of life (57 per cent) all or most of the time.³⁴

It is vital that the human ‘capital’ in culture and communities (however they operate) and the context they provide for a contributing life, is recognised and supported as a part of any overall approach to Aboriginal and Torres Strait Islander mental health.

Even though Jerara’s journey as relayed in this chapter is based on a composite experience from the perspective of a young Aboriginal man growing up and dealing with a mental health difficulty, in parts the issues are equally true for Aboriginal and Torres Strait Islander women. There also are important issues which are specific for Aboriginal and Torres Strait Islander women which cannot be ignored.

We must consider the diversity of Aboriginal and Torres Strait Islander peoples in supporting them to have a contributing life, however they define it.

Aboriginal and Torres Strait Islander leaders must be at the centre of thinking and decision-making about Aboriginal and Torres Strait Islander health and mental health at the national level.

Aboriginal and Torres Strait Islander social and emotional wellbeing will depend on the engagement of many agencies outside health – education, housing, welfare, employment and many others. Decisions must be made in partnership with leaders from:

- The National Health Leadership Forum of the National Congress of Australia’s First Peoples
- Aboriginal and Torres Strait Islander Mental Health Advisory Group
- The National Indigenous Drug and Alcohol Council
- The Aboriginal and Torres Strait Islander Suicide Prevention Advisory Group.

Australian governments must start thinking about Aboriginal and Torres Strait Islander peoples’ mental health in different ways.

The evidence shows a strong support for investing in culture and communities to support social and emotional wellbeing. Supporting self-determination and working in partnership should be part of any overall response. A shift away from top-down policies and programs to those led by communities is vital.



[Click to watch Maddison's story](#)

Thriving, not just surviving

Physical health

Maddison, New South Wales

After 30 years of living with anxiety and mental illness, I finally found a treatment that worked for me; sorting out my physical health is my final frontier.

I began having anxiety at the age of four, and by age six, it was so severe, that I was having panic attacks and purging my food on a weekly basis. It was 1976, and Mum took me to a counsellor, who was lovely, but had no idea about anxiety disorders, and just talked about ways to boost my self-esteem.

My condition worsened throughout my life with periods of non-stop obsessions and lengthy depression.

The turning point for me was in 2008 when, after my daughter was born, I was finally put on the right medication. Finally after 30-something years of torture I felt at peace. In so many ways my life now is unbelievably fantastic, but I still face challenges related to my mental health and my physical health.

Today I am on a medication regime which works for me mentally, but the medications have led to enormous weight gain – a problem I never had before. The weight gain and omnipresent exhaustion, has given me a new set of mental health issues.

My weight makes me anxious because of how people perceive me, and it increases my tendency to isolate myself socially and on top of this I now worry about my health for the future of my family.

Sometimes when I am physically unwell, or someone in my family is unwell, I know doctors or people around me don't always take me seriously; they think it's just my mental illness talking, which is hard. I'm doing my best though, by quitting smoking, cutting down alcohol, exercising, eating well – I feel like I'm finally walking the right path.

Introduction

Physical health

The physical health of people living with a mental health difficulty is worse than the general community. For people living with a severe and enduring mental illness their health is much worse – people with illnesses such as bipolar disorder or schizophrenia have heart-related problems, diabetes and obesity at much higher rates than the rest of the community.²³

One Australian study showed that people living with a mental illness had an overall death rate that was two and a half times greater than the general population.⁷²

To reduce these shocking levels of physical ill health, we need to ensure that health services work to prevent, identify and effectively treat those conditions. However, we know that this will be difficult whenever the barrier

of the ‘overshadowing effect’ in medical care exists – where treatment of a physical ailment is overshadowed and sidelined by the presence of a mental illness, and the whole person’s health and wellbeing are not considered.

The undeniable fact is that...

.....
...people with severe mental illness live between
10-32 years less
than the general population.^{21, 22, 23, 73}

People with a mental illness are dying younger – and this is only in part contributed to by people taking their own lives. They have higher rates of physical illnesses, and lower rates of getting the hospital treatment they need, compared to the general population.⁷²

The reduced life expectancies and ill health of people with the most severe mental illness undercuts their chances of leading a contributing life.

It is a life and death issue.

It is a national disgrace and it should be a major public health concern.

Mental health must be a national priority. Government funded programs must measure how they support people to achieve better physical health and longer lives – to close the gaps in life expectancy and quality of health for people living with a mental illness.

The Commission sees this as an injustice that runs contrary to the United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care² and the Convention on the Rights of Persons with Disabilities⁷⁴ which was signed by Australia in 2008, in which Article 25 states:

“Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability...”

The important issue of physical health is the theme for this Chapter in the 2012 Report Card.

What we know

For people living with a mental illness, poor health doesn't happen in isolation from the effects of lifestyle, genetic make-up and the medications which are prescribed for mental illnesses.^{75, 76}

Around 12 per cent of people living with a mental illness will also be living with a chronic condition such as asthma or diabetes, sinusitis or psoriasis.²⁰

Poor dental health is also a significant burden. Patients with severe mental illness are three and a half times more likely to have lost all their teeth than the general population, and around six times more likely to have decayed, filled or missing teeth.⁷⁷

Cardiovascular disease and mental illness have been found to be the two leading drivers for the burden of disease for Aboriginal and Torres Strait Islander peoples – accounting for 17 per cent and 15 per cent respectively of the overall burden.¹⁴ This is especially significant, when we know that the burden of disease in the Aboriginal and Torres Strait Islander community is two and a half times that of the general Australian community.¹⁵

These health disparities are greater again for people living with a psychotic disorder.

One study of people living with psychosis found tobacco smoking was at a rate two and half times more than the general population; that alcohol abuse for males was one and a half times that of the general population and for women it was two and a half times the rate; and that almost every second person in the study was obese (at 45.1 per cent).⁷⁵

The national survey of psychotic illness uncovered the extent of general health problems for people in this group:



Diabetes was at a rate over **3 times** found in the general population



One third carried the risk of a 'cardiovascular event' within five years



Half have metabolic syndrome, which is associated with an increased risk of cardiovascular disease and diabetes as a side effect of prescribed antipsychotic medications.

The finding regarding antipsychotic medications is most concerning.

Most Australians may not know treatments with prescribed psychiatric drugs may lead to worse physical health. There are increased risks for some specific treatments such as antipsychotics and for those with underlying vulnerabilities such as diabetes.⁷⁶ This can mean that the antipsychotic medications that are prescribed to manage

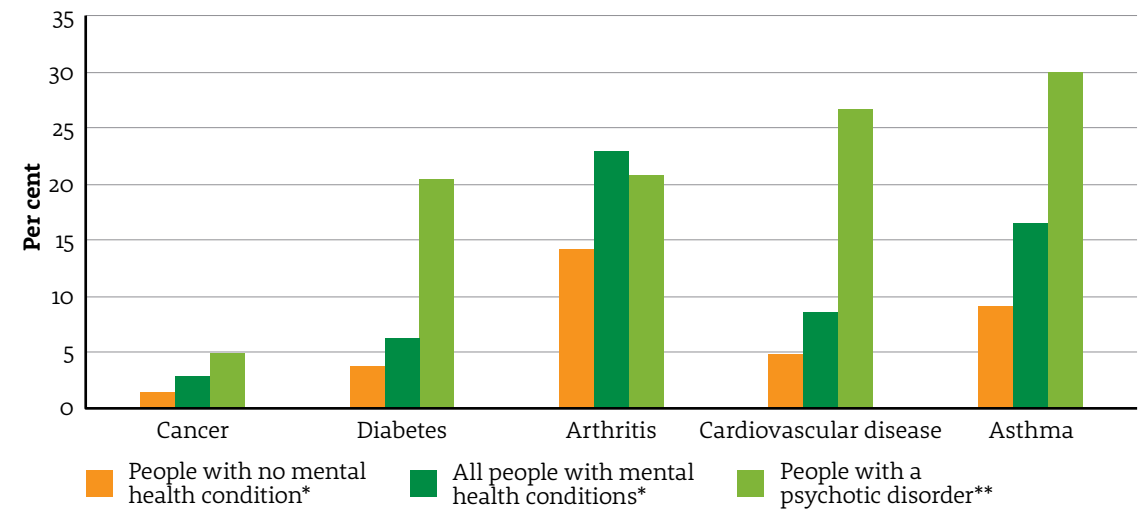
severe mental illnesses such as schizophrenia, contribute to the risk of having severe physical illnesses. The decision for people to take medications to improve their mental health, is made often with the knowledge that their physical health and quality of life will suffer.

If you are living with mental illness you have a 30 per cent higher chance of dying from cancer, compared to the general population.⁷² But increased premature death

is not confined to those with severe illness – depression can also lead to increased heart disease deaths.⁷⁸

These statistics mirror the burden of health difficulties endured by people living with mental health difficulties. It is evident that people with the most severe mental illness have a worse level of overall health than people with more common mental illnesses, which compounds the health difficulties they need to overcome.⁷⁶

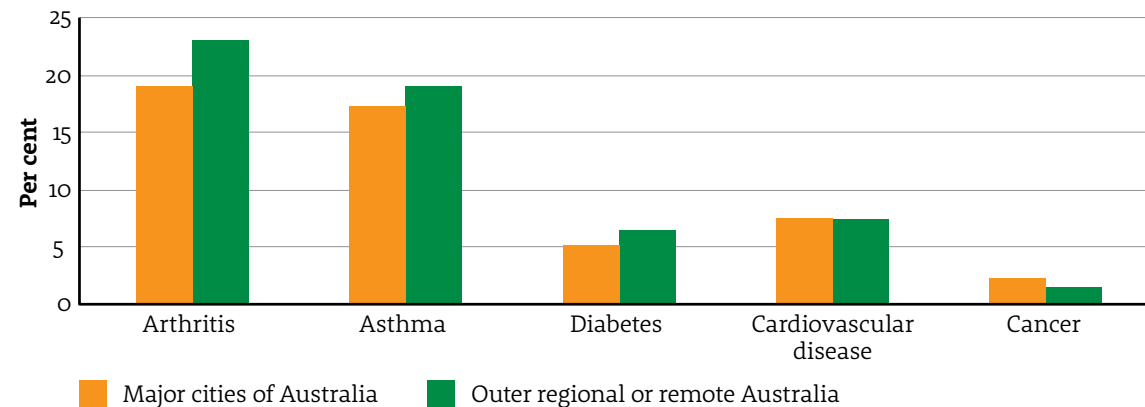
Percentage of people with a mental health difficulty experiencing a long-term physical health condition



Sources: *National Health Survey 2007-08; **National Survey of Psychotic Illness 2010.

For people living in outer regional or remote Australia in 2007 and who had a mental health condition, 23.4 per cent were found to have arthritis, 19.3 per cent had asthma and 6.5 per cent had diabetes. These rates are potentially higher than for some people with a mental health condition living in cities or inner regional areas.⁷⁹

Percentage of people with a mental health disorder with a long-term physical illness by location of residence



Source: National Health Survey 2007-08.

Over the last ten years across Australia and internationally, guidelines have recommended that people with severe mental illness have their physical health monitored on a regular basis.^{80,81,82}

However, we know from one study that while nearly 90 per cent of people living with psychosis had visited a GP in the past year; two-thirds reported they did not have a general health check or a cardiovascular-related health check.⁷⁵

Additionally, it is estimated that only one in five people with a mental illness has a GP mental health treatment plan^{11,83} – we must do much more than this.

The Commission supports a strong primary care approach to delivering health services for people living with a mental illness, as these approaches are well placed to be responsive to the person’s living circumstances, their complex health needs and the changing nature of their mental health requirements.

Equally, the Commission supports a strong primary care approach in early intervention when symptoms first arise in adolescence and prior to that for early childhood and family support. Programs providing support for families in stress with young children can improve parenting skills and outcomes for the children.^{84,85,86,87} This gives children a better chance at living a fulfilling and contributing life.

What we don't know

Where we need more evidence, and to shine a light

Each year an estimated 63,500 people with a psychotic illness seek treatment from public specialised mental health services.⁷⁵ However, the total figure is not clear because we have no publicly reported treatment data from the private sector or on those people who did not make contact with the health system.

Given the low levels of physical health monitoring of people with severe mental illness,⁷⁵ it is difficult to know the most effective service approach to increase monitoring and close the gap on life expectancy for people with complex and high health needs.⁸⁸

We need to know how best to reach people who do not seek medical help. Positive health seeking behaviour can be affected by depression or psychosis. Relying upon GPs or a primary practitioner to wait for people with severe mental illness to walk through the door isn't going to reach everyone. We need assertive and outreaching primary health care and to know how successful this is.

For this we need reliable and regular national population surveys to help us measure progress.

We need more research into the medications that treat mental illness and the significant side effects they have upon a person's health. We need this research to develop best practices for managing and reducing metabolic side-effects (such as weight gain, increased risk of diabetes and heart problems) and assessing what approaches work best with the people who rely upon these medications to sustain their mental health.

Good work has been done, but much more remains.

We need better primary care approaches to address the poor physical health of people living with a mental illness.⁷² These approaches to care need to be developed in collaboration between people living with mental illness, families, carer organisations and clinicians. This will mean that approaches to care in addition to medications are co-ordinated and result in effective and evidence-based service approaches.

This will ensure that people living with a mental illness are supported to have improved overall health, make informed decisions about their own health and manage their own recovery journey.

There is much research and there are many new treatments. However, even with the best of care we cannot always remove the full burden of a mental illness. Many treatments have side-effects and involve trade-offs, and models of care are not uniformly and universally agreed. Just as in cancer, where the best care does not always bring cure, so it is with mental illness – some people do not respond as expected to best practice treatments⁸⁹ or those treatments have unacceptable side-effects.⁹⁰

People living with such persistent mental illnesses can experience significant disability⁷⁵, and we know that in Australia mental illnesses are the largest single contributor to the non-fatal burden of disease.²⁹ We need to provide people living with a disability arising from their mental illness with the appropriate level of support.

Including psychosocial disability in the National Disability Insurance Scheme will make a real difference to the lives of people with the highest need, to be able to afford the support they need at the levels they require.

Including enduring mental illness as a national chronic disease priority would promote access to collaborative care programs provided by local practitioners, such as GPs and allied health professionals (e.g. physiotherapists, dental therapists, dietitians). Such programs support a long-term, whole-of-health perspective to improve overall health and wellbeing and can manage complex health issues, as currently is the case for chronic diseases such as diabetes, asthma and coronary artery disease.

Helping families and support people to thrive

Being a carer for someone living with a mental health difficulty has been found to be a long term commitment (more than six years for over half of respondents in one study) which can affect their own overall physical and mental health.⁹¹ This role is mostly undertaken by older women⁹² and is one that affects their overall health and wellbeing through added “worry, anxiety and depression”.⁹²

What it means for Kathleen, New South Wales

As a carer I need support to make sure I can thrive as well – and that means looking after my own mental and physical health.

I married in 1972 and have two daughters. Twenty years later, out of the blue, my husband began experiencing delusions and his symptoms made family life unpredictable, and wellbeing difficult to manage. I still had my husband, but he was different. One of my daughters also has schizophrenia as well as anxiety and depression and I am a carer for her.

As a carer you have myriads of emotions. When they are unwell you wake up in the morning and really wonder what type of day you are going to have.

There can be lots of stress in the role of a carer and this really impacts on your mental and physical health.

Grief is a strong emotion you can experience, as you feel that your loved ones have lost their normal lives.

I joined a carer support group to help me stay well. Life is a changing process and you need to believe in yourself. We have received invaluable support and help from our local respite services staff which needs to continue to enable other people to be supported.

Mental illness can and does happen to anyone, and carers need support too.

[Click to watch Kathleen's story](#)



2012 spotlight issue Reducing cardiovascular disease

People living with schizophrenia have a reduced life expectancy of 10 to 32 years, and the major killer is cardiovascular disease, occurring at a rate double that in the general population.^{73, 23, 21, 22}

Higher than average rates of smoking and reduced levels of exercise also add to this risk.

The persistent and significantly higher levels of cardiovascular disease for people with severe mental illness points to a lack of understanding of how to implement effective programs to reduce their risks – such as targeting weight, blood glucose, lipid (fats) control and physical activity.

The higher level of cardiovascular disease of people living with schizophrenia is in addition to other health problems that are experienced at higher rates than in the general population:

.....
they have nearly	they have	they smoke at a rate	they have high blood
twice	twice	2 to 3	5 times
the rate of being	the rate of having	times higher	cholesterol levels at
obesely overweight	diabetes		the rate of the general
			population ²³

In addition, people with schizophrenia have a higher prevalence of metabolic syndrome – a combination of medical problems which increases the risk of cardiovascular disease and diabetes.⁷⁶ For people with psychotic illnesses overall they have been found to have a higher rate of diabetes, at up to three times the rate of the general population.

Evidence indicates that there are significant barriers to effective, co-ordinated management of co-existing physical and mental health conditions, such as:

- people with a mental illness being treated solely for that illness
- poor integration of mental health and physical health services
- primary health care professionals' low confidence in working with people who have a mental illness
- mental health workers' low confidence in dealing with medical health issues

- people with a mental illness having concerns about using the service – from transport and access to issues of discrimination.⁸⁰

On a daily basis, care is being compromised by the unequal status and treatment of mental health and physical health conditions.

Australia needs to turn our programs and services around.

Reducing cardiovascular disease and deaths among people living with schizophrenia and other mental health conditions should be a major public health priority.

It requires a very clear set of strategies to reduce smoking rates, reduce other known cardiovascular risk factors, increase physical activity and improve diet and nutrition, and prevent the onset of, or actively manage metabolic syndrome.

Appropriate funding to support multi-disciplinary primary care through GPs and other primary care providers for those with enduring mental illness is essential. We need to track, monitor and respond to both their physical and mental health needs.

What the evidence shows is good practice

Good practice models are those which support self-management and collaborative health care approaches.

For people living with persistent mental health problems and complex needs, a collaborative approach between the person and their clinician supports them to manage their overall health and wellbeing. It takes an integrated approach to their total health needs with flexible and co-ordinated individual support which can address their previously neglected or unidentified chronic disease, or poor physical health.

Australian clinical guidelines and other reports that promote good practice and are based upon collaborative health care approaches involve key features such as:

- a team approach involving the person living with mental illness, their support person(s) and a diverse team of health professionals – dietitians, nurses, cardiologists, exercise specialists, diabetes specialists and consumer workers

- the development of clinical protocols for regular monitoring and screening of health indicators
- education of the health team in physical and mental health treatments and approaches, so that as individuals they can take responsibility for the whole health needs of the person

- a philosophy that good health for people with a mental illness is everyone's responsibility – in community services, non-government services, GP clinics and hospital units – and that communication across 'specialists' is essential.

In recent years, states across Australia have identified improved physical health as a priority, as seen by the development of good practice guidelines.

In 2009 the NSW Department of Health developed guidelines to identify "best practice" to support the adoption of a consistent, statewide approach to monitoring physical health in people living with mental health problems.⁸¹ The University of Western Australia in 2010 developed evidence-based clinical guidelines for assessment and monitoring of the health of people with a mental illness for the Western Australian Government.⁹³ In 2011 the Victorian Government released its report "Improving the physical health of people with severe mental illness: no mental health without physical health"⁸² that recommended directions for public mental health services to take to improve the overall general health, chronic illness and risks associated with severe mental illness for people.

Where the Commission is looking for continuous improvement

We have guidelines for checking the physical health of patients living with a mental illness, now we need clinicians and services to actively take them up.

We need to see real improvements in the delivery of physical health services to reflect the circumstances of people living with a mental health difficulty – usually one of unstable housing, lower household incomes and social isolation, so that appropriate health monitoring and interventions are relevant to their lives and effective for their health.

We need to make measurable advances in the reduction of premature deaths in people with serious mental illness and in the improvement of the physical health of people with mental illness.

We need to learn from other examples of health monitoring of priority health issues such as diabetes, which are routinely undertaken by GPs and primary care centres. Monitoring the physical health of people living with a mental health difficulty (of which we know a proportion will also have diabetes, heart disease or metabolic syndrome) should be on an equal footing as other chronic diseases, so that a person's overall health is maximised, their mental health improved and recovery goals advanced.



[Click to watch John's story](#)

Connections with family, friends, culture and community

Including families and support people in care

John, Victoria

I was diagnosed in my early twenties with schizophrenia, obsessive-compulsive disorder and anxiety. Overweight, depressed and lethargic, I was barely functioning as a human being. Medication side-effects gave me cravings for caffeine, cigarettes, alcohol and junk food. I had no social life, and had trouble communicating. My parents were in despair. Years passed, and I didn't improve despite taking medication.

Whenever my mum called the clinic with her concerns, they just increased my dosage. But she knew there must be an answer and refused to listen to people who said I should go into an institution. Mum persuaded me to visit a drop-in centre that provides social and life skills support.

One day, I blacked out and ended up in hospital where a neurologist, horrified at the amount of medication I was taking, discovered that the cause of many of my symptoms was actually due to my high dosage.

Mum took me back to the clinic where a different psychiatrist threw out most of my tablets. Within three months I felt alive again. I decided to lose weight, quit smoking and drinking and with the support of my brother-in-law, I started running round the block. I didn't think I could do it, I was so out of puff. But I took baby-steps, and within a year we ran a half marathon.

I'm guessing if I didn't have my family, I'd be dead. I don't know if that's a really bad thing to say or not, but I think I would be.

Introduction

Including families and support people

The families of people with a lived experience of mental health difficulties very often devote large parts of their lives to supporting and caring for their loved one.⁹¹

Regardless of how ‘family’ is defined – to include friends, spouses, siblings, children, support people and neighbours – their contribution to the lives of people with a mental health condition cannot be underestimated.

This chapter builds a picture of the support network – comprising families, friends and others – of people living with a mental health difficulty. It looks at a range of evidence regarding the contributions family, friends and support people make to the recovery process and sustaining someone living with a mental health difficulty, and the impacts upon their own lives.

Developing inclusive approaches is a focus in this Report Card, recognising the pivotal role that families and support people play in supporting those living with a mental health difficulty, while also sustaining their own mental health and wellbeing. Inclusive approaches also place people living with a mental health difficulty at the centre of their development.

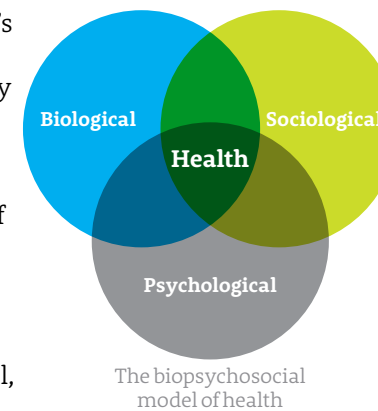
The Commission recognises that people living with a mental health difficulty can themselves be carers responsible for spouses, children or family pets – and that these responsibilities do not disappear when they become unwell or require admission to a mental health service.

The Commission also acknowledges that the journey support people and families take with the person they care for or support involves new experiences. This includes coming to terms with the fact that someone important to them has a mental health difficulty and the impacts that has on their relationship. It involves understanding the ‘language’ of mental health and the array of services and processes in place as well as learning about mental health issues and how to best contribute to the person’s recovery – all while ensuring that they themselves remain strong and able to continue providing care and support.

What we know

The role of families in a person’s recovery has changed dramatically over the last thirty years. Whereas family involvement was once seen as contributing to a person’s mental illness, today the role of family and support people in promoting mental health and wellbeing is positively acknowledged – recognising the wider interplay of biological, psychological and sociological factors upon a person’s mental health.

We know that the role of families, carers and support people has been demonstrated as important in helping the person they support to recover.⁹⁴ For example, the 2007 National Survey of Mental Health and Wellbeing identified that people living with a mental



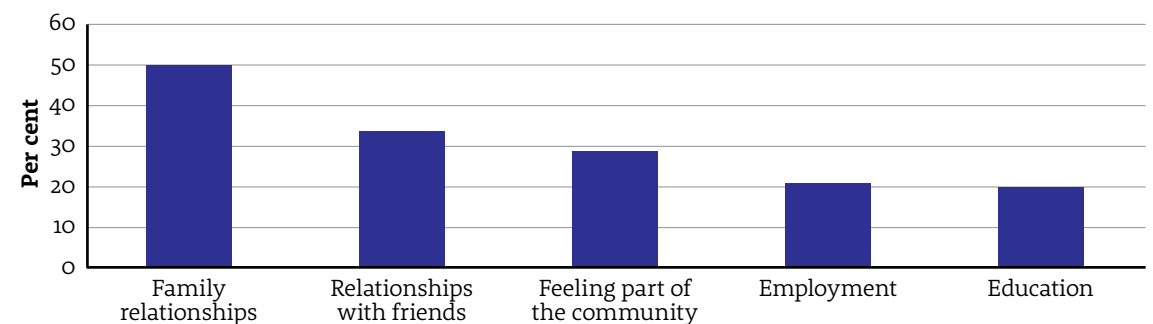
difficulty who had contact with family and friends had comparably better mental health, than those who were socially isolated.²⁶

We know that families and support people provide practical help in many ways – giving their time, providing living expenses and a home.^{95,96}

National surveys indicate that caring is a long-term commitment. More than a quarter of carers have provided care to a disabled or aged person for between 10 and 24 years, while a further quarter have provided care for between five and nine years.⁹⁷

For families, carers and primary carers, in particular, this can mean a move from full-time to part-time employment.⁹⁵ For some this means having to rely upon savings to make ends meet.⁹¹ These impacts go broader, and carers report that the most significant impacts are upon their family relationships, relationships with friends and feeling part of the community.

Proportion of carers who experience a large or very large impact on aspects of their life



Source: Wesley Mission 2012

What we don't know

Not all families and support people have choices about the level of support they provide – appropriate alternatives may not exist.⁹⁵

A 2010 survey of mental health carers found:

35% were never or rarely made to feel part of the caring team⁹⁵

61% lived with the person they were caring for⁹⁵

71% had their health deteriorate during their time as a carer⁹⁵

23% of those in jobs considered there had been no improvement in the flexibility of their workplace to support their carer role⁹⁵

69% needed respite, but 25.8 per cent had used it⁹⁵

We know that evidence-based models for family and support people inclusive approaches have been developed in Australia and elsewhere^{98, 99} which involve the carer, the person they are caring for and their health professionals working together. Yet Australian surveys have found that a significant percentage of support people (across a range from 20 per cent to 60 per cent) consider that they were rarely or never made to feel part of the 'caring team'.^{91, 95, 100}

In 2008, 71 per cent of mental health services in Australia had carer participation policies and just 25 per cent employed paid carer consultants.¹⁰¹ What were the barriers to employing paid consultants in those services that had already adopted inclusive policies?

It is evident that while good practice models for inclusiveness exist, they are not universally adopted.

Where we need more evidence, and to shine a light

Right now, we do not have national, standardised data on the nature of the care provided by support people to those living with a mental health difficulty, the costs involved, the commitments they make and how this impacts their lives. Their capacity to continue in their roles as they age is also uncertain.

The overall benefit to the general community of this care has not been measured either.

Without additional information we cannot respond to the specific needs of families, friends and support people. And without a greater understanding of their personal experiences of mental health services, we cannot provide services responsive to their needs.

In particular, we need three things:

One – A national system for measuring:

- the experiences of families and support people – which is used to evaluate services in all service settings – across mental health services, main stream health care, GPs and community-based services
- the extent to which inclusive approaches are reflected in available services and programs and the outcomes these are achieving (across health, support and other services, for example GPs)

• evidence in Australia of good practice already in place and what outcomes are being achieved.

Two – Public reporting of outcomes to inform ongoing service development.

Three – We need to invest in research so that family and support person inclusive services can be developed. This work should be extended to describe what such a model looks like, what it mean for existing services and be supported by a training guide for its implementation.

Children who provide support

It is estimated that approximately 30 per cent of children who start to care for someone before they reach age 16, will go on to have a long-term caring role – for more than 10 years.⁹¹

The impact upon the child's own social and emotional wellbeing, the social isolation due to their caring commitments, education, friendships and the stigma or discrimination they experience, no matter how much they may love the person they provide support to, cannot be ignored.⁹¹ We have a clear responsibility to support young carers and children of a parent with a mental illness as much as possible, and we recognise the important role that they play.

What it means for Kylie, Emma Leigh and Madeline, Victoria

We love our mum and she loves us. She was diagnosed with schizophrenia when we were babies, then with bipolar a decade later. We have always been mum's primary support. Our resilience as a family, respect for one another and honest communication have got us through.

We have always helped to cook and clean. We remind mum to look after herself and take medication. Sometimes, when mum heard voices we would lie either side of her and sing to drown them out. Now when she gets anxious, we reassure her that everything will be okay.

We have a strong support network of family, friends, neighbours and teachers. They all put a plan in place with us while mum was in hospital. Even our pets were looked after. When one of us had challenges at school and was bullied, mum moved us to a more supportive school, which we love. People acknowledge that we are more mature and understanding of others because of what we've been through.

We believed in mum when she quit smoking, studied and started working in the disability and mental health areas. We are a close team with the faith that, together, we can achieve anything.



2012 spotlight issue

Ensuring inclusion of family and support people

The Commissioners understand that in a real sense, families and support people can be left as ‘the person looking through the window’ – seeing what is happening to the person they support, knowing information that could shine a light on that person’s situation, but not being heard or seen.

Understanding the emotional and physical toll on families and support people, and that there are better ways of providing care, the Commission has made the inclusion of family and support people a priority in this first Report Card.

Research has shown that support people who are included and supported by mental health services report a more positive experience, and “are more effective carers”.¹⁰²

Inclusive approaches to providing care and treatment, that involve the support person as part of the health care team with the person they are supporting and the health professionals. Mental health services need to take leadership in supporting and promoting support people-inclusive policies and practice. For this to occur, some services will need to rethink how they provide for the involvement of families and support people.

It involves a new way of thinking:

- acknowledging that families and support people also need to recover, as caring for someone with severe or long-term mental illness has a serious impact upon their lives as well
- assisting support people in their roles – acknowledging that this involves promoting coping skills to sustain them, as well as practical skills, such as how to talk with someone who has psychosis, how to be most helpful, how to develop an understanding of what is going on, to support the person’s daily journey of recovery

It requires new ways of working:

- Adopting the implementation of inclusive policies as routine practice
- Promoting skill development of mental health service staff on what real involvement means and the contributions support people can make
- Providing professional training to implement family and support people inclusive programs

To make a difference in how we provide inclusive policies, we need committed action. To make a difference we need to measure how well inclusive approaches are reflected in service programs and what outcomes are being achieved.

What the evidence shows is good practice

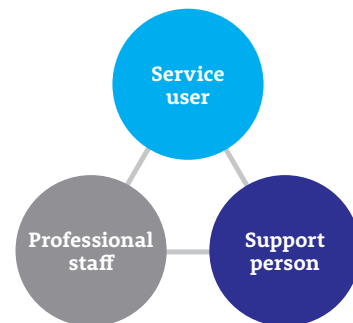
From the evidence that is available, we know that good practice models are those that are sustainable, responsive to the needs of people living with a mental health difficulty and that actively include families and support people as part of the caring team.

Inclusive family and support people programs developed in the United Kingdom by the National Mental Health Development Unit⁹⁹ (that operated until 2010) and the Meriden Family Program¹⁰³ are cases in point.

The **'triangle of care'** good practice approach promotes a therapeutic co-operation between the person living with a mental health difficulty using the service, their support person(s) and the professional staff – who work together to support recovery and sustained wellbeing.

It is a local service-based response to the people it serves. It aims to not only include support people, but to learn from them and to give them certainty about what they can expect from the service in terms of supporting them and the person they care for.

This program is supported by research and evaluation, and includes professional training programs to ensure that ongoing improvement in services is based on real experiences and evidence.



Where the Commission is looking for continuous improvement

Continuous improvement in strengthening and sustaining the role of support people lies in providing quality services which promote a family and support person-inclusive service approach and acknowledge their experiences and knowledge, in care planning.

The role of support people is not adequately acknowledged and supported within Australia and the current, informal system of care is not working well to sustain those involved. Key areas for improvement include:

Ensuring that support services are responsive to individual circumstances of both the person living with a mental health difficulty and their families and support people. This includes providing respite services which suit individual circumstances.

Adopting family and support person-inclusive approaches so that health and support services provide meaningful involvement.

Facilitating continuous improvement by having a standardised, national system to rate the experience of care, in all service settings – across mental health services, mainstream health care, GPs and community based services.

Improving workplace flexibility so that those supporting people living with a mental health difficulty may better balance their commitments to work and caring.

Endorsing family and support person-inclusive services and approaches at community, state and national levels.

Encouraging all Australian workplaces to develop and publish their policies regarding supporting employees with caring responsibilities.

The mental health and wellbeing of family, friends and support people and that of the person they are supporting is paramount. Inclusive approaches add to improving mental health outcomes – and that is what we have been told that families and other supporters want.



Ensuring effective support, care and treatment

Access to timely and quality interventions

Greg, Australian Capital Territory

Six years ago I fell into a deep depression, and was feeling suicidal after a catastrophic personal crisis. I contacted Lifeline for help and they arranged for an ambulance to take me from my country farmhouse to the local hospital, 40 kilometres away.

I was admitted to the psychiatric unit. I had arrived with only the clothes I was wearing, and became very anxious about not having a toothbrush or a change of clothes. No-one in my family knew where I was and the staff didn't seem to be helping me. What was going to happen to me?

I felt fearful. The nurses remained in an enclosed station, observing the patients from there. I couldn't comprehend this. Why weren't they out here amongst the patients? I felt isolated and confused with no-one talking to me.

My distress was increased by the strictly regimented structures like the service of food. Highly impersonal and strictly policed, if you missed your meal, or a cup of tea – tough luck. It was demeaning, impersonal and robotic. I felt dehumanised.

Finally, after three days I saw the visiting psychiatrist and was discharged and referred to a private facility in the nearest city. There, I was given a comprehensive introduction to the unit, assigned my own nurse, had my medication reviewed and my family was contacted.

The environment was comfortable and reassuring, the staff compassionate and accessible. The contrast between the two settings was startling.

Everyone should have access to appropriate care. No-one should have to undergo a treatment which is dehumanising. A correct diagnosis, access to high quality care, medication and treatment appropriate to my diagnosis, applying cognitive behaviour therapy, maintaining good physical health and doing the things I enjoy, all help me manage my illness and lead a fulfilling and productive life.

People in my privileged position who are able to afford top-level private health insurance have access to exemplary care and thus greater prospects for a speedy recovery than those who don't. However, even people with private health insurance cannot take advantage of it if they live in a rural city or town.

There is simply no choice available outside the major cities.

Introduction

Access to timely and quality interventions

To lead a contributing life, people living with a mental health difficulty need timely access to the right support and treatment, to quality evidence-based services attuned to their holistic needs and those of their family and support people.

Access to mental health services is influenced by the level of availability of services, their distribution across communities and regions, and their appropriateness to the person's needs and recovery goals.

The role of stigma or discrimination experienced or perceived by people living with a mental health difficulty in trying to access services or when using services, also has an impact upon how they connect with the services they need and therefore upon the opportunities for their recovery.

The Commission considers that quality mental health care has two facets – service standards of clinical treatments, and standards of practice that actively recognise the dignity of each person which respects their circumstance, culture or community.

The Commission considers that the provision of quality interventions for people living with a mental illness needs to be within a recovery perspective. That is, the range and type of services should be made available for people living with a mental illness to use, when needed, in the best way for them to continue and sustain their recovery.

Access to services has been a consistent theme raised with Commissioners through community meetings and consultations. Having the right balance of services available, more community-based options, timely and appropriate early intervention services and greater recognition of the challenges of living with continuing illness, have all been raised as essential. So too, were having improved interactions with community service systems and the Police.

Without access to effective services, contributing lives cannot be lived and paths to recovery are blocked.

What we know

The Commission believes that to ensure effective support, care and treatment for people living with a mental health difficulty, there needs to be an integrated and co-ordinated mental health service system in place.

Such a system would provide clinical and non-clinical support, hospital and community-based services, and effective and accessible treatments and programs. It would provide linked service pathways and allow linked data to measure service effectiveness and client outcomes.

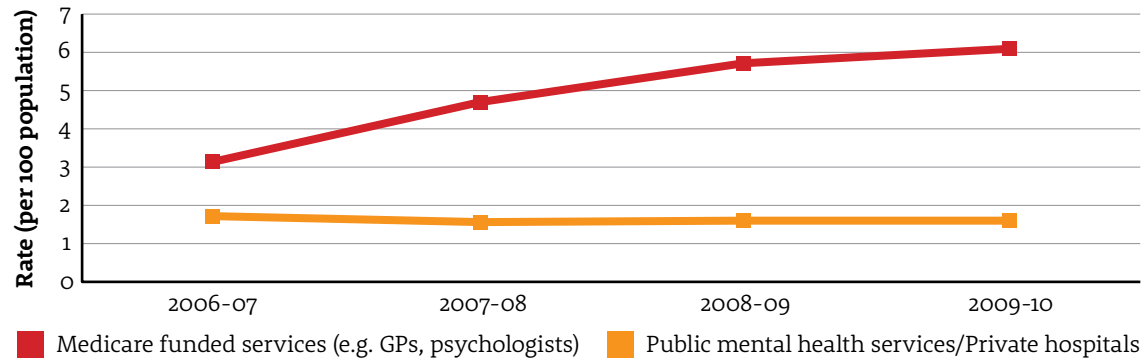
Such a system requires collaboration across the public, private, non-government and not-for-profit sectors, and a workforce that is located in both city and rural areas and is multi-skilled – incorporating clinicians, health professionals, peer and family workers and community support staff.

We know there is debate on the need for a balanced support system – one where acute intervention and hospital-based care is provided 'in balance' and integrated with a strong community-based sector.¹⁰⁴

Over the years 2004-05 to 2008-09 the number of contacts people made with public community mental health services contacts grew by 5.3 per cent.¹⁰⁵ Between 2007-08 and 2009-10 there was growth of 3.4 per cent of people using public mental health services (hospitals and other facilities) and of 10.8 per cent of people using private mental health services.¹¹

In 2010-11 spending on mental health was reported as \$6.3 billion across the public, private and community health sectors in Australia.³⁰

Trends in the proportion of the population using mental health services by service type 2006-07 to 2009-10



Source: COAG National Action Plan on Mental Health — progress report 2009-10

However, the growth in “private and public mental health care services” has been acknowledged by the COAG Reform Council as only keeping pace with population growth¹¹ – meaning that the proportion of people receiving these services did not change. In parallel with this, access has increased to Medicare funded GP, psychiatrist, psychologist and other allied health professionals for mental health needs.

If we use the mental health service target access rate of 12 per cent of the population (as proposed in the Fourth National Mental Health Plan Measurement Strategy¹³) an estimated 2.6 million people should be accessing mental health services each year;

however, it is estimated that only 8 per cent, or 1.7 million Australians used mental health services in 2009-10.³⁰

Therefore around 900,000 people each year are missing out on getting the services that should be available to them.

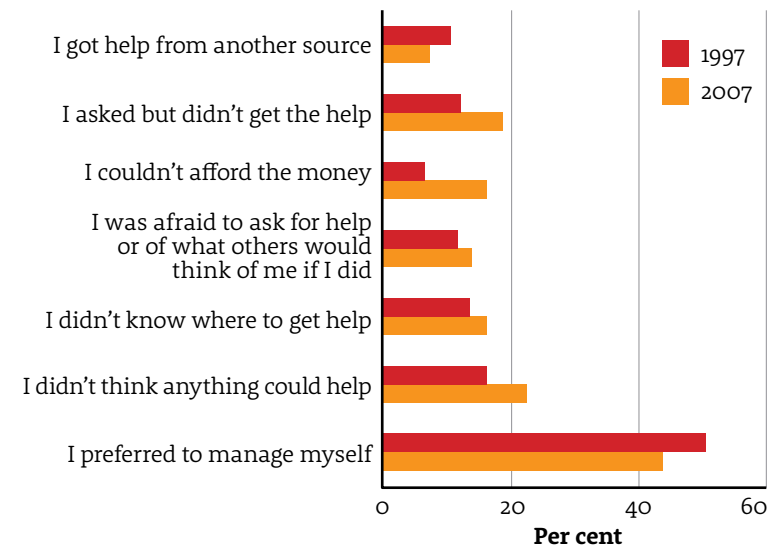
There is variability in levels of access and use of health care and support in the community. We know that there are unequal levels of access to GP services.²⁶ The further you live from a major city or inner regional area your access to a GP declines and you are less likely to have a GP mental health treatment plan – this is highest at 19.9 per cent of people with a mental illness aged 16 to

84 years in cities, slipping to 17.7 per cent in outer regional areas, but falling by half to 8.5 per cent in remote localities.¹⁰⁶

We know that just under two-thirds of people (65 per cent) who experienced a mental health condition in 2007 did not use services for their mental health needs in the 12-month period.¹⁰⁷

Of the 35 per cent of people who did use services, over half (52 per cent) felt their needs were not fully met. The main reasons given by 44 per cent of respondents were that they preferred to manage themselves. Twenty three per cent thought that nothing could help them, 19 per cent asked but didn’t get the help they needed and 14 per cent

Reason that the need for mental health services was not being fully met



Source: ABS National Survey of Mental Health and Wellbeing: People with a 12-month mental disorder whose need for mental health services was only partially or not met, by reason that perceived need was not met, 1997 and 2007.

were afraid to ask for help or had concerns about discrimination.¹⁰⁷

Furthermore, 26 per cent of people who used services reported they did not have their need for counselling met or it was only partially met and 29 per cent who used services reported they did not have their need for information met or only had their need partially met.¹⁰⁷

Since this time access to psychological services increased under the Better Access initiative. This was in terms of the numbers of people using at least one service under the program from 710,840 in 2007 to 1,130,384 in 2009)¹⁰⁸. Access to other psychosocial support services has also

increased under the Personal Helpers and Mentors program¹⁰⁹ and the Support for Day to Day Living in the Community program.¹¹⁰

However, we also know that increased access to services under these programs was not evenly shared across all communities. Under the Better Access program, people living in rural and remote areas had lower rates of access than those in cities. Young people also had lower rates of access¹⁰⁸.

From these separate pieces of information we start to see that services are growing, but not necessarily connecting with the people who need them most.

We also have an unclear picture of how people living with a mental health difficulty access the range of services they need, as we do not have information that lets us see the big picture to understand how each element – such as GP consultations, psychological counselling, individual support or hospital treatment – come together to provide an integrated system of care for each person.

What we don't know

Where we need more evidence, and to shine a light

We need to see that our services and support programs are providing evidence-based mental health care. We currently do not know how many services deliver evidence-based practice, or what steps they are taking to achieve consistent improvement in the delivery of best practice care.

We need more research and information to build up this picture across Australia, so that we know to what extent people with a mental illness receive best practice care and treatment, enable services to respond to this imperative and track if we are heading in the right direction.

As part of this approach, we need more evidence on people's experiences of services, and the experiences of their families and other support people.

Currently, surveys on experience of services are not part of a regular system-wide services assessment process. Surveys are undertaken periodically by non-government organisations, and while some jurisdictions have developed consumer survey tools for their public mental health services, not all routinely use them. We understand that the private sector through the Private Mental Health Alliance, is also working on a similar survey.

Yet overall we do not know if services are meeting the immediate or ongoing mental, physical and other support and recovery needs of those who use them.

We do not know if the services are of an appropriate quality or contribute to the person's recovery and improve their health outcomes.

We need to have nationally consistent outcome-based measures and routinely measure the experiences of care for people with a mental health condition, and their families and support people as a national standard.

There are safety and quality National Standards for Mental Health Services against which public, private and community mental health services are to be assessed. They are voluntary standards, and we do not know if they are regularly used to improve quality outcomes and routine service practice, or just as a check list. This is unlike all other safety and quality health care national standards which are mandatory.

We need to ensure that National Standards for Mental Health Services become mandatory so we can evaluate the quality of all services against the same standards, just as with any other health care service. More transparent reporting can lead to better quality services and health outcomes.

In short, we are currently unable to track if services are providing the right type of quality care and interventions – be it from a lived experience, family or government perspective – and whether these are making a difference.

Involuntary treatment, seclusion and restraint

Involuntary practices are those where the person involved does not agree to the treatment or procedures given to them.

Involuntary treatment: where someone with a mental health difficulty is given treatment, either in hospital or the community, when they have not given their agreement

Seclusion: when someone is confined in a specific room from which they cannot leave

Restraint: when someone's movements are restricted by the use of straps or belts (physical or mechanical restraint) or sedation (chemical restraint)

We are troubled by involuntary treatment practices for several reasons. Despite a national commitment to reduce or even stop secluding and restraining people some services still use these methods. We don't know the extent of these practices because they aren't publicly reported nationally.

The ongoing use of seclusion and restraint is not in line with human rights principles signed up to by Australia, such as the 1991 United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.²

We have been told by many people living with mental health difficulties and their families that seclusion and

restraint adds to the distress of a hospital admission. For certain patients it can cause exacerbation of fears, paranoia and trauma and as such is contrary to recovery practice.

We know from international research that the use of involuntary seclusion does not lead to better outcomes for people.¹¹¹

However the Commission understands that this is a

complex area – not least for the professional staff working in these facilities, as well as for safety issues.

Four jurisdictions (the Australian Capital Territory, Queensland, South Australia and Victoria) publicly report on seclusion events in health services – which are to be applauded – but we need this to be comparable and set within a national picture.

Despite the reduction, and elimination where possible, of seclusion in mental health services being an agreed national performance target since 2005¹¹², there is no routine and standardised national data collection relating to the use of seclusion (or restraint) for us to use to track our progress towards meeting this target.

The use of restraint is also not nationally reported – only Victoria, South Australia and Western Australia publicly report the incidents of physical restraint in their facilities.

So all we have are glimpses of trends. In Victoria, for example, in 2010-11 there were 4,694 episodes of seclusion, which was a decline of 23 per cent on the previous year.¹¹³ There were also 512 episodes of mechanical restraint in 2010-11; a decrease of 35 per cent compared with 2009-10.¹¹³

We know that involuntary hospitalisations across Australia have remained at between 30 to 34 per cent of all hospitalisations for psychiatric treatment over recent years (2005-06 to 2009-10).¹¹⁴

And we don't have the answers – not least because we don't know a lot about how much seclusion, restraint, involuntary admissions and compulsory community treatment orders are used. But we believe this is something that Australia should know about and look at closely.

We will be doing some more work, with others, in this area to inform our thinking and advice, and take a keen interest in monitoring the use of such practices.

If our goal for people with a mental illness is for services to be recovery-oriented, and have safe and effective interventions, then reduction in the use of seclusion and restraint needs to be vigorously

pursued and alternative evidence-based interventions put in place. We need to ensure the right of patients to have treatment provided in the 'least restrictive' manner² and to learn more about managing patient environments and treatment approaches to improve a sense of therapy and recovery.

Keeping families in the loop

Australian surveys have found that a significant percentage of families and support people (across a range from 20 per cent to 60 per cent) consider that they were rarely or never made to feel part of the 'caring team'.^{95, 100, 91} Yet we know that the role of families, friends and support people has been demonstrated as important in helping the person they support in their recovery.⁹⁴

What it means for Elaine's family, New South Wales

Our son became unwell at age 14 and was diagnosed with paranoid schizophrenia. When he turned 18 we no longer had access to any information about him despite him living at home. At times we have felt quite fearful, and find it difficult to support him when we are not adequately involved in or informed about his care.

As parents we seek out expert medical advice and support to give our son the best opportunity for a better quality of life. But many times he has been passed between different services because he was deemed too difficult or unco-operative and we have been left out of the loop.

Making contact with services to alert them to what might cause him to become anxious and prevent him from attending appointments has really worked for us. Having an understanding of the Mental Health Act and the system and not being afraid to question the treatments has also helped.

It is vital to have a good family network which is involved in planning and care and it is essential to be open and frank with services about where our son is at. Our son may have a mental illness, but he still deserves a decent quality of life, justice and respect.

[Click to watch Elaine's story](#)



2012 spotlight issue

The presence of gateways and barriers to accessing care

There are many barriers to getting the right support – financial affordability, geographic remoteness, culturally inappropriate services, complex care pathways, poor physical health, a lack of genuine choice, inflexible service models, waiting lists, fear and lack of service availability.

Barriers to quality care and support make a life more challenging than it needs to be. We need to improve access in regional, rural and remote areas, where, right now, it is markedly reduced.

It should not be this way.

Barriers to accessing care play out differently in each person's life. For vulnerable groups such as homeless people or those on lower incomes, barriers to care need to be broken through assertive outreach programs that connect with people where they live, responsive to their circumstances.¹¹

Barriers to care also change across age groups – we have no clear understanding of the unmet needs of children, youth, adults or older people for relevant health and social services; however, we know from listening to people that they face barriers when transitioning between services as their personal needs change.

There is also a demonstrable impact from mental health based discrimination. These are issues of self-stigma¹¹⁵ and discrimination experienced from a person's community and health professionals¹⁰⁰ which affect a willingness to seek health support. Discrimination in health settings is not to be tolerated, and does not uphold the

United Nations Convention on the Rights of Persons with Disabilities signed by Australia in 2008, that "Require[s] health professionals to provide care of the same quality to persons with disabilities as to others..."¹¹⁶

It is essential that our health services provide the same level of quality care equal to that of people with other illnesses to those living with a mental health difficulty. Given the higher levels of overall health problems and the need for routine monitoring and screening, it is imperative that barriers such as those based on discriminatory practices are totally rejected.

Likewise, barriers to getting good overall health care from your local practitioner are not acceptable. The unequal access to GPs²⁶ who are a gateway to physical care, mental health care, psychological counselling and referral to specialist care is a prime concern. This poses not only a barrier to getting good overall healthcare, but referral on to specialist care.

This is especially crucial for people living with severe mental illness, as managing their physical health is as important as their mental health, given their higher risk of metabolic health problems, cardiovascular disease, diabetes and obesity.

The Commission knows that, similar to international experience, Australia has high levels of unmet need¹¹⁷ with health services often out of the reach of those who most need them.

We need sufficient support and services in place to make access meaningful to meeting people's needs.¹¹

In Australia gateways to care for people living with a mental health difficulty are creaking, yet we know those well-oiled gateways to early intervention and both physical and mental health care are essential to improve lives.

What the evidence shows is good practice

There is an emerging and strong consensus internationally about what makes up an effective mental health service – the provision of assertive community-based treatment and intensive case management, delivered within a collaborative approach.

Such services increase access for people and have been found to promote independent living while achieving greater levels of satisfaction with services.^{118, 119}

Stepped care approaches, that provide a range of therapies and approaches, including using the internet or mobile phones, have been found to improve access for people living with common mental health conditions such as depression and anxiety.

The Commission understands that the levels of service provision, type of services provided and access to them vary greatly across Australia, yet we know that good practice does exist to tackle this inequality.

However, to support a system that works well we need a national ‘good practice’ standard. Access is only meaningful if the services being provided are meeting the needs of those with a lived experience of mental health difficulties, and achieving positive results.

Through roundtable discussions held by the Commission, we have become aware of good practice models in development by Police departments for that specific group of people with a mental illness who are more vulnerable to coming into contact with law enforcement agencies. There is evidence that improved connections between mental health services and the people who need them, as well as collaboration with and training of police forces can help ensure health issues do not unnecessarily become Police issues.

It is inevitable that in the course of their duty Police Officers will come across people with a mental health difficulty. Police Officers need to be able to recognise the role that they play in mental health support as part of their everyday duties.

One innovative model is the Victorian Police and Community Triage (PACT) program which connects local health and community service with people who, through their difficulties with their mental illness, homelessness or other social issues, come in frequent contact with Police.

This individualised support for people in the program has resulted in the number of Police incidents involving them falling by 64 per cent and the number of police units being dispatched decreasing by 60 per cent. This compares to smaller decreases of 17 per cent and 4 per cent, respectively, for people that were referred to police by PACT but did not participate in the program.¹²⁰

We also know that Police have reported that they devote a substantial and increasing amount of time on call-outs and incidents related to people with mental illness. NSW Police has advised that the number of incidents they attend with regard to the Mental Health Act increased by 25 per cent over the five years 2007-08 to 2011-12 – from 21,549 to 26,941.¹²¹

New training and practice models can free up Police time and provide the right type of mental health support needed. **The NSW Police Mental Health Intervention Team Training** is one example that provides Police officers with increased skills and awareness to deal with mental health related interactions. **The ACT’s Mental Health Community Policing Initiative** is another good initiative, working with ACT Health to improve decision-making in cases that involve people with a mental health difficulty, interagency co-operation and therapeutic outcomes for the person concerned.

These models can be strengthened by ensuring that Police undertake routine mental health awareness training. Steps to provide this education have already commenced in some jurisdictions.

Where the Commission is looking for continuous improvement

Beyond expansion of access to support services we need to see improvement in the outcomes and effectiveness of those services, and an assessment as to whether they are the right ones in which to invest.

We need a balanced support system, where acute intervention and hospital-based care is provided alongside a strong community-based sector.¹⁰⁴ Improvement can start to rebalance the system to:

Increase access to community-based and home-based care and services.

Expand new service approaches that provide early intervention and support an alternative path to a hospital admission, such as:

- the ‘patient-centred medical home’ that provides an integrated primary care approach, where the patient’s own physician (such as their GP) co-ordinates and leads a multi-disciplinary team for all their health needs,¹²² or one that provides crisis and acute interventions in the home with rapid ‘round the clock’

outreach services from multi-disciplinary teams, including mental health^{123, 124}

- specialised community-based peer run services such as ‘community recovery homes’ for people who need support or intervention in the early stages of deteriorating mental health.

Achieve agreement on what a balanced system looks like – the National Mental Health Service Planning Framework currently in development can be a starting point.

Further work can be done to build upon existing initiatives:

While access to psychological services has been increased under the **Better Access initiative**¹⁰⁸ and to other psychosocial support services under the **Personal Helpers and Mentors program** and **Support for Day to Day Living in the Community programs**, we need to be better informed as to how effective the Better Outcomes and its successor Better Access have been in increasing access for young people, men and people in rural and regional Australia.¹²⁵ Increased access to services does not necessarily equate with increased access to effective care.

We need as routine practice **program evaluation to measure rates of access**, especially for young people, homeless people and those on low incomes, CALD populations and the LGBTI community, people living in rural and regional areas and Aboriginal and Torres Strait Islander peoples.

e-health strategies have the capacity to effectively deliver information and support to many of the people currently not connected to services. Here, Australia needs to build on its successes to date.^{126, 127}

Overall, as a nation we need to urgently improve how peoples’ access and experiences of services are measured and use service experience data to support quality improvement, adopt a national standard for measuring experiences of support and invest in new pathways to support people who do not engage with traditional primary health or specialist mental health services.



[Click to watch Men's story](#)

Something meaningful to do, something to look forward to

Participation in work and employment

Men, New South Wales

Working is very important to me. Having a job helps my recovery, especially when it's my job to help others.

I was born in Cambodia and grew up in Vietnam in the 1960s. I first experienced mental illness in Vietnam in 1991 without it being diagnosed. My mum, my sisters and I migrated to Australia via New Zealand. I had a good prospect for work as a cook but became unwell. I was in and out of mental health services. It was uncomfortable to continue to live with my sister and her family. I relapsed and ended up in a mental health unit. When I was discharged I wanted to get a job so that I could live by myself.

I started working as a kitchen hand in two supportive businesses. The chef did the preparation the day before and I did the rest for the Saturday functions. I moved into my own home and this improved my mental wellbeing as well as my relationship with my mum, my sister and her family. Sometimes I go there to visit them and have lunch with them. We are all much more relaxed and happier.

One of my support people introduced me to a hospitality course, because I love and enjoy cooking (and tasting) food. Another thing which is important to me, besides getting a job, is that I want to help others which led

me to enrol in the course in 2009. I completed the course and got the certificate. I am very happy and proud of myself.

I became unwell, and have just undergone surgery for cancer and currently am in the middle of recovery therapies for that surgery.

Unfortunately I needed to leave my community housing because of the violent and aggressive environment there and I am waiting to hear about a new place to live.

I am currently looking for work again, including looking for work as a consumer representative, and I have done a certificate in consumer work in the hospital setting.

In the meantime I am working as a volunteer in a hospital with patients, doing some nurse aid work but also spending time with patients from Vietnam and Cambodia, going for walks, just talking to them. I hope that the volunteer work will turn into paid employment. I am hoping for three days a week.

Introduction

Participation in work and employment

People living with a mental health difficulty can and want to make a significant contribution to their community and society by engaging in meaningful work. For as long as they are unable to do so, our society, economy and the people themselves, are diminished.

Having something meaningful to do and to look forward to will differ from person to person and will reflect their own recovery goals. For some it may be community activities or volunteering, or for others getting a job or returning to work, but all should bring personal satisfaction and build personal connections.

There are many people who live with a persistent mental illness who also can have a contributing life in the Australian community. There are opportunities to be involved in supported employment, including Support for Day to Day Living in the Community program or other means of remaining involved in work and other activities that give meaning to people's lives.

Improving these opportunities requires shared efforts in areas of access to education and training, personal and workplace support and workplaces that are flexible and non-discriminatory.

The Commission takes a wide-angled view in this chapter, and looks to the range of opportunities for increasing participation, programs which provide broad-based support and how the employment sector can maximise the contribution of employees with a mental health difficulty.

We all value our health and wellbeing (including economic wellbeing) and that of our family and friends.

This chapter also explores the many benefits of employment for people with a mental health difficulty. This goes beyond just improving economic wellbeing; employment contributes to good mental health by encouraging and enabling personal contacts and social networks and friendships, promoting inclusion and fair access, helping to give meaning and purpose beyond financial and material reward. All of these contribute to and help support recovery.¹²⁸

For those endeavouring to join the workforce, or return to their job, the issue of workplace discrimination is very real, as it is for employees who also have a caring role. Eliminating discrimination in the workplace is important to the Commission and is a priority for collaborative work to bring mutual benefits to employees, their colleagues and managers.

Creating workplace cultures which are informed, aware, flexible and appropriate in their response is paramount to maintaining workplace mental health and wellbeing.

The area of employment of people with mental illness is capable of great change – and one where the Commission will work with industry leaders, small businesses and the community to improve productivity and wellbeing, and find ways together to assist employers and employees in achieving the best outcomes in the workplace.

What we know

People living with mental illness want the same work opportunities as everyone else.^{129, 130} Their participation rates in volunteering and in unpaid work of between 16 and 19 per cent for example, are similar to the rate of 20 per cent for the general population.¹³¹

However, the proportion of people with a mental health condition who are not in the labour force is more than one and a half times compared with the general population (32 per cent compared to 21 per cent).⁷⁹

We know that there are many benefits for people to gain from having work, such as expanding social relationships and skills, a better sense of self, involvement with others and financial independence,¹²⁹ but we also know there are obstacles such as lower education levels, lower socio-economic status and poor employment levels that makes it more difficult for people living with a mental health issue.

Seventeen per cent of people living with a mental illness have fewer social contacts, seeing friends or family just

once or twice every three months, which is almost half that (9 per cent) of the general population.¹³¹ Thirty eight per cent have a full-time job, much lower than 55 per cent for people without mental health difficulties.⁷⁹

As many mental illnesses develop during late adolescence to the mid-twenties, opportunities to complete schooling and further education are disrupted, as are future work and employment prospects.

The situation for people living with a severe mental illness highlights this mix of factors.

We know that half of the people who develop psychosis will do so by the time they are aged in their early twenties¹³² and that:



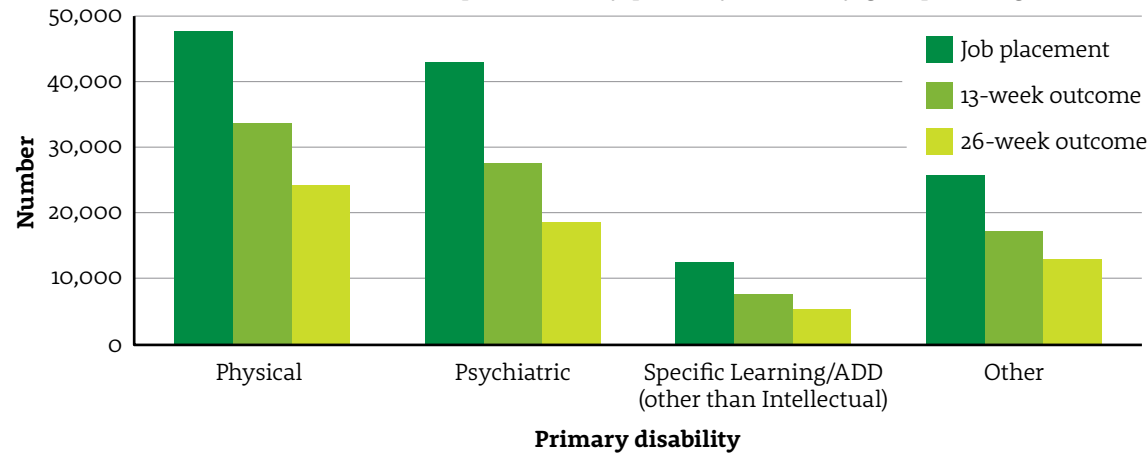
Only **32 per cent** of people living with psychosis complete high school...

Unemployment levels for people living with psychosis are reported as high as 67.3 per cent.⁷⁵ In comparison, unemployment for people with a mental illness identified in the National Health Survey (NHS) was 5.4 per cent, which was double that for people with no mental illness,

...compared to **53 per cent** in the general community.⁷⁵

at 2.6 per cent.⁷⁹ These unemployment levels from the NHS may well be an underestimate, as currently the seasonally adjusted unemployment rate for Australia is 5.4 per cent (as at September 2012¹³³).

**Disability employment services (DES) outcomes:
Still in work at 13 and 26 weeks after placement by primary disability group, 31 August 2012**



Source: Department of Education, Employment and Workplace Relations (DEEWR). Disability Employment Scheme monthly data.

We know that almost one in five people who experienced a mental illness in the previous 12 months live in the poorest economic circumstances, where 20 per cent of people live in households in the lowest income bracket, compared to 16 per cent of people with no mental illness.²⁰

In Australia 26 per cent of people have government pensions and allowances as their basic income, compared to 21.6 per cent for people without mental illness,¹⁰⁷ and for people living with a psychotic illness this dramatically increases to 85 per cent of people.⁷⁵

And we know that the reliance upon a Disability Support Pension (DSP) is increasing for people with a mental health or

psychological condition – having grown by approximately 76 per cent over the past 10 years.¹³⁴

We have to break this vicious cycle of disadvantage and waste of human potential. One way to change this is by making meaningful work and employment a priority for people with mental health difficulties.

Having meaningful work or employment can help turn these circumstances around. In 2012 we know that 50,452 people with a psychosocial disability arising from mental illness are seeking employment through the Disability Management Service and the Employment Support Services programs.¹³⁵

While the Disability Employment Service had success in placing 43,700 people with a psychosocial disability arising from mental illness in a job – after 26 weeks from starting work, less than half of people were still in the job.¹³⁵ This drop-off in employment however, is similar to other groups of people living with a disability.

We know that the opportunities to be gained from having meaningful work or a paid job are still not open to all. This discrimination and inequality needs to be challenged and changed.

What we don't know

Where we need more evidence, and to shine a light

We need more evidence to see how we can improve opportunities for social inclusion for people who miss out on participating in the community or employment.

The particular and specific needs of Aboriginal and Torres Strait Islander peoples and people from CALD communities, must be reflected in mentor programs, so that appropriate opportunities to re-engage with their community, develop confidence and participate are made real for them.

We need evidence on innovative employment schemes, such as social firms that link people living with mental health difficulties to permanent and 'durable' jobs, and to contribute to expanding the range of long-term work opportunities that are known to be effective.

We need to shine a light here, knowing that current disability employment programs are having job retention success rates of 50 per cent.

Evidence on the best innovative employment support schemes is also required for 'traditional' workplaces, to develop best practice programs to successfully support and retain people with more frequently occurring mental illnesses. Currently much of the evidence for supportive employment is for people living with serious mental disorders,¹³⁶ yet it is estimated that up to 14.9 per cent of workers in Australia will develop other psychological

or mental health difficulties during their working lives, including anxiety, depression or substance abuse.¹³⁷

We need to know what will help employers, managers and work colleagues with mental health issues in their workplaces. We need evidence to tell us what works for the range of workplaces, especially the significant number of small employers who employ almost a half of all workers in the private non-financial sector.¹³⁸

Something meaningful to do, something to look forward to

Employment options for people who provide support

Employment levels of people providing care are reported to be ten per cent lower than the general community (63 per cent compared to 73 per cent) and for female support people this falls even lower, to 50 per cent.⁹⁵

A recent Wesley Mission report into the impacts of caring for a person with a mental health difficulty found that 57 per cent of support people had their work and financial circumstance worsen, where 58 per cent reduced the hours they worked or studied and a third had changed to a less demanding job.⁹¹

What it means for Carol, Western Australia

Being a carer and working at the same time is very hard. I have several roles as a carer, teacher, counsellor and mother and I love what I do; but sometimes it's very difficult to perform all of these roles at once.

When our eldest boy was diagnosed with schizophrenia, I completed a program for carers so I could understand what to do to support him.

I took a year's leave from paid teaching to spend time with my son caring for him while he was attempting to begin his journey of recovery.

It was one of the best and perhaps most emotional years of my life. My son is now alcohol-free and also on the way to being nicotine-free, which is a huge achievement.

As my boys grew older their challenges and difficulties became more demanding on my time and energy. I took a year off and completed a Master of Health Counselling, linking my role and skills as a carer with my professional development. I thought this would be less demanding on me, but I developed depression and fibromyalgia which required more time off from paid work, although I did volunteer work to keep contributing.

I still get very tired sometimes in times of crisis and stress, but I am so proud of my son's effort and perseverance.



2012 spotlight issue

It's time for change on mental health at work

Australians need flexible and supportive workplaces, where employment discrimination on the basis of mental health is eliminated and employers and employees are provided with support so that the potential of the individual and the business are maximised.

Mental disorders account for 13.3 per cent of Australia's total burden of disease and injury¹³⁸ and are estimated to cost the Australian economy \$20 billion annually in lost productivity and labour participation.¹³⁹

The Organisation for Economic Co-operation and Development (OECD) has found that people with severe mental illness are “too often, too far away from the labour market” and that people with a common mental illness such as depression or an anxiety disorder are mostly “employed but struggling in their jobs.”¹⁴⁰

A person's mental health can change over time, with periods of overall good health and other times with poor mental health requiring time off work for treatment. From international studies we know that having a mental illness is the leading cause of sick days, disability benefits and reduced work performance in most industrialised countries.^{141, 142, 143, 144} The full contribution people living with a mental health difficulty can make in the employment sector may require flexible

approaches to work or workplace support, but the lens through which they are seen needs to be wide-angled.

In Australia, workers with job-related stress and mental illness are absent from work for 10.8 weeks a year,¹⁴⁵ where the longest absences from work were associated with stress or other mental conditions and physical injury.¹⁴⁶

We don't know enough about the preparedness of employers to manage this issue and the impact it has upon employees and the workplace: do businesses, public sector and community sector organisations have the appropriate understanding and skills to provide the right sorts of jobs and opportunities? Can they provide the right support to people working?

We want to see the same understanding and openness in the way we talk about mental health at work as we do when we talk about physical health or other issues – to have an understanding that mental health is far more than just “the absence of mental illness”.

Giving employers practical support in creating and maintaining a ‘mentally’ healthy workplace is a key element, particularly in light of the fact that poor workplace culture can lead to or exacerbate mental health difficulties and may affect a person's ability to function effectively in the workplace.¹⁴⁷ These approaches can improve productivity.

What the evidence shows is good practice

In Australia:



More than half (55 per cent) of people who suffered stress or other mental health conditions were absent from work for five days or more a year...

There are many things we can do in the workplace to ensure we are providing the right kind of support and intervening at the right time, through approaches such as systematic monitoring of sick-leave behaviour to detect longer-term or repeated absences and managing those by providing immediate support and retention strategies; or formal recognition and support for carers of people with a mental health condition in enterprise agreements.



...compared to **27 per cent** of people who suffered a work place injury overall.¹⁴⁶

The Commission considers this to be very important work and will work in collaboration with individuals and key bodies in sectors across Australia, particularly those outside the mental health sector, to improve the mental health of workplaces for all employees and businesses. It makes economic sense to do so.

Evidence shows that involvement in work has wide-ranging positive impacts – being “good for physical and mental wellbeing”; providing regular contact with people outside of your home; an increased sense of worth and financial independence; improvement in social skills and mental health.¹²⁹

Meaningful work has benefits beyond earning an income and opportunities. Individual Placement and Support (IPS) programs have strong evidence supporting their effectiveness in increasing access into a job and retaining the job over a period of time.¹⁴⁸ These have been found to be especially successful for people with more severe mental illnesses.

Such evidence-based programs have been pursued by Government – including the Job Access initiative, the Partners in Recovery Initiative, Support for Day to Day Living in the Community program, specialised Disability Employment Programs and the Personal Helpers and Mentors (PHaMs) initiative.

Recent evaluations of two programs, the Support for Day to Day Living in the Community and PHaMs, demonstrated the success achieved by participants in obtaining their goals and confirmed that a person-centred approach works well.

Workers in the Support for Day to Day Living in the Community program supported people with severe and persistent mental illness and was found to improve their community involvement, participating in training and education and their self-confidence. The program was positively accepted by both clients and service providers.¹¹⁰

PHaMs services provided individual helpers to assist people in achieving their day-to-day goals and to empower them to achieve their longer-term objectives. This approach had high levels of client approval with participants overall achieving improvement in their personal capacity, self-reliance and self-confidence; and in their level of community participation, social connections and day-to-day functioning. Clients reported their longer-term goals were to take up opportunities in education or employment, and getting and keeping a home.¹⁰⁹

These are significant results and provide hope for the future. We know a lot about what works; we need to see these evidence-based programs scaled up and more universally available.

Where the Commission is looking for continuous improvement

Discrimination towards people living with a mental health difficulty is one of the most powerful barriers to them being able to enjoy the benefits of meaningful work or a rewarding job.^{96, 149}

Overcoming discrimination is essential in helping people living with a mental illness to get work and keep it, especially if employers do not recognise the full contribution these employees make to the workplace.¹⁵⁰ It can also affect employees who care for a person living with a mental health difficulty.

The level of discrimination by employers has been found to be extraordinarily high. One study found 50 per cent of employers would “never” or “rarely” employ a person who they knew to have a mental health difficulty.¹⁵¹ This is a truly shocking finding.

Workplace education on ‘demystifying mental illness’ is supported by both employers and people living with a mental health difficulty as a good place to start to fight mental health discrimination

in the workplace.^{152, 153} This education involves employers, their managers and staff to help them have a clearer understanding of the more common mental illnesses and how this can affect an employee. The best programs take a corporate-wide approach and build this into their work culture and ethos.

One study on possible recruitment scenarios showed that an employer had a more positive attitude towards retaining an existing employee with a mental illness, rather than recruit someone new with a known mental illness.¹⁵² This underlines that knowledge about mental health and having worked with someone who has a mental health difficulty is important in changing attitudes. Negative attitudes can affect existing employees self-reporting their

mental health difficulties, and by doing so, can reduce their use of workplace support programs. Currently only seven per cent of employees with a mental health problem currently access job support under government and employer-funded Employee Assistance Programs.¹⁵³ This limits their opportunity to get the support that they need, and also for their employers to keep the skilled staff that they want.

As a further priority in increasing employment levels we need an improvement in developing educational opportunities for young people with severe mental illness to overcome barriers to participate in meaningful work or getting a job. Of all people who have no post-school qualification, 20.8 per cent have had a 12-month mental health difficulty.²⁰

The need to improve the education achievements of young people with severe mental illness is also driven by the education targets under the 2010 National Youth Participation Requirement.

This requires all young people to participate in schooling to Year 10, and then participate in full-time education, training or employment, until age 17.¹⁵⁴ This national education requirement may go some way towards the 2015 target that 90 per cent of all young people have a Year 12 certificate or equivalent VET qualification.¹⁵⁵ Governments need to ensure that young people with mental illness don’t miss out and that they are properly supported to complete their education.

Another priority issue that the Commission will look for is future improvement in the way we support people living with a mental health difficulty who are unemployed and on income support payments. This area needs major reform because the income of almost all recipients of the Newstart allowance falls below the poverty line.¹⁵⁶ There needs to be much greater practical and

other supports and initiatives for socially marginalised people, amongst whom those with mental disorders are overwhelmingly represented.¹⁵⁷

We need more responsive human services agency approaches. For people seeking to receive income support, who are under-employed or unemployed and experience a mental health problem such as anxiety, social phobia and depression, having to continually re-present for job interviews which are unsuccessful can damage their mental health and increase feelings of worthlessness. These problems are compounded further for people of CALD communities and Aboriginal and Torres Strait Islander peoples.

We need more active interventions to help unemployed people, by continuing some of the work that human services have already begun. Privatised employment agencies should be reviewed to see what they are doing to support unemployed people with mental health problems.

The end to employment discrimination on the grounds of mental health, the improvement of workplace mental health and wellbeing, increasing participation in community life and making improvements in education attainment for young people with a mental health difficulty will be of ongoing interest to the Commission.

We will continue to shine a light on these issues to see where these goals are being reached. These achievements will only be possible with the close collaboration and co-operation of employers, trade unions and many others in the employment, education and community sectors. Many have made a good start and many more want to follow. These are issues that we will return to and report on in the future.



[Click to watch Carmel's story](#)

Feeling safe, stable and secure

Having a home

Carmel, South Australia

I have had a lot of problems in my life with depression and anxiety, but I feel like I'm going really well now.

I take a lot of different medications, which all have long names that I can't remember. They seem to work, but they make me gain weight and make me tired. I built some skills at an activity program, which helped me get a job and it's been great for me to earn some money of my own. It was a great opportunity, but I wasn't really treated the same as everyone else; some people teased me there.

I feel like my help in the activity centre is really important. I like to feel like a part of the team there, and it keeps me busy; even the CEO will look at what I've done, and that makes me feel good. I like that I've been contributing for so long, that's why I keep coming here.

For about two years I was living in a car or staying with friends. I didn't really have anywhere to go for long periods of time.

I had to give my cat Maxine to one of my friends to look after, because it wasn't fair for her to live in the car with me. Through my support organisation I found a Personal Helper and Mentor (PHaM), and we worked together to get a house through Housing SA. I am really happy.

I am now able to have a shower whenever I want, and I can also cook meals at home. I have bought a BBQ to put in my small little backyard, and best of all, I got my cat Maxine back.

I feel very lucky.

Introduction

Having a home

Having a quality home provides a personal place for people to feel safe, stable and secure – safe from poorly maintained and impersonal accommodation; in stable housing where fears of being moved on or evicted no longer exist; to have somewhere to live independently and affordably, to socialise, enjoy privacy, have a pet or enjoy a calm haven from the world.

It is much more than four walls and a roof.

It allows us to live within a community, to feel part of that community. To both contribute to it and also enjoy the benefits that being part of a community can give – connections, meaning and purpose.

Having a safe, stable and secure home is important to the mental health and wellbeing of people and families, whereas poor housing and housing stress, together with other life stresses, can reduce psychological wellbeing.^{158,159}

For people living with a mental health difficulty, housing stress along with financial stress, the stress of unemployment or living with poor health can be seen as a consequence or contributing factor to mental illness.¹⁶⁰ For some it leads to the loss of their home and their social connections, and may result in homelessness or substandard housing and social exclusion.

For the most vulnerable and unwell, cycles of homelessness, unstable housing and poor mental health can become their total life experience.¹⁶¹

Contributing lives cannot be lived where recovery cannot be aspired to, or where lives are lived on the margins from communities, families, friends and support people, or from health, mental health and support services.

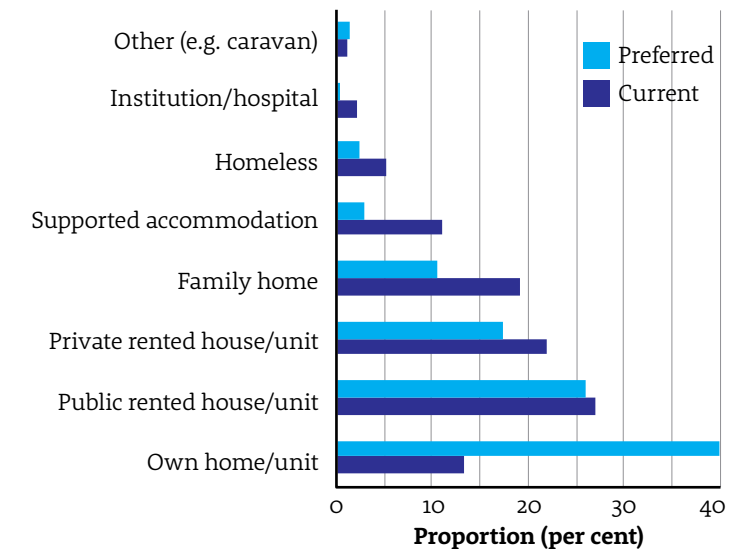
What we know

We know that generally for people who are living with a mental health difficulty, getting and keeping their own home is hard to achieve compared to the general community – fewer own their own home, or are paying off a mortgage,⁷⁹ more people rent their homes and their need for housing support is growing.

But for that smaller group of people who live with a severe mental illness we know they are more vulnerable to homelessness¹⁶¹ and experience higher housing stress. A considerable number live in unstable housing (42 per cent),¹⁶² half are renting their homes⁷⁵ compared to about one-third of all people with a mental health difficulty,⁷⁹ and just under a third reported they had had to move house in the past year.⁷⁵

But their current housing is not their preferred option – with most wanting to live in their own home or unit. More widely, requests for housing assistance by people living with mental health difficulties are consistently growing – 6 per cent each year between 2005-06 and 2009-10.¹⁰⁵

Accommodation for people living with psychosis – where they currently live and where would they prefer to live



Source: National Survey of Psychotic Illness 2010.

We know that the housing assistance needs of Aboriginal and Torres Strait Islander peoples with a mental health difficulty are **five times the rate** of non-Indigenous Australians.¹⁰⁵



The impacts of a person's mental illness that result in education and employment disadvantage, lower incomes, higher social isolation and reduced physical health all merge to further disadvantage them in keeping a home or becoming homeless.

This significant vulnerability to homelessness of people living with a mental illness is reflected in a national survey, where more than half the people who had ever been homeless had also had a mental health disorder in the previous 12 months.²⁰

In a Mission Australia report (the Michael Project) the complex needs of homeless

men with mental health difficulties was found to be present alongside drug and alcohol abuse issues, and poor physical health.¹⁶³

It is not surprising that over one in five adults aged 15 to 64 who are admitted to a mental health service are assessed as having significant problems with their living conditions.¹⁶⁴ For these people, is their hospital stay also their most stable accommodation?

Under these circumstances, how can we expect people to lead contributing and meaningful lives? With no home or safe, stable and secure base, how can recovery even begin?

What we don't know

Where we need more evidence, and to shine a light

To make a difference in the housing experience of people living with a mental health difficulty, we need to look to those living in the most vulnerable circumstances – people and families who are homeless or are at risk of homelessness.

The Australian Government has made a commitment under *The Road Home: A National Approach to Reducing Homelessness* to specifically achieve “no exits into homelessness’ from hospitals, mental health and drug and alcohol services and statutory care”.¹⁶⁵

The Commission is deeply concerned that since 2008, despite some attempts, there is still no reliable and robust national measure of exits into homelessness from human services or government mental health and drug and alcohol services and centres. This is an absolute priority for the Commission and should also be one for Australia.

As an indicator of delivering seamless services across different service agencies, ‘no exits into homelessness’ requires the mental health, housing and human service sectors to work together. We need to better see the extent of the non-government sectors’ contribution in providing supported housing and housing options for people who are homeless.

We have an incomplete national picture of the experiences that contributed to the homelessness of people who live with a mental health difficulty, and of homelessness among vulnerable families where a parent may have a mental illness. We need to monitor and get better data about how many people are affected by homelessness, and how it differs between rural and city locations to provide a meaningful response.

We need to shine a light on new approaches to primary care for people who are homeless and have a mental illness – provided where and how they need it.

We have an incomplete national picture of the extent to which people with a mental health illness become homeless when they leave a hospital, prison or juvenile justice centre. One small-scale study found that 13 per cent of people with a mental health difficulty reported they were homeless after they were discharged from hospital¹⁶⁶ and in another, 6.9 per cent reported they had “nowhere to live” after they were discharged.⁷⁵

Feeling safe, stable and secure

Providing support for the long-term

Studies of Australian families show us the extent to which they care for a relative who has a mental health difficulty – in one study, long-term carers were most likely to be caring for a parent (43 per cent) or their sibling (23 per cent).⁹¹ In another study, 61.4 per cent of support people lived with the person they were caring for.⁹⁵ Providing a home for their relative is a significant part of the support many people provide, and being able to continue to do this is a worry for them when they look to the future.

What it means for Pat and Keith, South Australia

We are a close family, my husband and I and four adult children. Our two sons both have treatment-resistant schizophrenia and live with severe psychosocial disability. Due to his inability to manage his financial affairs, we are the legal administrator of one of our son's affairs.

I gave up work to be their carer and we used our superannuation to purchase a home for both of them. We used to have a great support worker, but she left and other workers just didn't work out.

Recently it became impossible for them to continue living together in the same house. One moved out and was in hospital for five months.

He then lived with us for six months. Now he lives in private supported accommodation which is sub-standard and not a long-term solution.

We are extremely worried about who will look after our sons in the future when we are no longer able to help them and this worry impacts on our health. Our sons cannot advocate for themselves because they do not realise they have an illness.

We have very serious concerns about the future due to the lack of appropriate supported homes for our sons.

[Click to watch Pat and Keith's story](#)



2012 spotlight issue

Access to a quality home

Quality housing for a person living with a mental health difficulty can be described as being without housing stress – the absence of difficulties with “insecurity/tenure concerns, difficulties with repairs and landlords, frequent relocations, less controllable social interactions and stigma associated with poor housing.”¹⁵⁹

Living in quality housing is not a common experience for very many people with mental health difficulties. Surveys of people living with a mental health difficulty have found significant levels of concern about their current housing or the prospect of becoming homeless.

The National Survey of psychotic illness identified that 12.5 per cent of people living with a psychosis were unhappy with their home,⁷⁵ 25 per cent reported concerns about becoming homeless.⁷⁵

In another, most people felt that problems with neighbours, the high cost of rents and financial difficulties could put their housing at risk.¹⁶⁷

We know that people living with a mental health difficulty are competing in a rental market where overall rental affordability worsened over the years 2007-08 and 2009-10 for households living on the lowest incomes,¹⁶⁸ and half are being turned away from non-government mental health support services.

We see people being squeezed out.

They are being squeezed out of opportunities to live contributing lives from a secure and safe home and from access to the mental health support they need. These are complex issues, not single ‘mental health’, ‘housing’ or ‘social support’ issues. We know that people benefit from a co-ordinated approach to the provision of their health, housing and rehabilitation support services^{163, 161, 169} – connecting with them, connecting to where they live.

People living with a mental health difficulty are entitled to good access to housing, health care and government support. People and families who are most vulnerable to the risk of homelessness need priority assistance, and we need to continue to make available our collaborative housing programs to those most in need – the homeless, people in rural communities, Aboriginal and Torres Strait Islander peoples – to ensure that a quality home is available for all.

What the evidence shows is good practice

Programs where the person's individual needs and experience shape the service response^{161, 163, 170} by co-ordinating housing, mental health support and home assistance are examples of good practice in providing quality home environments for people living with a mental illness.

The success of these approaches centre upon having someone around to help when help is needed, to be watchful when things start to slide and being there giving support in a range of ways that are meaningful and relevant to the person's own experiences, circumstances and needs.

These co-ordinated approaches, such as the New South Wales Housing Accommodation Support Initiative (HASI), the Housing and Support Program (HASP) in Victoria and the Housing and Accommodation Support Partnership (HASP) and Returning Home in South Australia, aim to achieve successes at the personal level.

Under the HASI program people experienced improvement in their health, social networks and participation and in the quality of their housing.

the need for hospitalisation dropped for
84%
of residents

43%
were working and/or studying

94%
had established friendships

73%
were involved in social and community activities

more than
50%
enjoyed improved physical health

81%
were satisfied or very satisfied with family relationships¹⁷⁰

Co-ordinated and integrated support for people with severe and persistent mental illness and complex care needs, who need stable homes and support to keep well, avoid homelessness, and break the hospital cycle, is one priority under the 2012 National Partnership Agreement Supporting Mental Health

Reform. This will particularly focus on the needs of young and Indigenous Australians, people experiencing or at risk of homelessness, and those living in remote communities. This approach is applauded and the Commission will look to the successes under the new agreement.

Where the Commission is looking for continuous improvement

There are many areas that are not working well for people living with a mental health difficulty in terms of getting a home. One of these is getting access to the right mix of support services.

In one study nearly 60 per cent of non-government and not-for-profit agencies which work in the social support sector rated the demand for homeless/housing services and for mental health services as an area of high need that clients were missing out on. Just over half of these agencies (53 per cent) could not meet their current demand for mental health services.¹⁷¹

With such levels of people being turned away, people are not receiving the support they need and additional pressures can then be placed upon families and support people to fill the gaps.

This is a clear indication of what is not working well – access to good supported housing or to services to support you in your own home are essential to increase the

independence of people living with a mental health difficulty, support their recovery and reduce the burden that – especially ageing parents carry, where no other safe and secure options can be found to suit the person they care for. This means we need the right community workforce trained and available to provide the support to help someone keep their home and improve their overall social wellbeing.

The right type of support needs to be flexible.

The Commission looks for explicit recognition in government policy of the reality that for some people, living with a mental health difficulty also means having relapses in health. In turn, this may reduce their ability to sustain a home, a job or support networks.

Good housing enables people to feel safe, stable and secure. Having this safe, secure base supports people in their recovery. It's a basic need and one that the Commission will continue to give priority.

We look to more innovative approaches to supporting people during such times. One such approach seen by the Commission is a short-term peer-run residential respite service based in a supported home in the community. These services give people somewhere to go which is calm and supportive when they are not doing well, avoids people needing to be hospitalised and keeps them connected with their community, as they can use the home for a period to stabilise their health. Services such as these help people to maintain their recovery and their own home.

The Commission has heard through consultations that relapses can have knock-on

effects of changing a person's eligibility for support programs over the course of a year, or over the course of their illness, but housing need or vulnerabilities do not fade when your mental health improves.

This issue is critical. Forty four per cent of homeless people with a mental health difficulty reported in one study that financial hardship was the main barrier to stable housing.¹⁶⁶ This is not surprising given the high reliance upon income support – reported as high as 85 per cent of people living with psychosis⁷⁵ and where 30 per cent of all people receiving income support are reported as having a clinically diagnosable mental disorder.¹⁷²

While governments are improving the co-ordination of support services under specialist programs, it is essential for good work in one area not to be undermined by inflexible approaches in others. We are aware that “people who take up paid work often receive little reward due to the interaction of the tax and welfare systems which reduces their income as they earn more”.¹⁶⁰ Finally, we need to identify whether housing policies are inclusive and meet the needs of people with a mental health difficulty.



[Click to watch Jasmine's story](#)

Preventing suicide

Effective interventions

Jasmine, South Australia

Four years ago I decided to take my own life after I started to remember events from my childhood that I had suppressed. I attempted suicide and was discovered the following morning and taken to the hospital with damage to my right arm leaving it temporarily paralysed, but then sent home a week later to the exact same situation which led me to being suicidal in the first place, nothing was any different.

They ask you in the hospital if you have any support or assistance at home when you leave. If you say no, nothing really changes, so I don't even see why they ask in the first place.

I can go for days feeling distressed and not see anyone. The hardest part is asking for help, it's such a big deal. Once, I called a service for help and they told me they were going to send an ambulance. Before they sent the ambulance, they sent the police to make sure it was safe. I didn't know the police were coming. I understand why they sent the police first, but it was so humiliating and frightening when I opened the door to police torches in my face. I thought I was in trouble.

This can go on for years and helping someone who is feeling this way takes more than just a one-off intervention.

Introduction

Effective intervention

Suicide prevention is an important priority for the Commission and for us as a nation.

Suicide is an issue much broader than mental health alone, and is not restricted to any age group or community. It occurs when people believe there is no other option to the trauma, isolation, problems or hopelessness they are experiencing.¹⁷³

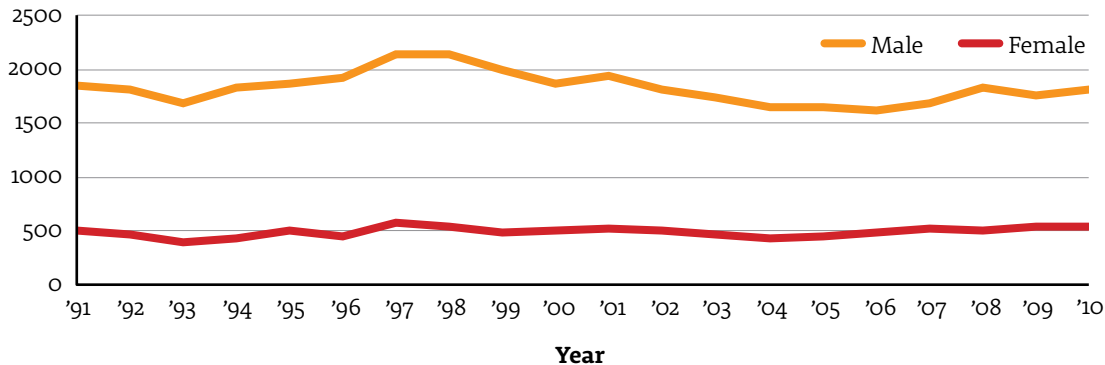
Leading a contributing life requires survival through the toughest times; strength and resilience, hope and optimism.

Australia has had a national approach to suicide prevention since 1995, when the first National Youth Suicide Prevention Strategy began. It has promoted programs

at the individual and community level, delivered in partnerships across the public and non-government sectors and in collaboration with community groups, employers, workplaces, schools, families and individuals. Research supports this targeted and co-ordinated approach as being the most effective.¹⁷⁴

While there has been a decline in suicide numbers since the peak in 1997, it has not been a sustained decline, especially for women, for whom numbers remained steady from 2001 to 2010.

Number of suicides, by sex, Australia, 1991-2010



Source: ABS Causes of Death, 2010

We cannot be complacent about:

Current levels of suicide and the even higher levels of reported suicide attempts

Suicides in populations where vulnerabilities exist such as lesbian, gay, bisexual, transgender and intersex people

Lives lost in our Aboriginal and Torres Strait Islander communities or in rural and remote communities

The suicide of those from culturally and linguistically diverse backgrounds, about whom we know so little when it comes to mental health¹⁷⁵

The rates of suicide deaths of young men

The suicide of people in hospitals, prisons or detention centres

These are all pressing issues.

In the first Report Card, this chapter focuses on effective interventions, timely responses to suicide and suicide attempts and the invisible issue of suicide clusters.

What we know

In Australia we know that...

...there are more than

2,000

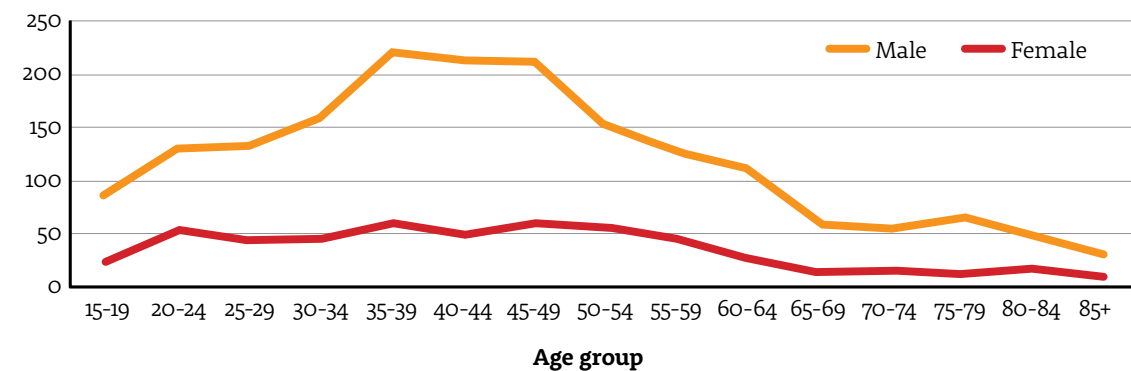
reported deaths from suicide each year²⁴

...there were an alarming

65,300

reported suicide attempts in 2007¹⁰⁷

Number of suicides in a single year, by sex and age group, Australia, 2010



Source: ABS Suicides Australia, 2010

But we also know that these reported suicide figures are considered an underestimate, as complex coronial investigations can take over a year to conclude and many suspected suicides may result in an open finding of cause of death.¹⁷⁶ As well, it is generally accepted that the number of suicides can sometimes be masked by road trauma and deaths which are declared accidental.

Suicide does not touch all communities equally.

Rates of suicide and self-injury are higher in some rural and remote locations around Australia. We know that suicides can occur in clusters when other people identify with the distress of the person who has taken their own life. But we don't yet have hard data to show why suicide risk is greater in some areas.

We know that specific groups are more vulnerable to suicide.

The suicide rates for Aboriginal and Torres Strait Islander peoples are about double that of non-Indigenous people.²⁴

More than 20 per cent of all deaths for young men and women in Australia are by suicide.

Men account for over three-quarters of all deaths by suicide, and their risk of suicide peaks between ages 35 to 49 and again in their late 70s and early 80s.

There are known risks that can increase the likelihood of suicide.

These are a complex mix of chronic unemployment, social isolation, depression, recent bereavement, financial stress, disconnection from families and friends, enduring chronic pain and alcohol and drug abuse.¹⁷⁷

Additionally, very high levels of psychological stress in a person's life are associated with higher levels of suicidal thoughts.¹⁰⁷

Part of this risk is the impact of living with a mental health difficulty.

Between 2001 and 2010 in Australia, over half (56 per cent) of the 4,932 suicide deaths that were recorded with a multiple cause of death included mental health and behavioural disorders as one of the causes.⁶² In a Western Australian study over the period 1980 to 1998, approximately half of people who had suicided had previously used a mental health service.¹⁷⁸

Importantly, we also know there are protective factors against suicide – being connected with family, friends, culture, school and communities; having someone who cares about you and having someone you care about; having positive attitudes and ways to tackle problems; having financial stability, good health and access to mental health support when you need it.¹⁷⁹

Preventing suicide depends on the presence of these and more protective factors, from an early age and throughout adulthood.

What we don't know

Where we need more evidence, and to shine a light

Building personal and community strengths to resist suicidal thoughts and prevent copycat suicides requires greater recognition of the relationship between the lack of access to primary care interventions by people and increased rates of suicide.

This is especially the case for Aboriginal and Torres Strait Islander communities where lack of access to suicide prevention support and support after a suicide has been identified, and where a response needs to be driven by those communities which acknowledges the “whole of community risk factors”.¹⁸⁰ Currently there is work underway to develop an Aboriginal and Torres Strait Islander suicide prevention strategy for the Australian Government by the Aboriginal and Torres Strait Islander Suicide Prevention Advisory Group. This important work will provide a way forward to address this complex issue.

Increasing access to support for depression has been shown to reduce suicides¹⁸¹ and this must be a primary focus of our efforts by ensuring care is available by better understanding how to remove barriers and reduce the stigma and discrimination that prevents people from seeking help¹⁹.

There is a need to shine a light on how more effective strategies can address these issues, and then to continuously monitor them as part of Australia's shared commitment to reducing suicide rates.

We also need to build on the evidence we have in managing the ‘hot spots’ or notorious locations which people

frequently use to suicide. Management of access to these high-risk areas and the provision of suicide support information at the locations have been developed at some sites as a partnership between local councils, suicide prevention organisations and government. One such example is the approach taken for the Gap Park in Sydney, involving the collaboration of the Australian Government, Lifeline, Woollahra Council, the Black Dog Institute, NSW Police and Wesley LifeForce to develop a range of initiatives for suicide prevention.

The evidence of success from these initiatives needs to be taken up and more broadly used across Australia.

We need to shine a light on areas where suicide prevention programs need more evidence to better understand where people in the community are most at risk and the effectiveness of interventions for them. This is a particular priority for the reported 65,000 people each year who attempt suicide.

We know, for example, that the ‘Specialist Services for Consumers at Risk of Suicide’ initiative under the Access to Allied Psychological Services (ATAPS) program received 2,312 referrals for support from people who were at risk of suicide (for the period 1 October 2008 to 30 June 2011¹⁸²). But we do not have timely information at the national level on the total

proportion of people who have contemplated or attempted suicide or self-harm who need these services. The program successfully expanded access to services, with higher levels of access in urban areas than rural areas (1,455 urban vs. 857 rural¹⁸²). We need to see how access to these services in rural areas can be improved.

We need evidence to tell us what is most effective in managing and reducing suicide clusters, but we have no timely data on their occurrences or patterns, and little research to inform a best response.¹⁸³

Routinely collected data and evaluations can support improvements in the delivery of effective interventions and increase responsiveness of services to people and local circumstances.

This would:

Accurately identify, at a local level, the localities or communities where there is greatest suicide risk or cluster patterns

Measure variation over time across the nation against suicide prevention factors and efforts

Link real-time risk factors such as bereavement, loss of employment, financial stress and mental health difficulties with services

Share or link information to enable the development of integrated service responses centred on the individual and their circumstances.

By improving our understanding and the breadth of evidence we can better support our communities.

Bereavement support for families

Evidence suggests that families affected by suicide grieve differently from others who are bereaved by a sudden death.¹⁸⁴ This may be because families experience high levels of stigma from the community, suicides are often kept secret and there are many unanswered questions.

Families bereaved by suicide are left with unresolved issues – questions as to what else could have been done, guilt and the difficult processes of police and coronial enquiries to endure. Their grief can affect their own health and family interactions, and heighten their own risk of suicide.¹⁸⁵

What it means for Cindy, New South Wales

I never saw myself as someone who would come to rely on a support group. I'd always been self-sufficient and life was good. That all changed when my daughter Victoria took her own life.

I should have seen the signs. Victoria had experienced self-harm, she'd been bullied and was diagnosed with Type 1 Diabetes. Victoria saw three psychologists but was never diagnosed with a mental illness; she was simply described as an "angry teenager" and was never prescribed medication. I was assured that teenagers who cut themselves rarely suicide. After Victoria took her life, a few of her friends revealed that she had talked about suicide, but no-one believed that a beautiful, intelligent girl with the world at her feet would actually take her own life. I shuddered at the memory of her screaming "I may as well kill myself". I wish so much that I could jump back into those moments.

I was lost and alone, despite being surrounded by family. No-one could relate to what I was going through. I knew that for the sake of my other daughter, I needed help. I wanted to be with Victoria so badly that I felt vulnerable to suicide myself.

I joined a support group for those bereaved by suicide. At last I was introduced to other people with similar experiences. Free from taboo and stigma, we could gain an understanding of the complexity of our situation, work through our tragedy and begin to heal. The Salvation Army Lifekeeper Memory quilt that I am pictured with represents a tiny fraction of the 2,000 Australians lost to suicide every year; a snapshot of real people, not just statistics, a number or a file in a coroner's office.

[Click to watch Cindy's story](#)



2012 spotlight issue

Timely, responsive and effective interventions

The follow-up on suicides and suicide attempts is of most concern to the Commission in 2012. We need timely information to strengthen the effectiveness of responses to reduce the number of people losing their life through suicide, and to better connect support services with people after a suicide attempt or when bereaved by suicide.

Better information and information systems can only improve responses where they work within broader suicide prevention strategies.

To tackle our highest suicide rates we need to tackle the obstacles in communities. This means being honest – not only about acknowledging the presence of suicide risks, whether they be high unemployment, drug and alcohol problems, poor mental health, social isolation and poor access to services, but having proven (evidence based) strategies in place for people to survive their own difficult circumstances. We need to overcome the silence in the community around suicide and to listen out for those people who need help.

Effective responses also need to happen at the right time. In Australia there is the lack of timely national information on suicide attempts and suicide events. Our most recent data is between two and five years old.²⁰ The national

suicide data reported by the ABS is useful, but it doesn't help us to respond in real time. More up-to-date information can assist to ensure services are directed to where they are most urgently needed, especially to break clusters of suicides in Aboriginal and Torres Strait Islander communities, among young people and in rural areas, and focus on the high risk among rural men. We know it can be done – prompt co-ordinated responses are already a feature of our emergency responses for communities traumatised by bushfire or floods.

With better information systems we can be alert to heightened local risks and connect better with people at risk. Opportunities for this could be led by the new Medicare Locals, with their responsibilities to plan for their

local populations, co-ordinate across health and other service sectors and implement suicide prevention programs. This could form the basis for a national system to ensure a shared approach to locally held information and provide the mechanisms to support this.

The Commission looks to the development of local, integrated and more timely suicide and at-risk reporting to provide a more informed basis for improving effective responses. Such an early-response reporting system would be community based and culturally appropriate, and support suicide prevention programs that promote community safety and reach the most vulnerable using up-to-date information from the 'first responders', such as Police officers, ambulance officers and mental health workers.

We know from our discussions that efforts are underway around Australia to address the need for timely information, such as the work of the Victorian Coroner to better link local real-time information with police and research organisations to inform more effective interventions and community responses to suicide.

The Commission welcomes the efforts of individual jurisdictions to address the problems of seeing more clearly and earlier where suicides are occurring.

These include: the recording of mental health-related call-outs in the ACT Police system and the integration of mental health counsellors in the police incident rooms; the mental health education, training and mentoring

initiatives in the NSW Police force; the trialling by Victorian Ambulance Services of a suicide or suspected suicide incident reporting procedure, which links with the reporting requirements of the Coroner and the trial by half the police forces in Australia of a mental health incident report.

The Commission cannot emphasise strongly enough that while Australia has made advances in suicide prevention, we cannot advance unless we tackle head-on the need for more accurate and local information, to support more effective and responsive services.

As a nation we cannot accept a toll where at least 45 people take their lives each week. Action needs commitment and a humane approach.

What the evidence shows is good practice

Research indicates that reducing suicide rates requires action at the whole population level; interventions in high-risk groups and settings and appropriate and effective responses to individuals identified at imminent risk of suicide.

Evidence supports strong components across a set of key areas – improved awareness and skills for front line personnel, whether they be GPs, police and ambulance services, families, school or work communities; improved mental health care and restricting access to means by which individuals may end their lives. Australia has adopted this approach.¹⁸⁶

In Australia these interventions have included ‘big picture’ approaches such as lessening the access to means such as poisoning from carbon monoxide car exhaust, access to poisons, the 1996 National Gun Buyback Scheme and removing barbiturates from the Pharmaceutical Benefits Scheme; increasing mental health understanding within the community and sensible approaches in the media, and

with the MindFrame and Living is for Everyone good practice initiatives.

Emerging evidence supports new e-health services as positive ways to increase access and provide timely interventions^{126, 127, 187} and suggests that more intensive approaches are needed to follow up after a suicide attempt, beyond standard discharge procedures. This means supporting people for up to 12 months after their suicide attempt.¹⁸⁸

The Commission acknowledges that Australia has a well-developed, evidence-based suicide prevention program, but there remains much to be done to reduce the tragedy of suicide among the most vulnerable people in our rural and remote communities and Aboriginal and Torres Strait Islander peoples.

Aboriginal and Torres Strait Islander peoples have told us that improving social and emotional wellbeing is essential for reducing suicide in their communities. This involves respect for their culture, skin relationship and gender, with a focus on strong relationships and empowerment of Aboriginal and Torres Strait Islander people as leaders and problem-solvers. We have heard that successful suicide prevention programs may include traditional healing, supported social activities such as music programs for children or mainstream counselling services delivered in a culturally appropriate manner.

Where the Commission is looking for continuous improvement

We must continue and strengthen our efforts to reduce suicides. Improvement needs to focus on expanding access to effective strategies and increasing awareness of early warning signs across the community.

In 2007, 41 per cent of those aged 16 to 85 who had suicidal thoughts and made attempts in the past 12 months, did not use mental health services. Of the people who did seek health services, 78 per cent saw a GP, 36 per cent saw a psychiatrist and 33 per cent saw a psychologist, among other health professionals.¹⁰⁷

We need continuous improvement in connecting people who are contemplating suicide or who have attempted suicide with services, and actively supporting them throughout the first year after a suicide attempt. Plus we need an improved understanding of suicide clusters by local agencies and communities and greater sharing of information to identify them early and then to direct fast response services.

As a matter of high priority, we must focus our interventions on people at imminent risk of suicide. This involves governments and non-government organisations supporting effective interventions which are shown to be:

- effective in finding and supporting the estimated 41 per cent of people who were at risk of taking their own lives in the past year but had no contact with mental health services in that time¹⁰⁷
- responsive to the early warning signs of suicide among family and friends, school and work colleagues, by strengthening peoples' awareness and ability to take action

- responsive to the isolation of rural and remote communities
- responsive to Aboriginal and Torres Strait Islander peoples' cultural and family strengths¹⁸⁹
- responsive to and continuing support for people at imminent risk – those who have attempted suicide or are known to have suicidal thoughts
- fast in responding to emerging suicide clusters in rural and Aboriginal and Torres Strait Islander communities, regional and urban communities, schools and other organisational settings.

Improvement can also start by:

Increasing access to GP and support services – especially for people living in rural and remote areas and in Aboriginal and Torres Strait Islander communities where their current levels of access to GP services is the lowest in Australia.¹¹

Pro-active and ongoing follow-up suicide prevention support services for people who have visited their GP or emergency department with suicidal thoughts, self-harm or after a suicide attempt.

In addition to reaching those who do not seek out or interact with services, we must also **protect those for whom there is a duty of care**. While the suicide of someone who is in hospital or another facility is measured, this information is not consistently reported publicly and we call for improvement with consistent national reporting of suicides in care.

We need to **better understand the role of social media in suicide**, suicide attempts and self-harm, and implement strategies to reach young people online and also to keep them safe.

Australia has made a continuing commitment to reducing the suicide rate, and the Commission will be monitoring and reporting on efforts to achieve this.

Where our work is taking us

The Commission has a busy work program ahead. Some of these activities have arisen from our research and discussions in developing the 2012 Report Card. Some have been included in the recommendations and findings we've made.

Our forward work program includes:

- **Undertaking** a regular qualitative, whole-of-life survey that will capture the experiences of people with mental health difficulties and their families and supporters. This will ensure that real experiences drive our future Reports and national reform directions and that people's voices and views are heard and respected
- **Looking** to governments to develop a set of national mental health performance indicators and targets that will tell an honest picture of how Australia is performing. If the Ten Year Roadmap for National Mental Health Reform doesn't deliver, we will work with others to develop these
- **Examining** how Australians really think and feel about mental health, mental illness and suicide, including stigma and discrimination. But also, what can be done to help them get the information they need and feel more comfortable talking about mental health and helping others
- With business leaders and other partners, **calling** for evidence on and working to advance good workplace practices. We will also take a broader look at the full impact of mental illness in Australia, on our work and the economy
- **Calling** for evidence on the best international practice in reducing and eliminating the use of seclusion and restraint, in partnership with the Mental Health Commission of Canada and key Australian bodies
- **Releasing** a snapshot on how to engage young people in our work to ensure that they have a voice in our future Reports and the drive for improvement
- **Working** with the Australian Commission on Safety and Quality in Health Care to look at what it takes to get the proper uptake of national mental health service standards and make them mandatory
- **Progressing** mental health workforce issues commencing with a collaboration with Health Workforce Australia on the peer workforce
- **Providing** policy input to the National Disability Insurance Scheme and Activity Based Funding
- **Supporting** the establishment of an International Knowledge Exchange to help in identifying and promoting evidence-based practice

Our review of the current data also showed many blind spots where we believe that future work by the Commission can add real value. In the longer term, for example, these may include a consideration of the research agenda for mental health and the translation of evidence to practice.

We will have to continue to make hard choices about what we focus the Commission's resources upon. And we will continue to collaborate with other community and government agencies, including other mental health commissions, to make use of every available bit of effort to drive improvement.

See you in 12 months' time

The development of Australia's first National Report Card on Mental Health and Suicide Prevention shows that people living with mental health difficulties, their families and supporters, have the best chance of a contributing life with a stable home, something meaningful to do, strong connections, access to effective care and treatment and good physical health.

The National Mental Health Commission has laid out what we believe needs to happen to start to achieve this more comprehensively. We have listened to people's experiences and we will continue to do so. This is the real report card for governments and communities.

We will be back with our second Report Card in 12 months' time, reporting on what's happened, whether people's experiences have changed for the better and where things have improved.

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Glossary

Aboriginal and Torres Strait Islander

A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander.

Activity Based Funding

Activity Based Funding (ABF) is a system for funding public hospital services where the health service providers (the hospitals) are funded based on the activity they undertake; with that activity being treating patients.

Anxiety

Anxiety is characterised by physiological arousal (including increased blood pressure, heart rate, over breathing), preparing for a “flight or fight” response. It becomes a disorder when it is out of keeping with the “threat” and causes distress to the individual and impacts negatively on day-to-day functioning.

Asthma

A common, chronic inflammatory disease of the air passages that presents as episodes of wheezing, breathlessness and chest tightness due to widespread narrowing of the airways and obstruction of airflow. The symptoms may reverse without treatment, but often treatment is required. Different medications can prevent the episodes or relieve them.

Better Access Program

The Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Schedule initiative (Better Access) commenced in November 2006.

Under Better Access, psychiatrists, GPs and psychologists (and appropriately trained social workers and occupational therapists) provide mental health services on a fee-for-service basis subsidised through Medicare. These services offer access to short term psychological therapies through private providers.

Bipolar Disorder

Characterised by repeated episodes in which the person’s mood and activity levels are significantly disturbed – on some occasions lowered (depression) and on some occasions elevated (mania or hypomania).

Borderline Personality Disorder

A personality disorder characterised by unstable relationships, poor or negative sense of self, inconsistent moods, and significant impulsivity.

Burden of Disease

Term referring to the quantified impact of a disease or injury on an individual or population, using the disability-adjusted life year (DALY) measure.

Cardiovascular Disease

Any disease of the circulatory system, namely the heart (cardio) or blood vessels (vascular). Includes heart attack, angina, stroke and peripheral vascular disease. Also known as circulatory disease.

Carer or support person

A carer is a person whose life is affected by virtue of a family or close relationship and caring role with a mental health consumer.

Chronic disease

Term applied to a diverse group of diseases, such as heart disease, cancer and arthritis, which tend to be long-lasting and persistent in their symptoms or development. Although these features also apply to some communicable diseases (infections), the term is usually confined to non-communicable diseases.

Support for Day to Day Living in the Community (D2DL)

An Australian Government funded Structured Activity Program aimed at improving the quality of life for individuals with severe and persistent mental illness by offering structured and socially based activities. The initiative recognises that meaningful activity and social connectedness are important factors that can contribute to people’s recovery.

Depression

A mood disorder with prolonged feelings of being sad, hopeless, low and inadequate, with a loss of interest or pleasure in activities and often with suicidal thoughts or self-blame.

Diabetes (diabetes mellitus)

A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is due to a relative or absolute deficiency in insulin, a hormone that is produced by the pancreas and helps glucose enter the body’s cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood, and it can have serious short- and long-term effects.

Disability Employment Services

Refers to two Australian Government funded programs for job seekers with disabilities to have immediate access to tailored services that are flexible and responsive to both their needs and those of employers.

This includes the Disability Management Service for job seekers with disability, injury or health condition who require the assistance of a disability employment service but are not expected to need long-term support in the workplace. It also includes Employment Support Service for job seekers with permanent disability and with an assessed need for more long-term, regular support in the workplace.

Involuntary treatment

Refers to a person being treated for their illness without their consent, in two ways, either in hospital or in the community. This may occur when mental health problems or disorders result in symptoms and behaviours that lead to a person’s rights being taken away or restricted for a period of time.

Lateral violence

Lateral violence, also known as horizontal violence or intra-racial conflict, is a product of a complex mix of historical, cultural and social dynamics that results in a spectrum of behaviours that include gossiping, jealousy, bullying, shaming, social exclusion, family feuding, organisational conflict and physical violence.

League tables

A colloquial term often used in Australian current affairs to refer to performance comparisons made between states and territories on various metrics of interest.

Malignant grief

Malignant grief refers to irresolvable, collective and cumulative grief that causes individuals and communities to cease functioning and causes death and suicide clusters in communities.

Medicare Locals Medicare Locals are primary health care organisations established to co-ordinate primary health care delivery and manage local health care needs and service gaps.

Medications

Mental health-related medications typically refers to five selected medications groups as classified under the Anatomical Therapeutic Chemical Classification System (World Health Organization), namely anti-psychotics, anxiolytics, hypnotics and sedatives, anti-depressants, and psycho-stimulants and nootropics.

Mental illness

Disturbances of mood or thought that can affect behaviour and distress the person or those around them, so the person has trouble functioning normally. They include anxiety disorders, depression and schizophrenia.

Metabolic syndrome

Metabolic syndrome is defined using the International Diabetes Federation metabolic syndrome consensus definition of at risk abdominal obesity based on waist circumference and at least two other at risk measures. The definitions of “at risk” for the individual components of metabolic syndrome are: waist circumference greater than or equal to 94 cm for males, greater than or equal to 80 cm for females; fasting high density lipoproteins less than 1.03mmol/L for males, less than 1.29mmol/L for females; fasting triglycerides greater than or equal to 1.7mmol/L; fasting plasma glucose greater than or equal to 5.6mmol/L; systolic blood pressure greater than or equal to 130 mmHg; and diastolic blood pressure greater than or equal to 85 mmHg.

Model of Care

A model of care defines the way health services are delivered. It outlines the group or series of services which are required for the optimum treatment of a person or population group for a specific injury or illness, those required across the stages of treatment and across the stages of care (from acute through to non acute and rehabilitation) whether that be provided in the community or hospital/facility or by different services.

Obsessive compulsive disorder

A form of anxiety disorder where repeated and unwanted thoughts and impulses disturb and dominate a person. Often involves rituals, such as excessive hand washing, checking and counting, which in turn cause anxiety if they are prevented or out of control.

The Personal Helpers and Mentors (PHaMs)

An Australian Government funded program which aims to provide increased opportunities for recovery for people whose lives are severely affected by mental illness. The program takes a strengths-based, recovery approach, and assists people aged 16 years and over whose ability to manage their daily activities and to live independently in the community is impacted because of a severe mental illness.

Post Natal Depression

Many women experience mood swings after the birth of a baby. However, postnatal depression (PND) describes the more severe or prolonged symptoms of depression (clinical depression) that last more than a week or two and interfere with the ability to function on a daily basis with normal routines including caring for a baby.

Psoriasis

An inflammatory skin condition characterised by red scaly patches on skin, itchiness and flaking of the skin.

Psychiatric disability

Psychiatric disability includes clinically recognisable symptoms and behaviour patterns frequently associated with distress and which may impair functioning in normal social activity. Psychiatric disability may be associated with schizophrenias, affective disorders, anxiety disorders, addictive behaviours, personality disorders, stress, psychosis, depression and adjustment disorders.

Psychosis

A more severe degree of mental disturbance, often involving fixed, false beliefs known as delusions.

Recovery

A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.

Restraint

When somebody’s movements are restricted by the use of straps or belts (physical restraint) or sedation (chemical restraint).

Schizophrenia

A group of serious mental disorders where imagined and disordered thoughts are key features, often with problems of behaviour, mood and motivation, and a retreat from social life.

Seclusion

When someone is confined in a specific room that they cannot leave.

Sentinel events

A relatively infrequent, clear-cut event that occurs independently of a patient’s condition; it commonly reflects hospital system and process deficiencies, and results in unnecessary outcomes for the patient.

Sinusitis

An infection or inflammation of the sinuses.

Sistergirl

A colloquial term sometimes used by Aboriginal and Torres Strait Islander peoples. This term can have multiple meanings; including a term for Indigenous transgendered women, Indigenous gay men or a term of address between Indigenous women.

Specialist mental health service

Specialised mental health services are those with a primary function to provide treatment, rehabilitation or community health support targeted towards people with a mental disorder or psychiatric disability.

Stigma

Stigma is a mark of disgrace that sets a person apart when a person is labelled by their mental illness they are seen as part of a stereotyped group. Negative attitudes create prejudice which leads to negative actions and discrimination.

Stolen Generations

The term ‘stolen generations’ refers to Aboriginal and Torres Strait Islander Australians who were forcibly removed, as children, from their families and communities by government, welfare or church authorities and placed into institutional care or with non-Indigenous foster families.

Substance use disorder

A disorder of harmful use and/or dependence on illicit or licit drugs, including alcohol, tobacco and prescription drugs.

Sudden Infant Death Syndrome

Also known as cot death. It refers to the sudden and unexpected death of an infant where the cause is unknown.

Suicide

Suicide is the deliberate taking of one’s life.

Suicidal ideation

Persistent, intrusive thoughts of wishing to be dead, or deliberate planning or actual attempts to take one’s own life.

Abbreviations

ABF	Activity Based Funding	NHMC	National Mental Health Commission
ABS	Australian Bureau of Statistics	NHS	National Health Survey
ACT	Australian Capital Territory	NMHP	National Mental Health Plan
AIHW	Australian Institute of Health and Welfare	NSMHWB	National Survey of Mental Health and Wellbeing
ATAPS	Access To Allied Psychological Services	NSW	New South Wales
CALD	Culturally and Linguistically Diverse	NT	Northern Territory
D2DL	Day to day living program	OECD	Organisation for Economic Cooperation and Development
DES	Disability Employment Services	PACT	Police and Community Triage
DSP	Disability Support Pension	PBS	Pharmaceuticals Benefits Scheme
GDP	Gross Domestic Product	PHaMs	Personal Helpers and Mentors
GP	General Practitioners	PND	Post Natal Depression
HASI	Housing and Support Initiative	Qld	Queensland
HASP	Housing and Support Partnership	SA	South Australia
IPS	Individual Placement and Support	SIDS	Sudden Infant Death Syndrome
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex	Tas	Tasmania
MBS	Medicare Benefits Scheme	VET	Vocational Education and Training
NDIS	National Disability Insurance Scheme	Vic	Victoria
NGO	Non-Government Organisation	WA	Western Australia

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