

**Submission to the Royal Commission into  
Victoria's Mental Health System  
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SANE Australia acknowledges the Aboriginal and Torres Strait Islander peoples as the traditional custodians of the land on which it operates, and pays respect to Elders past, present and emerging. SANE acknowledges the impact of transgenerational trauma on the social and emotional wellbeing of our First Nation’s people and is committed to advocating for improved mental health services for Aboriginal and Torres Strait Islander Communities.

## **Executive summary**

Founded in 1986 in Melbourne as the Schizophrenia Australia Foundation, SANE Australia is a national mental health charity working to make a real difference in the lives of people affected by complex mental health issues through support, research and advocacy. SANE's vision is for an Australia where people affected by complex mental health issues live long and fulfilling lives, free from stigma and discrimination. The SANE Australia group includes the Anne Deveson Research Centre and The Dax Centre.

SANE welcomes the opportunity to provide a submission to the Royal Commission and acknowledges the shared responsibility of governments, peak bodies and service providers to implement the findings of this important inquiry.

The definition of a 'system' is "a set of things working together as parts of a mechanism or an interconnecting network; a complex whole". Despite the hard and dedicated work of many skilled individuals, the current reality of mental healthcare in Victoria is a fragmented, disparate set of entities and processes. While there have been efforts to improve the model of care available to young people, the increased investment and system enhancements seen in the youth system has not been extended to adults aged over 25.

Deficiencies in other health and social care services impact negatively on service provision and solutions cannot continue to be piecemeal and siloed. A whole-of-government response, including collaboration between state and federal governments, is required to address the current crisis.

There have been numerous federal Royal Commissions, Senate Inquiries, recent Victorian Auditor General Reports, and a significant number of Coronial inquests that have all made recommendations to improve Victoria's mental health system. Current processes underway by the federal Productivity Commission, along with Royal Commissions into institutional abuse, family violence, aged care and disability will further impact the current landscape, in addition to the evolving implementation of the National Disability Insurance Scheme.

This Royal Commission provides a watershed moment for Victoria to deliver much-needed mental health system reform. Implementation of the recommendations flowing from this Royal Commission can help ensure that all Victorians affected by complex mental health issues are treated with dignity, respect and have the opportunity to lead long and contributing lives. It also has the potential to reposition Victoria as the national leader in mental healthcare and catalyse change across jurisdictions, as has occurred with family violence reform. Furthermore, if the Victorian Government is able to work constructively with the Commonwealth Government in a true spirit of bipartisanship, there is the very real possibility that Victorians could have access to the best mental health services in the world.

SANE would like to acknowledge the important contribution that those with lived experience of complex mental health issues provide to our work and the way in which they have informed this submission. Behind every statistic and story is a person who, in many cases, has been let down by the systems that exist to support them. Central to the work of this Royal Commission is the tacit understanding that these systemic failures must not continue.

SANE has identified three key themes which have guided the formation of this submission:

## Appropriate care and support must be available when people need it

*“Accessing support when you need it is the best possible signal that recovery is possible”.*

Current blockages to accessing therapeutic care significantly impact on the recovery journey of people affected by complex mental health issues and their support network. For mental health care to appropriately support people and do no harm, it must be readily accessible and delivered in a way that is appropriate for the people accessing it. From acute tertiary-based services, to support following a suicide attempt, to community-based psychosocial programs – all Victorians deserve access to quality mental health care.

## Services need to be integrated to achieve the best outcomes for people affected by complex mental health issues

*“Choice about my mental health care would give me back some of the control my illness tries to take away”.*

People affected by complex mental health issues have needs that extend beyond mental health services. They also experience greater levels of disadvantage than the general population, including poor physical health, poverty, unemployment, loneliness and isolation. Our systems should be designed to meet people’s needs, wrapping around them during times of crisis, rather than requiring them to access support via multiple entry points, retelling their story numerous times.

## Communities must be free from stigma and discrimination to prevent mental illness and to assist people in their recovery

*“I deserve to feel like I am part of my community”.*

Communities that are inclusive and free from stigma and discrimination achieve greater outcomes for people affected by complex mental health issues. While significant progress has been made to reduce stigma towards higher prevalence disorders such as anxiety and depression, other conditions remain poorly understood. There is much more work to be done to educate the general public about how best to support their family, friends, neighbours and colleagues living with complex mental health issues creating communities where people feel valued and respected.

Action is also required to reduce public and structural stigma that results in discrimination towards people affected by complex mental health issues.

## Our ten key recommendations

### Appropriate care and support must be available when people need it

That the Victorian Government:

- Urgently increase funding for clinical mental health services commensurate with population growth, distribution and demand (Recommendation 1).
- Provide adult community mental health hubs to meet the clinical and psychosocial needs of adults living with complex mental health issues (Recommendation 2)
- Resource the implementation of a comprehensive, integrated online and telephone support service for people affected by complex mental health issues, their families and friends (Recommendation 3).
- Increase statewide availability of evidence-based therapies such as Transcranial Magnetic Stimulation (TMS) throughout the public health system, especially in rural and regional communities (Recommendation 20).
- Increase access to carer support within mental health services, including through the expansion of the carer peer workforce (Recommendation 56).

### Services need to be integrated to achieve the best outcomes for people affected by complex mental health issues

That the Victorian Government:

- Ensure mental health and related social services manage the referral and handover of people presenting with mental health related issues, allowing entry at any point in the system (Recommendation 7).
- Establish a dedicated, well-resourced and holistic case coordination function to assist people experiencing complex mental health issues who are ineligible for the NDIS to navigate the mental health system and other services required (Recommendation 8).

### Communities must be free from stigma and discrimination to prevent mental illness and to assist people in their recovery

That the Victorian Government:

- Provide significant funding for stigma reduction activities including increased core funding for operation for the Dax Centre and its stigma reduction initiatives that engage the Victorian public (Recommendation 66).
- Contribute funding for the StigmaWatch program to support safe and responsible media reporting of complex mental health issues in Victoria (Recommendation 67).
- Increase capacity of programs to support people affected by complex mental health issues to participate in the community in the ways that are most meaningful to them (Recommendation 18).

## Background

### SANE Australia

SANE Australia is a national mental health charity working to make a real difference in the lives of people affected by complex mental health issues through support, research and advocacy. SANE's vision is for an Australia where people affected by complex mental health issues live long and fulfilling lives, free from stigma and discrimination. The Dax Centre and the Anne Deveson Research Centre also form part of the SANE Australia group.

Founded in 1986 in Melbourne as the Schizophrenia Australia Foundation, SANE Australia's focus is on supporting the approximately four million Australians affected by complex mental health issues. This includes approximately 800,000 Australians who live with severe and persistent illnesses such as schizophrenia, bipolar disorder, personality disorder, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and severe depression and anxiety. However, this figure is likely to be an underestimation due to the reliance on diagnostic criteria, outdated data, and population growth. For every person affected by mental health issues, there is a network of additional people impacted, including carers, family, friends and colleagues who often play a critical role in supporting their recovery.

Headquartered here in Victoria, SANE's work includes promoting mental health literacy, destigmatising poorly understood mental health issues, online peer support and information, specialist helpline support, research and advocacy.

The SANE Help Centre was established in 1998 and was Australia's first mental illness specific telephone helpline. Through the Help Centre, we provide confidential, professional support to those affected by complex mental health issues. While it is difficult to ascertain exactly how many Help Centre callers are based in Victoria (due to the reliance on self-reporting, to protect callers' privacy and anonymity), of the callers that chose to disclose their location in the last 18 months (approximately 50% of callers), a large proportion (33%) were residents of Victoria.

The SANE team moderate two online peer support forums; one to support those with lived experience of complex mental health issues and one to support those caring for them. Of the 11,000+ users of these forums in the last four months, approx. 26.7% were based in Victoria<sup>1</sup>. SANE supports these people by conducting research (through the Anne Deveson Research Centre, which I explain below), through advocacy activities and the SANE Help Centre's delivery of online and telephone support services (explained further below).

In the thirty-three years since its establishment and despite significant improvements in community attitudes towards illnesses such as anxiety and depression, little has changed to reduce the stigma and discrimination facing people affected by complex mental health issues. There is still much work to be done.

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<sup>1</sup> Using the population statistics published by the ABS (Australian Demographic Statistics, Cat. no. 3101.0), and the statistics on the number of Victorians experiencing severe mental illness presented to the Victorian Parliament's Public Accounts and Estimates Committee in relation to the Victorian Budget 2019-20 (ie. 2-3% of the Victorian population), as outlined in this document: [https://www.parliament.vic.gov.au/images/stories/committees/paec/2019-20\\_Budget\\_Estimates/Presentations/2019-20\\_BE\\_presentation\\_Mental\\_Health.pdf](https://www.parliament.vic.gov.au/images/stories/committees/paec/2019-20_Budget_Estimates/Presentations/2019-20_BE_presentation_Mental_Health.pdf)

Further increasing SANE's impact and presence in Victoria was its merger with The Dax Centre, based in the Kenneth Myer Building at the University of Melbourne, in April 2018. The Dax Centre houses the Cunningham Dax Collection, a collection of more than 15,000 artworks created by people who have experienced mental illness or psychological trauma, many of whom were resident in Victoria's psychiatric institutions. The Dax Centre is a world leader in the use of art to raise awareness and reduce stigma towards those affected by mental illness. Through educational programs targeting high school and University students, as well as public exhibitions, it engages, informs and encourages community connections and conversations about mental health. These programs could be extended to include workplaces to reach more Victorians.

SANE's newest initiative, the Anne Deveson Research Centre (ADRC) has increased SANE's ability to conduct extensive research across Australia. The ADRC will partner with research institutes, other mental health organisations and people with lived experience of complex mental health issues, to undertake practical research that will drive better social outcomes for Australians affected by complex mental health issues.

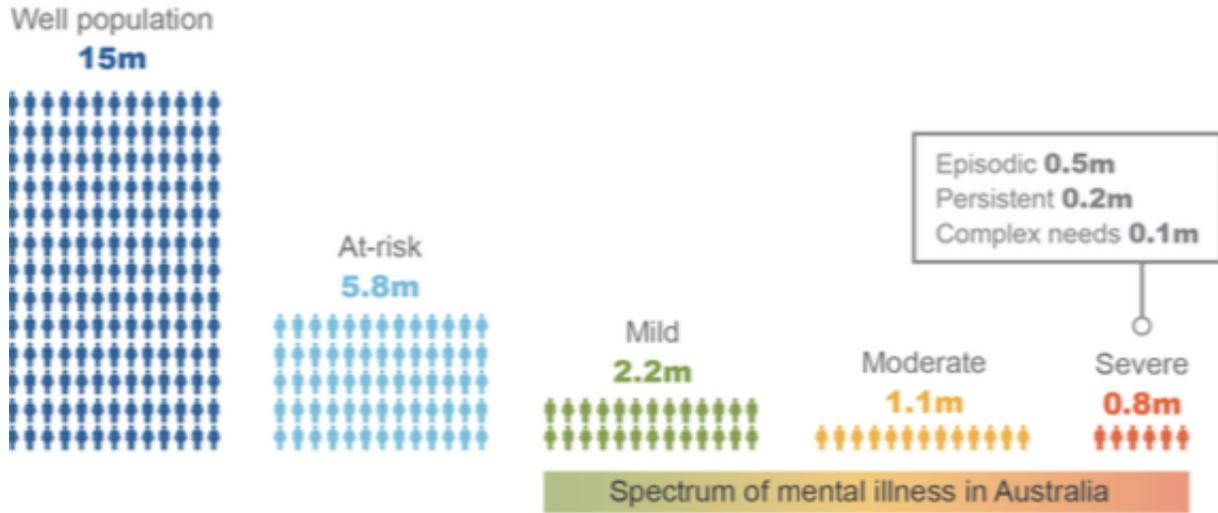
The flagship project of the Anne Deveson Research Centre is the development of the National Stigma Report Card, a multi-year partnership with the Paul Ramsay Foundation. This project will examine for the first time how Australians living with complex mental health issues experience stigma and discrimination across a range of areas, including housing, education, employment, health services, in interpersonal relationships and in media representations, to help drive positive change. A National Stigma Report Card will be created from a comprehensive survey of 7,000 Australians living with complex mental illness about their experiences of stigma and discrimination. This is the largest survey of its kind conducted in Australia to date. Other priorities include; ensuring that people have the right social supports as they recover from a complex mental health issue, along with issues related to housing, justice, employment and education.

## Context

Mental illness is a major contributor to the burden of disease affecting approximately four million Australians. This represents a significant impact on the health, wellbeing and productivity of our communities. When one individual is affected by mental illness, there is also an impact on their family, friends, co-workers and neighbours who are often required to support these individuals and pick-up the shortfall of our healthcare system.

Of the four million Australians affected by mental illness, approximately 800,000 are affected by severe and complex mental health issues. Based on population estimates, this means there are approximately 200,000 Victorians who may benefit from comprehensive wrap-around mental health care from health and social services.

Figure 1: Distribution of mental illness across the Australian population



Source: Productivity Commission Issues Paper, January 2019.

Many people living with complex mental health issues require an integrated service response across the care continuum (Mercer, 2012; Rizzo, 2016). There is currently no mechanism to provide a holistic and person-centred response, which has a significant impact on outcomes. People accessing the system tell us case managers have been overwhelmed, resulting in care that is predominately risk-management focused, instead of therapeutic. Appropriately funding a safe, therapeutic, holistic and integrated mental health system would be an investment in our community.

### Complex mental health issues

Complex mental health issues are often classified as severe and persistent requiring multiagency support. Illnesses considered complex include schizophrenia, bipolar disorder, personality disorders, eating disorders, post-traumatic stress disorder, and severe and enduring mood and anxiety disorders. The needs of people with complex mental health issues are not homogenous and a broad suite of system responses are required. This includes recognising, assessing and responding to those with a lived experience of trauma.

SANE Australia believes the term “illness” places a strong focus on the medical and biological aspects of complex mental health issues, however, not all aspects of complex mental health issues are medical. The people we serve may or may not want to refer to themselves as ill, even though they may be affected by the issues that come with the illness. The use of the term “health issues” expresses a holistic intent that ‘illness’ does not, and in turn plays a part in how people living with mental health issues are encouraged to view their capacity for inclusion and participation in their communities more broadly.

## Accessing the system

### Access barriers

We know that many Victorians affected by complex mental health issues have difficulty accessing the support they need, when they need it. Chronic underinvestment and the resulting access pressures, often delay therapeutic intervention and can exacerbate someone's condition.

The threshold to access Victoria's specialist mental health system has increased as a result of finite resources. Expenditure on mental health services in Victoria has failed to keep pace with demand, with spending currently at \$202.21 per capita (ABS, 2019). This is the lowest rate in the country.

In 2017-18, Victorian Department of Health and Human Services data indicates that there were 57,501 adult mental health clients registered with public mental health services in Victoria (DHHS, 2018). Hospitalisations have increased by 6.7 per cent, coinciding with a reduction in average length of stay. This supports anecdotal evidence from people affected by complex mental health issues, families and support services that people experiencing acute psychiatric crisis are often prematurely discharged.

Although compulsory admissions have decreased slightly, the length of compulsory treatment has risen from 64.6 days in 2016-17 to 76.8 days, highlighting the mounting distress and complexity people are presenting with. Many people report that inpatient treatment offers crisis response and monitoring, but is often not a therapeutic experience.

Similar access pressures are observed in the community mental health system. The implementation of the National Disability Insurance Scheme has further changed the service landscape, resulting in a significant number of individuals experiencing disruption to service provision, or worse, losing access to services. Access difficulties in the community mental health and psychosocial recovery setting can drive people affected by complex mental health issues towards acute crisis, thereby adding pressure to the tertiary mental health system.

1. Urgently increase funding of clinical mental health services commensurate with population growth, distribution and demand.

For people affected by complex mental health issues, access blockages can mean that the acuity of their presentation increases before they receive adequate support. Anecdotally, many people affected by complex mental health issues report experiencing exacerbations in their condition that are too complex for the primary care and supporting systems, but they find themselves unable to gain access to specialist clinical mental health services.

There is a significant gap in service provision between primary healthcare and tertiary specialist mental health services. Complex mental health issues are often categorised as low prevalence, but represent a high proportion of presentations in the public mental health system. The inadequacy of service tiers can often impact the acuity and severity of people's experiences, with a lack of early and appropriate intervention when they become unwell, as well as contributing to the bottle-necking of inpatient services. Prevention and Recovery

Centres (PARCs) are a good example of a sub-acute clinical setting, however these are not widespread or readily accessible across the state.

2. Provide adult community mental health hubs to meet the clinical and psychosocial needs of adults living with complex mental health issues.
3. Resource the implementation of a comprehensive, integrated online and telephone support and referral service for people affected by complex mental health issues, their families and friends.

## Inappropriate access

The rate of mental health presentations per 10,000 people has increased significantly over the past decade (66.5 to 90.1) (ABS, 2019). Due to the access pressures highlighted above, some people affected by complex mental health issues will enter the mental health system via first responder attendance and transfer to an emergency department. There can be significant trauma associated with attendance by first responders when a person is experiencing psychiatric crisis, frequently resulting in the use of force or restraint.

First responders require appropriate clinical skills and training to respond to the needs of people experiencing complex mental health issues and avoid doing harm. Early evaluation of the Police, Ambulance and Clinical Early Response (PACER) initiative found that mental health clinical assessment improved information flow between police and mental health services (Allen Consulting Group, 2012).

4. Improve training and support for first responders attending mental health related incidents, particularly where the individual is experiencing severe and complex mental health issues and/or has a history of trauma.
5. Expand capacity of the PACER service across Victoria.

An emergency department does not provide a therapeutic environment for someone who is acutely mentally unwell. Long waits, over stimulation, and limited access to trained mental health clinicians and the use of security personnel in lieu of a locked ward, are just some of the issues associated with providing mental health care in emergency departments.

6. Increase capacity of emergency departments to better respond to mental health related presentations.

## Public and private parity

The current Australian health system was founded on three Medicare Principles, including the principle of Equity in Service Provision. This principle instils in the system an expectation that states will ensure residents receive equitable access to healthcare, regardless of geographical location. Although Australians are fortunate to have access to universal healthcare, the mental health system offers a solid example of inequity between public and private offerings in relation to access, duration and quality of care.

The average length-of-stay for inpatient treatment within metropolitan Melbourne is 9.1 days in the public system, whereas inpatient treatment in the private system ranged from 8.9 to 28.6 days in the same period (DHHS, 2018, PPHDRAS, 2019). This is despite the large number of people presenting with acute, chronic and complex mental illness to the public system. Many newer, evidence-based or less invasive treatments are also not readily available in the public system, such as Transcranial Magnetic Stimulation (TMS).

Many people affected by complex mental health issues are incurring significant cost to access the private system for fear of being unable to access the public system during times of crisis. Ensuring access to the public system for the people who need it will ensure decisions around accessing private care are made by choice, not necessity.

## Navigation

Victorians affected by complex mental health issues experience significant barriers while navigating the mental health system. The complex interplay of service tiers and funding arrangements has resulted in a mental health system that is fragmented and confusing to access. Current service composition is often dependent on self-navigation, rather than the system responding to an individual's needs through accessible and assertive outreach. This places an unnecessary and unfair burden on consumers and their families during times of acute crisis.

People affected by complex mental health issues may enter the mental health system via primary care as the gateway, but may require additional support to access specialist services. Many consumers report presenting to services only to be told that they are ineligible, and being cold-referred to another service. This experience can discourage people from seeking help in the future. This differs to the youth mental health system where entry into the system is streamlined in some communities through headspace and EPPIC. Further assistance is required to manage the referral and handover of adults presenting with complex mental health issues. This could be facilitated by peer workers.

7. Ensure mental health and related social services manage the referral and handover of people presenting with mental health related issues, allowing entry at any point in the system.

People with a lived experience of accessing the system tell us that case management by Area Mental Health Services often provides risk-management without holistic care coordination. This has been further exacerbated by the introduction of the National Disability Insurance Scheme, which has resulted in an evolving landscape of new, consolidated and decommissioned providers. During times of crisis, it is often up to the individual, their family and support network to locate the most appropriate part of the system, rather than the system being equipped to correctly identify and respond to an individual's needs.

8. Establish a dedicated, well-resourced and holistic case coordination function to assist people experiencing complex mental health issues who are ineligible for the NDIS to navigate the mental health system and other services required.

9. Work with the Commonwealth Government to ensure that NDIS coordinators are trained and supported to navigate the mental health system and other services required.

## Discharge

Due to access pressures in the acute clinical mental health system, many people affected by complex mental health issues report premature discharge from hospital. For many, this can be a point in their recovery journey of high-risk, relapse and acute distress.

Effective discharge planning requires the ability to refer people to an adequately funded community mental health service sector. Discharge planning should also include efforts to identify strengths, and gather personal goals and aspirations. These are all elements of a person's identity and presentation, beyond symptomatology and medication management, and will ensure patients are better equipped to be discharged from inpatient care. Assessment of safety upon discharge should also be broadened to include assessment of imminent harm including homelessness and family violence.

10. Broaden discharge planning to include key details, such as personal goals and strengths, to better facilitate a person's recovery and ensure that the individual and those around them are supported to meet their recovery goals.
11. Increase funding of the community mental health system to better support people affected by complex mental health issues upon discharge.
12. Improve assessment, referral and support for people at risk of imminent harm being discharged from mental health services.

## Safety

People with a lived experience of accessing the system tell us that mental health inpatient units are not always safe places to be. The mounting complexity and psychological distress of people presenting to tertiary mental health services can affect the wellbeing and recovery of others seeking treatment. Many women report feeling unsafe in a mixed ward setting and would prefer a more gendered approach. Addressing some of the barriers preventing early intervention is one way to improve the wellbeing of those seeking help, but further work is needed to ensure mental health services are safe and therapeutic.

13. Consider options for improving safety during inpatient admissions.

The Safewards Project, developed by the Victorian Department of Health and Human Services, arose from findings that a significant number of adverse events, involving aggression, violence and absconding, occur in Victorian psychiatric inpatient units. Moreover, inappropriate responses to these events, including the use of seclusion and restraint, were used frequently. The Safewards trial from 2016-19 was found to reduce the use of seclusion by up to 36 per cent (Fletcher, 2017). Ongoing monitoring and evaluation of the Safewards model is required to ensure the transparency of outcomes and continued progress towards the elimination of seclusion and restraint.

## Regional and rural areas

As outlined in the National Rural Health Alliance’s submission to the ‘Accessibility and quality of mental health services in rural and remote Australia Inquiry’ conducted by the Senate Standing Committee of Community Affairs (2018), “the prevalence of mental health professionals in regional and rural areas is about one third to two thirds that in Major Cities, and in remote areas a sixth to a third that in major cities”<sup>2</sup>.

A lack of adequate funding for rural mental health services contributes to difficulties accessing appropriate services and other tragic outcomes, such as the higher suicide rates in rural and remote areas. Tele-web services, such as SANE’s Online Peer Support Forums and Help Centre provide much-needed support to those unable to access other forms of treatment, they need to exist alongside quality in-person assessment and care, particularly for those affected by complex mental health issues who require specialist care and support. Mental health services should be available to all, regardless of where you live, with accessible pathways available for those living in remote parts of the state or in areas where there are other barriers to access.

### Case study: Kylie, Indigo Shire

Kylie is a loving mum, a former nurse, peer worker and long-time contributor to mental health advocacy. Kylie has also lived with a diagnosis of schizoaffective disorder for twenty years. Access to clinical mental health and support services is limited where she lives in a small rural community in the Indigo shire. There is one local service that Kylie refuses to go to. In her view, the built environment is not conducive to recovery and she does not feel safe there.

During times of crisis, she must travel to a neighbouring town to seek help. Kylie works the one day of the week when the case manager visits her town which means she must go without this service, impacting her ongoing clinical support.

Kylie feels that her physical health has been neglected by the mental health system, with many clinicians ignoring significant side effects of her medications. This includes weight gain, cardiovascular issues, and high levels of sedation impacting her motivation. Kylie has also experienced significant memory impairment following a course of electroconvulsive therapy last year. She believes her physical health is just as important as her mental health and services should respond better to a person’s health needs.

When asked what good quality mental healthcare looks like, ‘choice’ is a strong theme for Kylie. Improved choice about who forms her treating team, where she receives treatment, and the types of treatment important to her. She is hopeful that access to the National Disability Insurance Scheme will create more choice in terms of the services that she feels will best support her mental health. Kylie worries about people in her community who cannot gain access to the National Disability Insurance Scheme but still require ongoing mental health support.

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<sup>2</sup> [http://ruralhealth.org.au/sites/default/files/submissions/sub37\\_NRHA.pdf](http://ruralhealth.org.au/sites/default/files/submissions/sub37_NRHA.pdf)

This inequity also contributes to those in rural and remote areas being unable to access innovative evidence-based treatments. For example, there is growing evidence of the efficacy of TMS as a safer alternative to Electroconvulsive Therapy (ECT). However, TMS machines are rarely available outside of metropolitan centres or private hospitals, meaning that those in rural and regional areas, and those without private health insurance, continue to undergo ECT and experience more negative side effects.

14. Increase availability of clinical mental health services in regional and remote areas.

In instances where referral to a metropolitan or regional service away from home is required, there must be appropriate referrals and planning in place for ongoing support. Consideration should also be given to the economic impact of seeking treatment away from home, noting that people affected by complex mental health issues and their support network can incur considerable costs travelling to access mental health treatment.

15. Increase funding for rural and remote consumers and carers, including reimbursement for costs associated with travelling to access mental health treatment.

## **Prevention and early intervention**

The World Health Organisation describes the conditions in which people are born, grow, live, work and age as impactful on their health, and in particular, their mental health. The social determinants of health acknowledge the relationship between social inequity and disparities in health status. Prevention of mental ill health, therefore, is the responsibility of all governments across all portfolios and the mental health system cannot be viewed in isolation. There are many intersecting systems that determine the risk and severity of someone developing mental illness. Prevention requires community-wide promotion of safety and inclusion. In our schools, in our workplaces, in our communities.

16. Implement and monitor the findings of the Royal Commission through a whole-of-Government response.

There has been an increased focus on mental health promotion, primarily focusing on high prevalence mild-to-moderate conditions. Awareness raising and quality education programs about complex mental health issues are currently lacking, but would greatly assist efforts towards prevention, early intervention and the reduction of stigma and discrimination.

17. Increase the funding allocation for prevention and early intervention initiatives for people affected by complex mental health issues.

People affected by complex mental health issues can sometimes experience loneliness, isolation, stigma and discrimination. Community inclusion initiatives are important to foster a sense of belonging and connection (Harvey et al. 2015). While mental health promotion and education can assist in improving the community's understanding of complex mental health issues, more work is needed to ensure no one is left behind.

18. Increase capacity of programs to support people affected by complex mental health issues to participate in the community in the ways that are most meaningful to them.

## Models of care

A robust specialist mental health system is responsive to the needs of those it services. For people experiencing severe and chronic mental health issues, the availability of a holistic, evidence-based, trauma-informed model of care is crucial.

### Holistic care

Mental illness involves a complex interplay of bio-psychosocial factors requiring a holistic treatment model. By considering the whole person and their individual needs, mental health services can better support recovery. This may include innovative tools such as psychotherapy, 'social prescribing', dietary support, exercise therapy, housing, education, and vocational pathways. There is no ideal prescription for all, as the needs of each individual are different and our system needs to reflect this better by providing person-centred care.

Many people working within our system have a diverse range of skills, but to better support the holistic needs of people affected by complex mental health issues, assessment that is broader than clinical symptomatology is required. Multi-modality teams are required throughout all tiers of the mental health system, in order to provide timely and accurate referrals to the health and social services integral to recovery.

19. Increase availability of multi-modality team structures to better support the assessment and response of the biological, psychological and social needs of people affected by complex mental health issues.

### Evidence-based treatments

The availability of new, safer and more effective treatments is an important cornerstone in any health system. In mental health care, this includes the availability of new medications (requiring inclusion in the Pharmaceutical Benefits Scheme), access to psychological treatment, including Open Dialogues, and innovative, new therapies, such as Transcranial Magnetic Stimulation (TMS).

20. Increase statewide availability of evidence-based therapies such as Transcranial Magnetic Stimulation (TMS) throughout the public health system, especially in rural and regional communities.

For many people experiencing mental health conditions, psychotherapy can be as effective as, and an important adjunct to, pharmaceutical treatments (Leichsenring & Rabung, 2008). Many people who experience complex mental health issues require more than the ten psychology sessions per year allocated in the Better Access program.

Other psychotherapeutic approaches that may be used include supportive therapy, psychodynamic therapy, cognitive training, social skills training, family therapy and motivational interviewing (Salam et al, 2013; Stone, Gabbard and Gabbard, 2014; Ridenour, 2016).

21. Influence the Commonwealth Government to establish appropriate funding mechanisms to support people living with complex mental health issues to access evidence-based care to allied health including psychology sessions.
22. Expand the number of psychotherapeutic approaches available to people living with complex mental health issues.

## Trauma-informed care

The relationship between trauma and complex mental health issues is well established (Copeland 2007, May 2016, Malarbi 2017). An experience of trauma can cause mental illness and can exacerbate psychological distress. For some, the experience of hospitalisation, seclusion, restraint or coercion can be traumatising or triggering of past trauma (Ross 2014). It is important that all mental health services, and all personnel that work within those services, practice trauma-informed care.

23. Ensure all Victorian mental health services practice trauma-informed care.

## Support for people experiencing personality disorder

A recent review conducted by SANE, commissioned by the National Mental Health Commission, found that approximately 6.5 per cent of Australian adults meet the diagnostic criteria for at least one personality disorder. In terms of interface with the health system, people affected by personality disorders are over-represented. It was estimated that approximately 26 per cent of people presenting to emergency departments due to mental health concerns are experiencing some form of personality disorder, while 25-43 per cent of adult inpatients and 23 per cent of adult outpatients meet the criteria for Borderline Personality Disorder. The review found that the current mental health system fails to meet the needs of people living with personality disorder.

There are a range of services and programs in the community for consumers with personality disorder including the statewide service Spectrum, but many of these programs have limitations in scope, service number and regional accessibility that impact or impede evidence-based treatment. It is recommended that individuals with personality disorder participate in psychotherapy that is evidence-based and designed specifically for the treatment of personality disorder, if available (National Health and Medical Research Council, 2012).

24. Work with the Commonwealth Government to prioritise research into effective treatments into personality disorders.

## Workforce issues

### Attraction and retention

When a system is under pressure, so too is its workforce. People working in the mental health system are working in a resource-constrained environment and are also the public face for

the system's failures. Limited funding and system limitations impact on the ability for clinicians and support staff to properly do their jobs.

Another strong incentive for addressing the system's current shortfalls is to attract and retain capable and motivated clinical staff. This is particularly relevant in rural and remote areas where staff attraction and retention can be challenging.

25. Implement incentives to attract and retain quality mental health staff in regional and remote areas.
26. Increase ongoing training and support for mental health staff, including the use of lived experience stories of complex mental health issues.
27. Create opportunities for people affected by complex mental health issues to pursue opportunities throughout the health system, beyond peer roles.

## Peer workforce

A peer workforce is a core component of our mental health system. Peer workers can use their experiences to positively support others affected by mental health issues, but can also aid in service design and operations. Anecdotally, it is reported that peer workers are not well understood, appropriately remunerated by all mental health services, are not available in all services, and are not well supported.

28. Expand the availability of peer workers to better support people affected by complex mental health issues, their families and networks.

## Service planning and operability

### Data collection

Data currency assists us in better understanding the needs of the population using mental health services. Current data sources are outdated, with the latest National Survey of Mental Health and Wellbeing dating back to 2007. The survey includes diagnosis, but should be updated to include other measures that reflect complexity.

29. Work with the Commonwealth Government to undertake a new National Survey of Mental Health and Wellbeing that is inclusive of complex mental health issues.

The collection of data is important to inform service design and planning and ensure the system is responding to the needs of people experiencing mental illness. It is also necessary to ensure both the system and decision-makers are accountable for the services delivered. Although the established Mental Health Annual Report is a positive step toward increasing transparency, there are still a number of priorities that do not yet have outcome and indicator measures. These include:

- Victorians with mental illness are supported to protect and promote health
- Victorians with mental illness participate in learning and education

- Victorians with mental illness participate in and contribute to the economy
  - Victorians with mental illness are socially engaged and live in inclusive communities.
30. Develop outcome and indicator measures for all remaining outcomes in the Outcomes Framework by 2020-21.

The outcomes that matter most to people affected by complex mental health issues need to be included. These may include indicators that include physical health status, community inclusion, or experiences of stigma and discrimination. Outcomes related to a person's mental health status and daily living should also be explored.

31. Incorporate outcome measures that are meaningful to people living with complex mental health issues.

## **Pathways and interfaces**

### **Lack of coordination**

People with complex mental health issues interact with a number of different parts of the mental health and related health and social care systems. All too often, processes such as intake and assessment are duplicated, highlighting the lack of integration across service streams. This inefficiency can detract from important therapeutic work as services are forced to respond to administrative requirements. Such inefficiencies are rife in a system relying on multiple types of funding and fee-for-service models. Incentives need to be built into the funding model to encourage providers to work together and coordinate services for people affected by complex mental health issues.

32. Work with the Commonwealth Government, Primary Health Networks and Local Hospital Networks to explore funding models that promote service integration for people affected by complex mental health issues.

### **Continuity of care**

All too often, people affected by complex mental health issues and their families and friends are forced to tell their story multiple times – to multiple clinicians, across multiple services. Our system is not joined up and is, at times, far from seamless. To improve efficiencies, maximise recovery and ensure that people affected by complex mental health issues feel valued and heard, the system should facilitate the transfer of a person's needs. This applies both within the public mental health system and other social care services.

33. Introduce integrated case-taking across all mental health services.
34. Work with the Commonwealth Government to improve current interface issues between state and federally funded mental health and social services.

## Physical healthcare

SANE encourages the Royal Commission to analyse and address the intersection between the physical and mental health of those living with complex mental health issues. This is an area of concern that is often overlooked, despite research finding a clear link between poor mental health and poor physical health, and vice versa.

Research conducted by Palmer, Lewis, Stylianopolous and Furler (2018) found that those living with complex mental health issues are 2.5 times more likely than the general community to develop cardiovascular disease and metabolic syndrome, which contributes to those living with complex mental health issues dying 10–20 years earlier than the general population<sup>3</sup>. Nearly 80 per cent of people living with serious mental illness who die before the average life expectancy of 79.5 years for men and 84 years for women, do so due to physical health conditions. This translates to a loss of between 10 and 36 years of expected life (RANZCP, 2016).

Stigma and discrimination by health services can sometimes result in a person affected by complex mental health issues having their physical health concerns minimised or neglected. The impact of some psychotropic medications, including antipsychotic medications, can also impact physical health, which requires ongoing monitoring. For example, significant weight-gain is a common side-effect of this class of drugs, and can increase cardiovascular and metabolic risk-factors.

In addressing these issues, there is also a need to consider adverse impacts associated with traditional public health campaigns that aim to address physical health. For example, inappropriate obesity related campaigns have been attributed to increased presentations of eating disorders. Approaches need to be holistic, person centred and free from stigma and shame.

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<sup>3</sup> <https://www1.racgp.org.au/ajgp/2018/december/primary-care-prevention-of-the-cardiovascular-heal>

## Case study: Sarah, Metropolitan

Fueled by a family, sporting and school environment where weight loss was celebrated, Sarah experienced body image issues as an adolescent. A desire to be 'healthy' and lose weight through restriction and over exercise resulted in Binge Eating Disorder.

Unlike many, Sarah was able to access private care and support for her Binge Eating Disorder attending a group program with other women led by a dietician and psychotherapist. Her mental health and her relationship with food improved markedly, but her weight continued to increase.

Despite knowing her history of an eating disorder, three years ago her General Practitioner encouraged her to lose weight through a range of medical approaches to weight loss, inviting her to consider medication and bariatric surgery. While the medication was initially 'successful' in helping her to lose weight, a plateau ultimately led Sarah regain some of this weight and to again seek out treatment for her eating disorder and her distress at not being able to meet these weight loss goals.

Sarah now manages her wellbeing through a new GP, supported by a multidisciplinary team which includes a clinical psychologist, non-diet approach dietician and exercise physiologist. This comes at a significant financial cost – her share of the private health insurance she holds with her partner is almost \$250 a month. Fortnightly psychology appointments are \$200 each and her group exercise program is \$100 a week. Dietetics appointments can be \$80-\$120 a session.

Sarah acknowledges that she is very lucky to have the mental health literacy, financial resources – including private health insurance - and flexibility to be able to maintain her recovery in this way.

Sarah's story highlights the importance of having specialist trained health professionals working in a multidisciplinary team to support the wellbeing of people living with mental illness and taking a holistic view to managing physical and mental health challenges.

35. Improve the interface between mental health services and primary care providers to better support the physical health of people affected by complex mental health issues.
36. Increase availability of prevention initiatives that better support the physical health and health literacy of people affected by complex mental health issues.

Although smoking rates are declining, people who experience complex mental health issues are still more likely to smoke and are not quitting at the same rate as the general population. It is estimated that 60-70 per cent of people with lived experience of psychosis smoke (Morgan 2014). As well as the significant impact on health, many people affected by complex mental health issues are also facing significant financial burdens due to tax levy increases on tobacco products. This means their smoking habit is harming their physical health and their financial wellbeing.

Quit Victoria has a number of tools to support people affected by mental health issues stop smoking, however further funding is required to expand and integrate these initiatives with mental health support services.

37. Increase funding for smoking prevention campaigns that specifically encourage people affected by complex mental health issues to quit smoking.

### Suicide prevention

The tragic impact of suicide on the lives of so many Australians is recognised in the Government's Fifth National Mental Health and Suicide Prevention Plan which calls for a national, coordinated systems-based approach to suicide prevention that includes, among other elements, the need for public information campaigns to support the understanding that suicide is preventable.

The causes of suicidality are complex and diverse. People affected by complex mental health issues are anywhere from 10 to 45 times more likely to die by suicide than the general population (Chesney et al 2014). The risk is highest for those living with borderline personality disorder (BPD), one of the most stigmatised and poorly understood conditions, but is also high for those living with anorexia nervosa (31 times higher) and schizophrenia (13 times higher).

The Victorian Government has committed to halving the suicide rate by 2025. To successfully meet this target, significant increased investment is required to better respond to those experiencing acute psychological distress and suicidal behaviours. Most notably for those living with complex mental health issues. As noted earlier, suicide prevention requires a whole-of-government and a whole-of-community response. Initiatives should be embedded throughout our health system, including early intervention and support following a suicide attempt.

Current suicide prevention trials led by Primary Health Networks seeking to work with local communities to develop and implement coordinated place-based approaches to suicide prevention, as well as the Hospital Outreach Post-suicidal Engagement (HOPE) initiative, require expansion across the state.

Thomas Joiner's Interpersonal Theory of Suicide prevention identifies 'perceived burdensomeness' as a key belief for individuals who are having suicidal thoughts. This opens up the possibility of peer-to-peer communication to create and disseminate compelling messaging and stories that resonate strongly with target audiences and, over time, may contribute to changing attitudes and behaviour of people with suicidal ideation.

38. Increase funding for, and the availability of, assertive outreach following a suicide attempt across the state.
39. Provide additional funding for evidence-based suicide prevention initiatives, including through peer-to-peer storytelling.

## Education

The median age of onset for many mental illnesses is between mid-teens and mid-20s (Kessler et. al. 2007). The education system therefore provides an important opportunity for mental health prevention and early intervention (DSS, 2017). Increased investment is required to promote mental health awareness, particularly of complex mental health issues, in educational settings and support educators to identify students at risk of mental ill health.

40. Fund mental health promotion initiatives in educational settings including schools, universities and TAFEs inclusive of complex mental health issues.

Students who are caring for loved ones affected by complex mental health issues will require additional support to thrive in an educational setting, while balancing the demands of their caring role and studies. For many, the complexities they face as a result of their caring role are often not identified and they are therefore not offered additional support to complete their studies. Young carers are more likely to have poorer school attendance, leave school or face difficulties participating in the workforce than their non-carer peers (DSS, 2017).

41. Increase identification of young carers in educational settings such as schools, universities and TAFEs, and increase the level of support available to them.

## Employment

Participation in meaningful work can promote mental health. By providing people with purpose, financial independence, connectedness and a better standard of living, employment can support both physical and mental health. Some people affected by complex mental health issues find it difficult to find and maintain employment. Exclusion and under-employment are all too common for people experiencing complex mental health issues. Governments spend significantly more on income support than they spend on supporting people affected by complex mental health issues to find or return to meaningful employment.

Some work situations can increase the risk of, or exacerbate, mental health issues. If, for example, the culture in a workplace is stigmatising, people are faced with job insecurity or placed in high stress situations, this can create a negative workplace environment. The Mentally Healthy Workplace Alliance was born out of recognition that mentally healthy workplaces benefit individuals, businesses and the economy. SANE Australia is a member of the Mentally Healthy Workplace Alliance and is committed to ensuring that all Australian workplaces are supportive environments.

There is not yet adequate data on the prevalence of structural discrimination in relation to complex mental illnesses. Attitudes in workplaces around illnesses such as depression and anxiety are starting to change as a result of many factors, including initiatives such as the Mentally Healthy Workplace Alliance and 'R U OK Day?' and workplace education strategies.

42. Ensure that public and workplace-based mental health promotion campaigns such as the Mentally Health Workplace Alliance are inclusive of complex mental health issues.

Returning to work after experiencing acute mental illness can enhance recovery and reduce reliance on income support measures. Employment programs provided by community mental health support agencies are often limited in scope and availability.

43. Increase capacity of community-based mental health support agencies to deliver employment support programs to people affected by complex mental health issues.
44. Explore opportunities within the Victorian Public Service to employ people affected by complex mental health issues that are seeking to return to work.

## Housing

Safe and affordable housing is a fundamental ingredient for both preventing mental illness and promoting recovery. It is also a basic human right. People affected by complex mental health issues often face housing insecurity and homelessness, which can trigger or exacerbate their condition. There are many reasons for this, including the impact of deinstitutionalisation, lack of affordable housing stock, and the unacceptably long waitlists for social and public housing.

The Housing First model prioritises safe and permanent housing as the first step in securing multidisciplinary support (AHURI, 2018). Given the intersection between homelessness and mental health issues, intersectionality and available referral pathways between the two systems is critical. Investment in safe and affordable housing, and support to maintain that housing, is also an investment in mental healthcare.

45. Increase availability of programs to support people affected by complex mental health issues to maintain stable housing, including access to the private rental market.
46. Increase social housing availability with increased triaging for people affected by complex mental health issues, as per the Housing First model.
47. Increase the number of people affected by complex mental health issues housed in social and public housing and actively monitor and reduce the waitlist.
48. Increase the number of supported housing placements for people affected by complex mental health issues.

The number of people sleeping rough in Victoria has increased due to a lack of crisis accommodation. A significant proportion of people sleeping rough are affected by mental illness with the Australian Institute of Health and Welfare reporting that 17,772 people affected by mental health issues presented to homelessness services last year (ABS 2018). In addition to the significant health and safety risks posed to people sleeping on the streets, more resources are required from our Emergency Departments and frontline services.

49. Increase availability of emergency relief housing, with integrated referrals to health and social care services, for people affected by complex mental health issues.

## Justice

As acute mental health services fail to meet demand, many people experiencing acute psychiatric crisis are ending up interacting with the criminal justice system. Police attendances to mental health related callouts are increasing, requiring specialist training and expertise. The Police, Ambulance and Clinical Early Response (PACER) initiative is an example of partnering first responders with people with mental health expertise, however this is not consistently available across the state.

50. Increase availability of PACER teams across the state.

In some cases, the prison system is operating as the mental health provider of last resort. This reality sees some individuals entering the criminal justice system when appropriate clinical treatment and support may have been able to prevent this outcome. Imprisonment itself can have a devastating impact on someone's mental health. Whenever possible, people experiencing complex mental health issues should not be imprisoned.

Victorian prisoner numbers are continuing to rise, with \$1.8 billion in new investment dedicated to increasing the capacity of Victorian prisons in the latest state Budget. The rise in prisoner numbers demonstrates a failure to adequately address the social determinants that drive offending behaviour.

People who have contact with the criminal justice are more likely to have experienced a mental health condition. Many have incredibly complex needs, intersecting across a range of health and social services, which may or may not be related to their offending behaviour. Mental health complexity is also higher within the prison context with an estimated 40–43% of prisoners meeting diagnostic criteria for a personality disorder (Tye and Mullen, 2006; Butler et al, 2007; Shepherd, Campbell and Ogloff, 2018). Past experiences of trauma and intergenerational trauma are also common.

51. Increase availability of evidence-based treatments for people living with personality disorders within Victorian prisons.

52. Introduce trauma-informed care training for all correctional staff.

For prisoners experiencing acute psychiatric crisis who require compulsory mental health treatment, there are significant delays in accessing treatment at Thomas Embling Hospital (Forensicare, 2018). This may increase the acuity and severity of their presentation, as well as the application of strict regimes within the prison walls while awaiting admission.

53. Increase the capacity of the forensic mental health system to provide tertiary mental healthcare to prisoners affected by mental illness in a therapeutic, clinical mental health setting.

Leaving prison can be a difficult time for many prisoners who are faced with concerns around stigma, housing, employment, reconnecting with family and friends and managing substance use issues. Prisoners are also more likely to experience suicidal behaviour post-release (Kariminia et al. 2007). Connection with community and mental health supports is crucial

during this time. For prisoners released on assessment and treatment orders, access blockages in the community can result in reincarceration.

54. Increase support affected by complex mental health issues for people on remand and post-release.

## **Support for carers and families**

People affected by complex mental health issues are often supported by a community of family, friends, colleagues and neighbours. Systemic failures that impact people living with complex mental health issues also impact the people who support them. Caring without adequate support can affect mental health, wellbeing, employment and financial status (Cummins, 2007; Diminic, 2017).

Dynamics of care are individual and unique. Just as not all people affected by complex mental health issues have the same needs, nor do carers. The system should provide tailored support to carers, based on their individual preferences and circumstances.

The Better Support project, led by SANE Australia in partnership with the University of New England, found that caring for a relative at risk of suicide can elicit experiences of powerlessness and alienation, highlighting the gap in knowledge between mental health professionals and family members. For example, families have reported a lack of communication with health care providers following a suicide attempt by a loved one (Kjellin and Ostman, 2005; Cerel, Currier and Conwell, 2006; McLaughlin, 2016).

Working with carers, family and friends can improve outcomes for people affected by complex mental health issues, yet many carers and support people still report being excluded from treatment and discharge planning. Although steps have been taken to improve carer inclusive practices across mental health services, many services still fail to identify carers and offer support. Appropriate identification of the people providing support to those affected by complex mental health issues is key in promoting their recovery.

55. Require inpatient mental health services to identify carers supporting people affected by complex mental health issues when planning for treatment and discharge.

'The economic value of informal mental health caring in Australia: summary report' commissioned by Mind Australia in 2017 estimated that primary mental health carers provide a total of 102 million hours of care, estimated to be worth \$60.3 billion, to their care recipients (Diminic, 2017). The emotional and economic cost to carers can be significant. SANE supports the Caring Fairly campaign, seeking a fairer deal for unpaid carers.

56. Increase access to carer support within mental health services, including through the expansion of the carer peer workforce
57. Increase available funding to assist carers and families cover the economic costs of unpaid caring through the Carer Support Fund.

## Specific needs

SANE is committed to advocating for safe, culturally appropriate, inclusive mental health services for all people, regardless of their ethnicity, faith, disability, sexuality or gender identity.

### Aboriginal and Torres Strait Islander communities

Intergenerational trauma, racism and discrimination impacts on the social and emotional wellbeing of our First Nations people. Along with the compounding effect of the social determinants of health, this means that Aboriginal and Torres Strait Islanders are more likely to experience complex mental health issues than other Australians. All services working with people from Aboriginal and Torres Strait Islander communities should be culturally safe, so as to encourage help-seeking and not inflict further harm.

The suicide rate of Indigenous Australians is twice that of non-Indigenous Australians and Indigenous children is five times more likely to die by suicide than non-Indigenous children (Dudgeon, 2014). Community prevalence surveys also report that 4–16 per cent of Aboriginal and Torres Strait Islander populations meet the diagnostic criteria for personality disorder (Parker, 2010). In addition to the need for an increase in programs that respond to the needs of people affected by personality disorder, further investigation is required into how best to meet the needs of Aboriginal and Torres Strait Islanders experiencing complex mental health issues.

58. Require cultural safety accreditation for services responding to Aboriginal and Torres Strait Islander people affected by complex mental health issues.
59. Continue working with people from Aboriginal and Torres Strait Islander communities to co-design appropriate suicide prevention strategies and models of care.

### Older adults

The voice of older people living with chronic and complex mental health issues is seldom heard and there are limited resources available for people aged over 65 affected by mental illness. With an ageing population, increased investment is urgently required to meet demand and ensure that older Victorians living with complex mental health issues are supported to live meaningful lives.

## Case study: Maddie, North-east Melbourne

Maddie has a lived experience of psychotic illness, acquired brain injury and physical disability (hemiparalysis). Owing to Maddie's clinical complexity, she now resides in residential aged care in Melbourne's outer north-east, the cost of which is covered by her disability support pension. After transitioning from the community into care, Maddie lost access to psychosocial support services that are not funded to provide support to someone living in residential aged care. Her financial situation does not permit access to private psychiatric services.

The National Disability Insurance Scheme commenced in Maddie's region two months before she turned 65. She was technically eligible at that time, but due to the confusion associated with the scheme's rollout and the fact that she resides in residential aged care, she did not gain access to the scheme.

Despite Maddie's mental health issues and premature entry into an aged care setting, the services available for her complex psychosocial and mental health needs include primary care and acute mental health services - if her clinical needs escalate. There is currently no psychosocial support or in-reach services offered. Maddie's case represents an example of failed service integration between State and Commonwealth funded services, a lack of continuity of care over the life course, and highlights the inadequacy of services for older Victorians living with complex mental health issues.

60. Increase capacity for Victorians aged over 65 affected by complex mental health issues to access the clinical mental health system.
61. Work with the Commonwealth Government to improve the interface between mental health services and residential aged care, ensuring ongoing, specialist mental health support is available for people living with complex mental health issues.
62. Work with the Commonwealth Government to provide in-reach psychosocial support services in residential aged care settings.

## Culturally and linguistically diverse communities

All mental health services should consider cultural appropriateness and responsiveness in service delivery. While it is important to be culturally responsive and sensitive, a person-centred response is required in every situation. Issues facing people from culturally and linguistically diverse communities are not homogenous. Services should be designed from a lens of cultural responsiveness relevant to the communities they serve, but also offer a tailored response appropriate to the individual.

People from culturally and linguistically diverse communities who have English as a second language may have lower health literacy, which can impact their help seeking behaviour, management and understanding of mental health issues (ABS, 2009). The availability of interpreters is crucial to ensuring communication between people affected by mental health issues and their treating team, but greater consideration needs to be given to ensuring that

mental health promotion materials and service provision is accessible for people from culturally and linguistically diverse backgrounds.

Some people from culturally and linguistically diverse communities, particularly those from refugee backgrounds, may have experienced trauma. Mental health services must incorporate trauma-informed care when responding to people from culturally and linguistically diverse communities who have previously experienced trauma.

63. Co-design mental health promotion materials, inclusive of complex mental health issues and trauma, with culturally and linguistically diverse communities.

## LGBTI

SANE was proud to endorse the joint statement by Thorne Harbour Health, Rainbow Health Victoria, and Switchboard Victoria together with 43 other organisations, providing recommendations on how best to support the mental health of people who are lesbian, gay, bisexual, trans and gender diverse, and intersex.

## Dual diagnosis

People affected by complex mental health issues experience substance use issues at a far higher rate than the general community, with research suggesting that around 50 per cent also have a drug or alcohol problem (DHHS, 2016). The relationship between mental illness and alcohol and other drug use is bidirectional. It can be hard to tell which problem came first – the substances or the mental illness. Having a mental illness can make a person more likely to use drugs to self-manage their symptoms in the short-term. Other people use substances that may trigger the first symptoms of mental illness. The use of drugs can also exacerbate the symptoms of mental illnesses and impair the efficacy of some medications.

Despite this common relationship, many people affected by complex mental health issues and co-occurring alcohol and other drug issues do not receive an integrated treatment response. The alcohol and other drug sector and the mental health sector operate separately, both under-resourced and at capacity. Drug patterns and the limited number of rehabilitation beds also impacts on the mental health system, with an increasing number of people with drug-related issues and withdrawal presentations occupying psychiatric inpatient units.

Improving interoperability between the two systems will provide a more holistic and person-centred response (Stalger et al 2010). This may include integrated needs assessment, joint case management and increasing the number of addiction specialists operating within the mental health system.

64. Explore options for better integrating the mental health and alcohol and other drug treatment pathways.
65. Increase capacity of the alcohol and other drugs sector to better respond to the rehabilitation needs of people affected by substance use issues.

## Stigma and discrimination

Australians living with complex mental health issues experience unacceptable levels of stigma and discrimination, which can adversely impact their wellbeing in a number of ways, including worsening of psychological distress, inhibition of help seeking and treatment adherence, limiting of personal relationships, and a reduction in their ability to achieve educational and vocational goals (Wells et al., 1994; Link et al., 1997; Corrigan, 2004). For some people affected by complex mental health issues, they may experience high levels of distress associated with receiving a diagnosis, barriers to help seeking, significant side-effects from medications, and social isolation. Stigma and discrimination may also be compounded by other forms of disadvantage, including poverty and unemployment, or marginalisation on the basis of cultural, linguistic, gender or sexual identity.

The National Stigma Report Card project will see the development and execution of two national surveys of up to 7,000 participants living with complex mental health issues. The project will examine the experience of stigma and discrimination across a suite of domains including housing and homelessness, employment, education, welfare and social services, finance and insurance, justice, media, health and mental health services. This will enable a deeper understanding of the experience of stigma and discrimination and target future advocacy and policy reform efforts.

People affected by complex mental health issues still report stigma and discrimination preventing them from receiving appropriate care and support. By providing accurate information and appropriately responding to misinformation, we can tackle the social norms that give rise to stigmatising and discriminatory behaviour.

In April 2018, The Dax Centre merged with SANE Australia. The common goal of both organisations is to raise awareness of mental illness and its consequences and ramifications with an aim to reduce stigma and discrimination surrounding mental illness. The merger provides new opportunities to grow The Dax Centre's programs in Victoria and nationally. The Dax Centre is a world leader in the use of art to raise awareness and reduce stigma towards mental illness. Through exhibitions and educational programs, it seeks to engage, inform and encourage community connections and conversations about mental health.

The Dax Centre includes a gallery space, education programs and also houses the Cunningham Dax Collection. It has an annual program of art exhibitions featuring works from the collection, new works specifically commissioned for our gallery and touring exhibitions. All of the works are created by people with a lived experience of mental illness and are curated to encourage community connections and conversations about mental illness and psychological trauma.

66. Provide significant funding for stigma reduction activities including increased core funding for operation for the Dax Centre and its stigma reduction initiatives that engage the Victorian public.

Stigma and discrimination are the result of complex social processes and are shaped over time. Factors such as media reporting which inappropriately links mental illness to violent crime or attitudes of health professionals that some patients have no prospect of recovery feature heavily in the stigma faced by many of those SANE serves.

67. Contribute funding for the StigmaWatch program to support safe and responsible media reporting of complex mental health issues in Victoria.

## Human rights and self-determination

Upholding human rights and promoting participation in clinical decision-making should be a core premise of the Victorian mental health system. This is important for issues surrounding compulsory treatment, the use of seclusion and restraint, and the elimination of coercive treatment.

### Case study: Sophie, Gippsland

Sophie is a health professional living and working in Gippsland. She has previously received an array of mental health diagnoses, including Borderline Personality Disorder. Her most recent diagnosis is Bipolar Disorder with a co-occurring eating disorder.

Throughout the course of her illness, she has been hospitalised more than 50 times. She has received treatment in both the private and public systems, being transferred to the public system when her acuity could not be managed in the private system. Despite the complexity of Sophie's needs, she has not been offered ongoing case management and communication between services has been poor.

From Sophie's experience across a range of inpatient services, she noticed a lack of consistent protocol in responding to her Eating Disorder. Decision-making regarding the use of invasive treatments such as seclusion, mechanical restraint, or nasogastric feeding were not consistent across services. This compelled Sophie to write an Advanced Statement to have some control over her treatment.

Sophie believes that Advanced Statements are a positive symbol but are still used selectively by some clinicians. She has found some of her treatment preferences have been ignored or only partly adhered to. This includes her preference for de-escalation techniques rather than the use of seclusion. Sophie has also observed that she could amend her Advanced Statement during periods when she was acutely unwell, resulting in a statement which is not reflective of her treatment goals when she is in recovery.

Sophie would like to see the status of Advanced Statements strengthened to be legally binding, with increased safeguards to prevent amendment during periods of acute illness. She also believes further workforce training is required to ensure clinicians practice shared decision-making.

While the Mental Health Act 2014 introduced Advance Statements as a mechanism to elucidate consumer's treatment preferences, uptake remains very low. This may be due to limited awareness of their existence or a belief that Advance Statements are unlikely to be taken into consideration. Further promotion and profile raising of the opportunity to complete Advance Statements is required to ensure more people affected by complex mental health issues have their preferences respected as part of their treatment planning.

68. Increase uptake of Advance Statements among Victorians with complex mental health issues.

## **Victoria's response to the National Disability Insurance Scheme implementation**

The rollout of the NDIS has exacerbated the challenges faced by those living with complex mental health issues, roughly 200,000 Victorians, falling through the cracks and failing to be provided with the psychosocial supports that are critical to their recovery. With many states redirecting funds that were previously resourcing community-based psychosocial supports into the NDIS, many of these psychosocial support services have been unable to continue. This has caused significant distress and disruption for people accessing services.

While SANE has welcomed efforts from state and federal governments to address funding shortages for services that are not covered by the NDIS, much more needs to be done to guarantee that people living with complex mental health issues are not left worse off as a result of the reforms.

These psychosocial services need to extend to include additional support for initiatives promoting access to safe and secure housing, opportunities to further their education, and securing meaningful employment. This Royal Commission has an important opportunity to highlight and explore those approaches to these issues which are showing promise and should be adequately resourced, as well as the areas where change is still required.

69. Increase availability of psychosocial support and continuity of care for Victorians affected by complex mental health issues who are ineligible for the NDIS.

## **Informing the future**

Although it is important to focus on the aspects of mental health care that are not working well, efforts should also be made to highlight good practice. Tried and tested innovations that are achieving good outcomes for people affected by complex mental health issues should be scaled across the state. This reduces the number of bespoke programs available and improves equity of access for all Victorians.

Collaboration within the mental health sector is key to successfully implementing the findings of this important inquiry.

70. Incentivise and fund collaboration within the mental health sector to support implementation and best-practice support to people experiencing mental health issues.

The findings of this Royal Commission should be analysed by all Australian governments to ensure all jurisdictions are working to provide the best possible mental health care systems.

71. Ensure the Royal Commission's findings and recommendations are shared across all jurisdictions.

There is also an opportunity to leverage the work of the Productivity Commission's Inquiry into Mental Health, as the final report is due 23 May 2020 and the date of the interim report is yet to be released. Recommendations made by the Royal Commission should therefore be consistent with the findings of that inquiry to maximise the possibility of meaningful and cohesive reform.

72. Consider findings from the Productivity Commission Inquiry into Mental Health when developing recommendations.

*"Hope is a really important thing to get you through some of those really dark times. It's important to appreciate it because I remember a time when there wasn't any. And once you find it, it's important to hold on. It will come, hope does arrive." Ali, SANE Peer Ambassador*

## Glossary of key terminology

**Anne Deveson Research Centre (ADRC):** An initiative of SANE Australia driving social outcomes for Australians living with complex mental health issues, their family, friends and colleagues.

**Better Access:** A scheme provided via the Medicare Benefits Schedule enabling access to psychiatrists, general practitioners, psychologists and other trained mental health clinicians on a fee-for-service basis subsidised through Medicare.

**Case management/Case co-ordination:** The mechanism for ensuring continuity of care across inpatient and community settings, accessing and co-ordination of the range of services necessary to meet the individual and identified needs of a person within and outside the mental health service.

**Complex mental health issues:** On the spectrum of mental health, complex mental illness is severe and persistent. Often the illness is episodic and requires multiagency support. Illnesses considered complex include: schizophrenia, bipolar, personality disorders, eating disorders, post-traumatic stress disorder, and severe and enduring mood disorders.

**Continuity of care:** The provision of ongoing uninterrupted barrier-free access to the necessary range of health care services and other support agencies, with the level of support and care varying according to individual needs.

**The Dax Centre:** Houses the Cunningham Dax Collection of more than 15,000 artworks created by people who have experienced mental illness or psychological trauma, many of whom were resident in Victoria's psychiatric institutions. The Centre seeks to change community views towards mental health issues through art.

**Early intervention:** Therapeutic intervention that occurs early in life, early in the trajectory of the illness, or early in an individual episode.

**Lived experience:** People who are recognised as having unique expertise and understanding due to direct experience or close observation (current or previous) of mental health issues, irrespective of whether they have a formal diagnosis or have accessed services and/or received treatment. Many people may prefer to use other terms such as consumer, service user, peer, survivor or expert by experience.

**Local Hospital Network (LHN):** Statutory entities established by state and territory governments to directly manage public hospital services within a defined geographical area and their budgets.

**National Disability Insurance Scheme (NDIS):** A national scheme providing individualised support for eligible people with permanent and significant disability.

**Peer Ambassador:** Someone with personal lived experience of complex mental health issues and is a respected, trained and representative of SANE. Peer Ambassadors speak in the community and the media and use their voice to support the key vision and mission of SANE.

**Peer support:** Social, emotional and practical support provided by people who have experienced mental health issues.

**Person centred care:** Treatment and care provided by health services that is responsive to the needs of the individual and their support network.

**Primary healthcare:** The first level of contact with the health system via GPs or community health centres,

**Primary Health Network (PHN):** Independent primary health care organisations established by the federal government to commission health services. There are 31 PHNs across Australia.

**Restraint:** The restriction of an individual's freedom of movement by chemical, physical or mechanical means.

**Seclusion:** The confinement of a person at any time of the day or night alone in a room or area from which free exit is prevented.

**Social and emotional wellbeing:** A holistic Aboriginal definition of health that is inclusive of mental health, emotional, psychological and spiritual wellbeing. This includes issues disproportionately affecting Aboriginal and Torres Strait Islander communities such as grief, suicide, self-harm, loss and trauma.

**Stepped care:** A staged hierarchy of clinical and support interventions ranging in intensity to match an individual's needs.

**Stigma:** The attitudes that people hold about someone's experience of mental ill health inclusive of public stigma and self-stigma.

**Support person:** A person providing support to someone affected by mental health issues. It may be family member, friend, colleague or neighbour. This person is referred to as a 'carer' under the Victorian Mental Health Act.

## References

Allen Consulting Group. (2012). Police, Ambulance and Clinical Early Response (PACER) Evaluation: Final Report.

<https://www2.health.vic.gov.au/about/publications/researchandreports/Police-Ambulance-and-Clinical-Early-Response-PACER-Evaluation-Report>

Australian Bureau of Statistics (ABS). (2009). Health literacy. *Australian Social Trends*.

<https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features20June+2009>

ABS. (2019). Mental health services in Australia. <https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-contents/expenditure-on-mental-health-related-services>

Australian Housing and Urban Research Institute (AHURI). (2018). *Housing, homelessness and mental health: towards system change*.

<https://www.mentalhealthcommission.gov.au/media/252441/Housing-homelessness-and-mental-health-towards-systems-change.pdf>

Australian Institute of Health and Welfare. (2018). Health and Welfare Services:

Homelessness services. <https://www.aihw.gov.au/reports-data/health-welfare-services/homelessness-services/overview>

Australian Private Hospitals Association (APHA). (2019). *Private hospital-based psychiatric services 2017-18: Annual Statistical Report*. <http://www.apha.org.au/wp-content/uploads/2019/04/PPHDRAS-Annual-Statistical-Report-for-2017-2018.pdf>

Brackertz, N., Davidson, J., & Wilkinson, A. (2019). Trajectories: the interplay between mental health and housing pathways, a short summary of the evidence, report prepared by AHURI Professional Services for Mind Australia, Australian Housing and Urban Research Institute, Melbourne.

[https://www.ahuri.edu.au/\\_data/assets/pdf\\_file/0010/40303/Trajectories-the-interplay-between-mental-health-and-housing-pathways.pdf](https://www.ahuri.edu.au/_data/assets/pdf_file/0010/40303/Trajectories-the-interplay-between-mental-health-and-housing-pathways.pdf)

Cerel, J., Currier, G.W., and Conwell, Y. (2006). 'Consumer and Family Experiences in the Emergency Department Following a Suicide Attempt', *Journal of Psychiatric Practice*, 12(6). Retrieved from:

[http://journals.lww.com/practicalpsychiatry/Fulltext/2006/11000/Consumer\\_and\\_Family\\_Experiences\\_in\\_the\\_Emergency.2.aspx](http://journals.lww.com/practicalpsychiatry/Fulltext/2006/11000/Consumer_and_Family_Experiences_in_the_Emergency.2.aspx)

Chesney, E., Goodwin, G. M., & Fazel, S. (2014). Risks of all-cause and suicide mortality in mental disorders: a meta-review. *World Psychiatry*, 13(2), 153–160.

Department of Health and Human Services. (2018). *Victoria's Mental Health Services Annual Report 2017-18*. The Victorian Government.

Copeland, WE, et al. 2007, 'Traumatic events and posttraumatic stress in childhood', *Archives of General Psychiatry*, 64:5, 577–584.

Cummins, R. (2007). Special Report 17.1. The Wellbeing of Australians – Carer Health and Wellbeing. Deakin University. October, vi–vii.

Department of Health and Human Services. (2018). *Victoria's Mental Health Services Annual Report 2017-18*. <https://www2.health.vic.gov.au/mental-health/priorities-and-transformation/mental-health-annual-report>

Department of Social Services. (2017). Young Carers Research Project: Final Report, September 2002. Australian Institute of Family Studies. The Longitudinal Study of Australian Children Annual Statistical Report 2016. Melbourne.

Diminic, S., Hielschler, E., Lee, Y., Harris, M. Schess, J., Kealton, J. & Whiteford, H. The economic value of informal mental health caring in Australia: summary report. The University of Queensland.  
[https://www.mindaustralia.org.au/sites/default/files/publications/The\\_economic\\_value\\_of\\_informal\\_mental\\_health\\_caring\\_in\\_Australia\\_summary\\_report.pdf](https://www.mindaustralia.org.au/sites/default/files/publications/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf)

Dudgeon P, Milroy H, Walker R. (2014). Telethon Institute for Child Health Research/Kulunga Research Network, in collaboration with the University of Western Australia. Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice.

Fletcher, J., Spittal, M., Brophy, L., Tibble, H., Kinner, S., Elsom, S. & Hamilton, B. (2017). 'Outcomes of the Victorian Safewards trial in 13 wards: Impact on seclusion rates and fidelity measurement', *International Journal of Mental Health Nursing*.  
<https://onlinelibrary.wiley.com/doi/full/10.1111/inm.12380>

Forensicare. (2018) Yanith Bilang: Quality Account 2017-18.  
<https://www.forensicare.vic.gov.au/wp-content/uploads/2018/10/FC17-FC-Quality-Account-2018-V11-WEB.pdf>

Harvey, C., Brophy, L., Parsons, S., Moeller-Saxone K., Grigg., M. & Siskind, D. (2015). People living with psychosocial disability: Rehabilitation and recovery-informed service provision within the second Australian national survey of psychosis. *Australian and New Zealand Journal of Psychiatry*. 50(6):534-47. doi: 10.1177/0004867415610437

Kariminia, A. Law, M., Butler, T. Levy, M. Corben, S. Kaldor, J. Grant, L. Suicide risk among recently released prisoners in New South Wales. *Medical Journal of Australia*. 187;7.

Kessler, R. C., Amminger, G. P., Aguilar-Gaxiola, S., Alonso, J., Lee, S., & Ustün, T. B. (2007). Age of onset of mental disorders: a review of recent literature. *Current opinion in psychiatry*, 20(4), 359–364. doi:10.1097/YCO.0b013e32816ebc8c

Kjellin, L. and Ostman, M. (2005). Relatives of psychiatric inpatients - do physical violence and suicide attempts of patients influence family burden and participation in care? *Nordic Journal of Psychiatry*, 59(1); 7–11.

Malarbi, S. (2017). Neuropsychological functioning of childhood trauma and posttraumatic stress disorder: a meta-analysis. *Neuroscience, & Biobehavioral Reviews*. 72;68–86.

May, CL. & Wisco B. (2016). Defining trauma: how level of exposure and proximity affect risk for posttraumatic stress disorder. *Psychological Trauma*. 8:2; 233–40.

McLaughlin, C. *et al.* (2014) 'The burden of living with and caring for a suicidal family member'. *Journal of Mental Health*, Routledge, 23(5); 236–240. doi: 10.3109/09638237.2014.928402.

Mental Health Commission Queensland. (2019). Reducing mental health stigma in the workplace Retrieved from: [https://www.qmhc.qld.gov.au/sites/default/files/reducing\\_mental\\_health\\_stigma\\_in\\_the\\_workplace\\_january\\_2019.pdf](https://www.qmhc.qld.gov.au/sites/default/files/reducing_mental_health_stigma_in_the_workplace_january_2019.pdf)

Mercer, S., Gunn, P., Bower, S., Wyke & Guthrie B. (2012). 'Managing patients with mental and physical multimorbidity. *British Medical Journal*, 245:e555p.

Morgan, V. A., McGrath, J. J., Jablensky, A., Badcock, J. C., Waterreus, A., Bush, R. Mackinnon, A. (2014). Psychosis prevalence and physical, metabolic and cognitive co-morbidity: data from the second Australian national survey of psychosis. *Psychological medicine*, 44(10), 2163–2176. doi:10.1017/S0033291713002973

Palmer, Lewis M, Stylianopolous V. & Furler J. (2018). Primary care prevention of the cardiovascular health crisis for people with severe mental illness: the elephant in the room. *The Australian Journal of General Practice*. <https://www1.racgp.org.au/ajgp/2018/december/primary-care-prevention-of-the-cardiovascular-health>

Parker, R., & Milroy, H. (2010). Mental illness in Aboriginal and Torres Strait Islander peoples. In N. Purdie, P. Dudgeon, & R. Walker (Eds.), *Working Together: Aboriginal and*

Torres Strait Islander mental health and wellbeing principles and practice. (pp. 113–124). Commonwealth of Australia, Canberra.

Productivity Commission. (2019) The Social and economic benefits of improving mental health: Issues Paper. <https://www.pc.gov.au/inquiries/current/mental-health/issues/mental-health-issues.pdf>

Rizzo, V., Rowe, J., Kricke, G., Krajci, K. & Golden, R. (2016). AIMS: A Care Coordination Model to Improve Patient Health Outcomes, *Health & Social Work*, 41:3, 191-195, <https://doi.org/10.1093/hsw/hlw029>

Ross, D., Campbell, J., & Dyer, A. (2014). Fostering trauma-free mental health workplace cultures and reducing seclusion and restraint [online]. *Social Alternatives*, 33:3, 37-45. <https://search.informit.com.au/documentSummary;dn=854909170437678;res=IELAPA>

Staiger, P., Thomas, A., Ricciardelli, L., McCabe, M., Cross, W., & Young, G. (2011). Improving services for individuals with a dual diagnosis: A qualitative study reporting on the views of service users. *Addiction Research & Theory*, 19:1, 47-55, doi: [10.3109/16066351003637278](https://doi.org/10.3109/16066351003637278)

Shepherd, S. M., Campbell, R. E., & Ogloff, J. R. P. (2018). Psychopathy, antisocial personality disorder, and reconviction in an Australian sample of forensic patients. *International Journal Of Offender Therapy And Comparative Criminology*, 62(3), 609-628.