



MHCN mental health carers nsw

Cheap and Unequal; Australia's Approach to Human Rights and Mental Health MHCN's Contribution to; Free and Equal: An Australian conversation on human rights

Mental Health Carers NSW (MHCN) is the peak body for people with lived experience as carers, family members or kinship groups of people living with mental illness in NSW. MHCN is a community based, non-government organisation that represents the voices of mental health carers in NSW so that they are heard in policy and service reform. We endeavour to empower mental health carers across the state to engage with mental health reform and advocacy processes and to build their capacity in care. MHCN's vision is for compassionate communities that value, include and respectfully support people with lived experience of mental illness; their carers, family members and kinship groups. In this report MHCN explores the Australian commitment to its citizen's human right to the best possible mental health for the Australian Human Rights Commission's Conversation on Human Rights.

In 1993, the report by the Human Rights Commission (then HEROC) on the human rights of people living with a mental illness identified systemic human rights abuses including; seclusion, restraint and maltreatment of people with a mental illness in service settings as well as inadequate access to community based mental health care. The "right to the enjoyment of the highest attainable standard of health," was recognized as a human right in the 1966 "International Covenant on Economic, Social and Cultural Rights" and specifically confirmed for people experiencing disabilities under Article 25 of the 2006 United Nations Convention on "The Rights of Persons with Disabilities," (which includes psycho-social disability associated with experience of persistent mental illness).

This right is fundamental for individuals to enjoy many other human rights and freedoms. However, *mental* health remains chronically underfunded in Australia, receiving only 7.41% of the total Australian health budget although it represents at least 12% of the burden of disease. While law reform has reduced (but not eliminated) maltreatment, chronic underfunding of mental health has frustrated Australia's best efforts at achieving broader mental health reform and many of the issues identified in the 1993 HEROC report remain pertinent today. Underfunding must now be considered the primary barrier to reform.

MHCN's report on human rights and mental illness demonstrates that a lack of accountability across all levels of governance has been fundamental to the perpetuation of unacceptable outcomes for people living with mental illness and their carers, including lack of access to basic services and failure to have systems in place to support those lacking capacity to manage their own care. This amounts to the systemic failure to respect and support the right of people in Australia, with lived experience of mental illness, to the best possible health.

At present, legislative and administrative mechanisms which would enable people with lived experience to hold services and government accountable for absent, inaccessible, adequate or negligent mental health care are limited. For instance, section 43 and 54 of the NSW Civil Liability Act (2002) make it extremely difficult if not impossible to hold public bodies legally accountable for negligent mental health care. Section 191 of the NSW Mental Health Act (2007) states that health

professionals and police officers who are exercising their functions under the Act cannot be held liable for any damages or injury caused to the person.

The human cost of underfunding mental health care is significant. However, there is no legal responsibility on any Australian government or state or federal agency to deliver access to competent, safe and effective mental health treatment, even when people are in crisis and would benefit from support to make safe decisions for their own wellbeing. There is a clear and unambiguous *moral* obligation upon the community to provide care to its vulnerable members and this is supported by international human rights conventions.

The inadequate scale of the mental health system in Australia excludes many people, even the sickest, from access to care. A lack of appropriate support for people who live with persistent, chronic mental illness in the community, significantly impacts upon the quality of their lives and the lives of their families and carers. Families and carers unhesitatingly throw themselves into the yawning gap in our medical and social service system, and they too often pay an enormous personal cost, financial, physical and/or mental. Underfunding also places intolerable burdens upon the inadequate numbers of clinicians and other workers that *do* work in the system, to their own physical and mental cost.

Underfunding of mental health also has consequences when individuals experiencing a mental health crisis are turned away from emergency departments or are discharged from inpatient units without receiving the full duration of proper care. These cases attract public outrage when it ends tragically in the death of a person. These cases demonstrate that New South Wales and other states are not funding care to all who should receive it under the standard criteria, when they are 'at risk of harm to self or others' (e.g. the Mental Health Act (NSW) 2007). If services were fully funded to meet this need it would be rare for them to refuse admission to people who fit the 'at risk' criteria, or to discharge people who are still at risk in order to allow someone sicker in to the facility. But this experience is commonplace across Australia. The underfunding of mental health creates many victims across the whole community.

MHCN supports the Australian Human Rights Commission ('AHRC') proposal to implement a Human Rights Act in Australia as outlined in the technical issues paper. MHCN agrees with the AHRC that a Bill of Rights should require positive action by government to fully realise the equal enjoyment of human rights, like the right to the best possible health, and provide enforceable remedies to individuals when these rights have been breached. This Bill would create an avenue to seek remedy when the actions of government and/or health services breach or fail to deliver their human rights. The Bill should also provide mechanisms for disadvantaged groups, such as people with lived experience of mental illness and/or caring, to participate in defining the processes that government should set up to actualise their human rights and to hold services and even governments to account when human rights are not upheld. They should also codesign a framework for monitoring and reporting on achievements, progress or obstacles in these areas in addition to enforcement and remedies for breach. Finally, public access to evaluative data will be critical to inform meaningful participation by citizens so the Bill should demand transparent reporting on progress by governments.

Otherwise Australian's including those with lived experience of mental illness and their families and carers will be obliged to continue to live under governments that claim to 'respect' human rights but do not fund them.

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Executive Summary

Mental health underpins the autonomy and capacity of individuals to participate in all aspects of society. The right to the highest attainable standard of mental health is therefore considered indispensable to human dignity and for individuals to be able to exercise many other human rights. The right to mental health establishes an obligation for states to provide timely, acceptable and affordable healthcare and to address the underlying determinants of mental ill health such as poverty, marginalisation and adverse early life experiences. Appropriate resourcing of the mental health system is therefore critical to meet Australia's human rights obligations.

The Australian Medical Association states that mental health care is '*grossly underfunded*' receiving only 7.41% of total health funding, although mental illness represents at least 12% of the total burden of disease.¹ This number has remained relatively stable for the past three decades, in spite of the repeated recommendations of numerous inquiries to increase mental health funding to a point where it is adequate relative to burden of disease experienced by the Australian population. The limited funding environment;

- places immense pressure on emergency departments and acute mental health services;
- limits access to mental health supports especially community supports for vulnerable populations; and,
- has hampered efforts to achieve meaningful improvements to the outcomes achieved by the people obliged to use the fragmented and inadequate Australian mental health sector.

The impact of mental illness in Australia is extensive. Around a half of all Australians will experience poor mental health at some point in their lifetime, about 20% of Australians experience mental ill health in any given year and 2-3% of Australians will experience severe mental illness.² There are at least 240,000 mental health carers in Australia,³ many of whom have no choice but to forfeit career, education and financial opportunities to provide care to the people Australian state and federal governments consistently fail. The total value of mental health caring has been estimated at \$60.3 billion based on the cost of providing equivalent services.⁴

Chronic underfunding of the mental health system by state and federal governments has led to;

- Unacceptable delays in accessing care demonstrated by substantial wait lists for community based programs and extended delays in emergency departments;
- Inadequate access to community based services which contributes to extended hospital stays, poorly coordinated care and hospital readmissions;
- The near absence of prevention and early intervention services and inequitable access to these services for the most vulnerable populations;
- A culture of crisis management and risk prevention, which contributes to the use of more restrictive forms of care and therefore the abuse of human rights in service settings.

Several decades of mental health inquiries demonstrate a critical lack of capacity within the mental health system which contributes to systemic failure to uphold the human rights of mental health consumers and their carers and families. Five iterations of the National Mental Health Plan have sought to address these issues and have intended to build an integrated service system, to provide adequate access to community-based care, prevention and early intervention and to embed a culture of recovery-oriented practice throughout the mental health sector. The mental health system remains

¹ The Australian Medical Association (2018) 'Position Statement on Mental Health', The Australian Medical Association, Canberra.

² ABS (2007), 'National Survey of Mental Health and Wellbeing: Summary Report', ABS, Canberra.

³ Diminic et al. (2017), 'The economic value of informal mental health caring in Australia; Summary Report', Mind Australia, Heidelberg Victoria

⁴ *ibid.*

poorly integrated with a lack of coordination between mental health services in different settings and with other health and support systems. It lacks the capacity to intervene when people first become unwell in the community and to respond to mental health crises in a timely manner. While the rhetoric is right, past reform efforts have failed to address these issues because the commitment of resources has fallen far short of what is required to achieve meaningful outcomes.

This indicates a need for a better system of accountability to ensure that government is responsible for investing to provide the highest possible quality of mental health care. Accountability requires transparent data collection and reporting in addition to well-resourced advocacy, complaints and legal mechanisms to respond to issues with quality of care. At present people with lived experience of mental illness and caring, families and kinship groups, do not have access to a robust system which would enable them to hold professionals and government accountable for substandard mental health care. Nor is there an adequate system in place which would support people with lived experience of mental illness and caring to participate in designing a mental health system that upholds their rights. Ultimately, improving accountability and transparency in funding mental health services will improve outcomes for people with lived experience of mental illness, their carers and their whole community.

Three Decades of Mental Health Reform with Limited Effect

In 1993, the **National Inquiry into the Human rights of People with Mental Illness** conducted by the Human Rights and Equal Opportunity Commission (HREOC) reported on widespread systemic human rights abuses of people living with mental illness. Decades later, many of the issues the raised by the 1993 HREOC inquiry remain pertinent to the experiences of people living with mental illness and their carers and family members.

The 1993 inquiry described an acutely underfunded mental healthcare system, wherein individuals living with mental illness were routinely denied access to services and without other supports in place, while family members were left to provide ‘continuous care’ at home. The inquiry identified numerous systemic problems including widespread stigma, discrimination and disadvantage, poor integration of services, the excessive use of involuntary treatment and restrictive practices in mental health settings and poor reporting and accountability mechanisms in mental health services. In particular, the inquiry identified that the shift from psychiatric institutions to mainstream hospitals had not resulted in additional funding to community care. The inquiry noted that;

“There are fundamental and widespread inadequacies in the ‘community care’ available to the majority of Australians affected by mental illness. These deficiencies are incompatible with the rights of those individuals to appropriate care, treatment and rehabilitation and in some instances, compound the ignorance and stigma still commonly associated with mental illness.”⁵

This prompted decades of ‘strategic reform’ in mental health which aimed to shift from a hospital-based system that provided ‘crisis response’ to a system which would provide prevention, early intervention and ongoing care and management of chronic mental ill health in a community-based setting. Notable reform efforts include; five reiterations of the national mental health plan, new services and programs (for example the Commonwealth Better Access Scheme and the Housing and Accommodation Initiative in NSW, ‘HASI’) and major structural changes (notably the recent introduction of Primary Healthcare Networks (PHNs) and the shift to activity-based funding). While there has been significant progress, particularly in directing policy to mandate a person-centred and

⁵ Human Rights and Equal Opportunity Commission (HREOC) (1993) ‘Human Rights and Mental Illness; Report of the National Inquiry into the Rights of People with Mental Illness’, HREOC, Sydney.

recovery-oriented models of care, numerous structural, access and service issues identified by the 1993 inquiry remain pertinent many years down the track.

The 2014-2024 “Living Well Strategic Plan for Mental Health in NSW” describes the issue as follows;

“We can see with hindsight that underspending on community activity was in part because the hospitals were and remain such a powerful centre of gravity. They have been and continue to be in NSW and Australia more broadly the main locus of funding and the centre of professional careers. And because they are more expensive than community support, they have sucked funds out of other programs in a self-perpetuating loop.”⁶

Over the past three decades, there have been numerous inquiries, reviews and audits noting critical structural problems that impact upon the human rights of people living with mental illness and their family and carers. Several reiterations of aspirational reform that has not linked to practical solutions, substantial new investment or tangible outcomes and accountability frameworks. Each has been followed by yet another review identifying the same issues. In 2014, when John Mendoza resigned as National Mental Health Commissioner, he wrote the article, “*Whereto mental health reform in Australia: is anyone listening to our independent auditors?*”, which cheekily described this cycle as a ‘*rerun of Groundhog Day.*’⁷

The limited success of numerous attempts at ‘strategic reform’ in mental health has prompted the current Productivity Commission inquiry into mental health to ask;

“Why have past reform efforts by governments over many years had limited effectiveness in removing the structural weaknesses in healthcare for people with a mental illness? How would you overcome the barriers which governments have faced in implementing effective reforms?”⁸

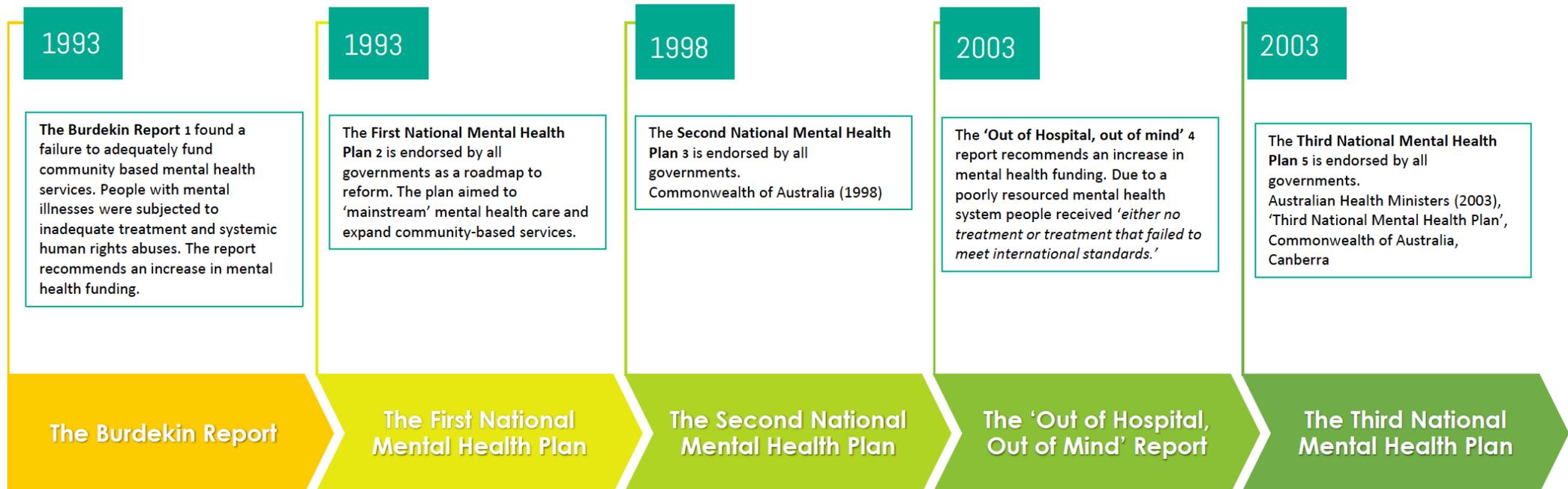
Three decades worth of mental health inquiries provides substantive evidence that the mental health system is in urgent need of reform. Past reports repeatedly describe a mental health system which is poorly integrated and identify significant gaps in service provision, especially in community care. They identify a failure to address underlying determinants of mental ill health by providing prevention and early intervention services to people at risk of developing mental ill health, through to a lack of intensive care coordination and case management for individuals experiencing chronic mental ill health. Numerous inquiries have noted the use of restrictive practices and involuntary care of people living with a mental illness as a systemic human rights issue. In 2017, even after decades of reform, the review of seclusion, restraint and observation in NSW Health Facilities tragically could not find a single example of a cohesive therapeutic program in NSW public mental health facilities. In the face of overwhelming evidence, it is unacceptable for government to continue to ignore the root cause of these issues; that the mental health sector needs to be appropriately resourced so that the highly skilled and well-intended workforce is able to build a quality and humane system which upholds the rights of people experiencing mental ill health.

⁶ Mental Health Commission of NSW (MHCNSW) (2012) ‘Living Well; A Strategic Plan for Mental Health in NSW’, MHCNSW, Sydney.

⁷ Griffiths, K., Mendoza, J. & Carron-Author, B. (2015), ‘*Whereto mental health reform in Australia: is anyone listening to our independent auditors?*’, Medical Journal of Australia, 202(4): 172-174.

⁸ Productivity Commission (2019), ‘Issues Paper; The Social and Economic Benefits of Improving Mental Health’, Productivity Commission, Canberra.

Mental Health Reform Timeline



1. HREOC (1993), 'Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with a Mental Illness', AGPS, Canberra

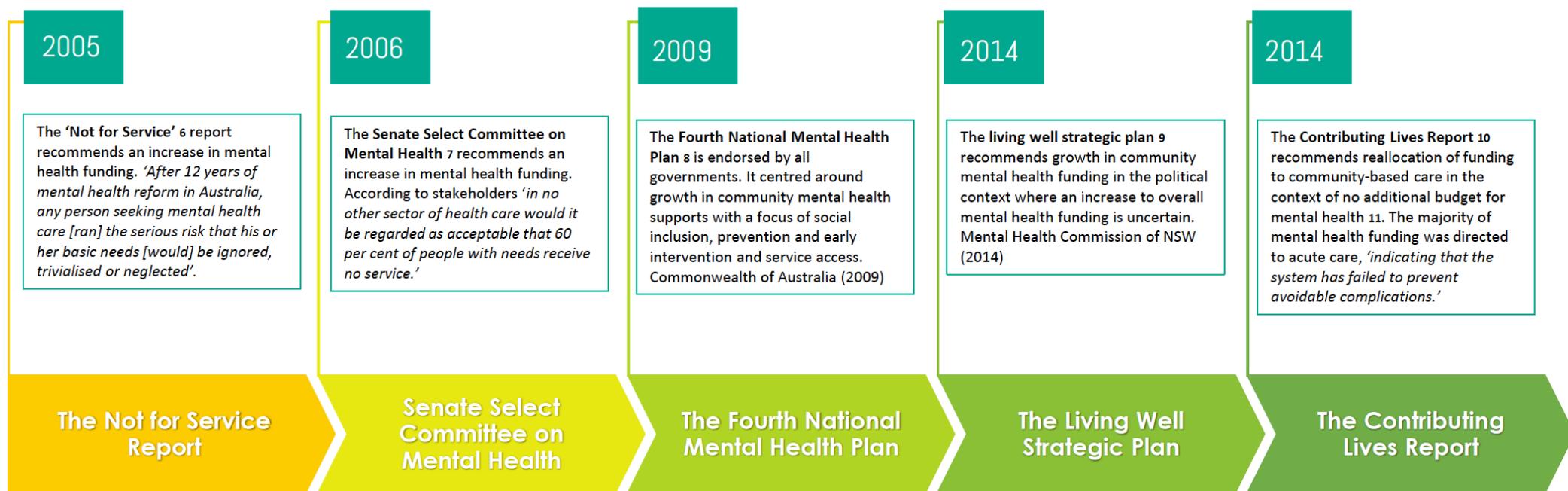
2 Commonwealth of Australia (1993), 'First National Mental Health Plan', Commonwealth of Australia, Canberra

3 Commonwealth of Australia (1998), 'Second National Mental Health Plan', Commonwealth of Australia, Canberra

4 Groom G, Hickie I, Davenport T. 'OUT OF HOSPITAL, OUT OF MIND!' A report detailing mental health services in Australia in 2002 and community priorities for national mental health policy for 2003-2008. Canberra: Mental Health Council of Australia, 2003.

5 Australian Health Ministers (2003), 'Third National Mental Health Plan', Commonwealth of Australia, Canberra

Mental Health Reform Timeline



6. Mental Health Council of Australia (2005), 'Not For Service: Experiences of Injustice and Despair in Mental Health Care in Australia', Mental Health Council of Australia, Canberra

7. Commonwealth of Australia (2006) 'A national approach to mental health – from crisis to community: final report of the senate select committee on mental health', Commonwealth of Australia, Canberra

8. Commonwealth of Australia (2009) 'Fourth National Mental Health Plan', Commonwealth of Australia, Canberra

9. Mental Health Commission of NSW (2014) 'Living Well: A Strategic Plan for Mental Health in NSW 2014-2024', Sydney, Mental Health Commission of NSW

10. National Mental Health Commission (2014) 'Contributing Lives, Thriving Communities; The National Review of Mental Health Programmes and Services.' Sydney, National Mental Health Commission, Sydney

11. National Mental Health Commission (2019) 'Submission to the Productivity Commission Inquiry into the Social and Economic Benefits of Improving Mental Health', National Mental Health Commission, Sydney

Mental Health Reform Timeline



12. Commonwealth of Australia (2017) 'Fifth National Mental Health Plan', Commonwealth of Australia, Canberra

13. Commonwealth of Australia (2018) 'Report of The Senate Select Committee into the Accessibility and quality of mental health services in rural and remote Australia', Commonwealth of Australia, Canberra

14. The Productivity Commission (2019) 'The Social and Economic Benefits of Improving Mental Health – Issues Paper', The Productivity Commission, Canberra

An Evidence Based Roadmap to Reform

The work of previous mental health inquiries have provided an evidence based roadmap for mental health reform. Key recommendations have included:

Increase Mental Health Funding

Sustainably increase mental health funding to “more closely reflect the burden of disease and to satisfy significant unmet need.” As recommended by the **Human Rights and Equal Opportunity Commission (HEROC)** in 1993, **the Mental Health Council of Australia** in 2003, the **Senate Select Committee on Mental Health** in 2006 and the **Australian Medical Association** in 2018.

Increase Access to Community Supports

Use increased mental health funding to bolster access to community mental health services. There is broad consensus that a larger portion of mental health funding should be directed to community based care. This has been recommended by **HEROC** in 1993, the **Senate Select Committee on Mental Health** in 2006, the **NSW Mental Health Commission (MHCNSW)** in 2014, **the National Mental Health Commission (NMHC)** in 2014.

Improve Service Integration;

The mental health system is fragmented with numerous gaps in services as well as costly doubling up of services. Poor service integration results in a failure to provide coordinated care to individuals throughout their journey. This issue has been in inquiries including; by **HEROC** in 1993, the **Senate Select Committee on Mental Health** in 2006, the **NSW Mental Health Commission** in 2014 and the **National Mental Health Commission** in 2014. There is broad consensus that structural reform of the mental health system is required to improve service integration.

Improve Government Accountability;

The fragmented nature of the mental health system is contributed to by a lack of clearly delineated responsibility between states and Commonwealth Government to provide mental health services. At a system wide level. Such as identified by **HEROC** in 1993, the **National Mental Health Commission** in 2014 and the **Productivity Commission** in 2019. Governments should strike a new national agreement on mental health which clearly defines responsibility and accountability of both Commonwealth and State governments for the design, provision and evaluation of mental health services and sets standards for the public reporting of mental health service data.

⁹ HREOC (1993) op. cit.

¹⁰ Groom, G., Hickie, I. & Davenport, T. (2003) 'Out of Service, Out of Mind!' The Mental Health Council of Australia, ACT

¹¹AMA (2018) op. cit.

¹² Commonwealth of Australia (2006) 'Report of the Senate Select Committee on Mental Health', Commonwealth of Australia, Canberra.

¹³ The National Mental Health Commission (NMHC) (2014), 'Contributing Lives, Thriving Communities; the Report of the National Review of Mental Health Services', The National Mental Health Commission Canberra.

¹⁴ HEROC (1993) op. cit.

¹⁵ Commonwealth of Australia (2006)

¹⁶ MHCNSW (2014) op. cit.

¹⁷ NMHC (2014) op. cit.

The Right to the Highest Attainable Standard of Health

“Despite clear evidence that there can be no health without mental health, nowhere in the world does mental health enjoy parity with physical health in national policies and budgets or in medical education and practice.”¹⁸ - Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Mental health is a fundamental human right which states have a responsibility to uphold. According to the Lancet Commission on sustainable development states have a responsibility to use a positive rights-based approach to support the wellbeing and dignity of people living with mental illness and those at risk of poor mental health, and to *‘enable an environment that promotes mental health for all’*.¹⁹ Core obligations for states include non-discriminatory access to health services and this involves state action to ensure that mental health consumers have equitable access to health care. This right requires states to take action to guarantee *‘equal access to rights-based mental health services, including the equitable distribution of services in the community.’*²⁰ This implies that states have a responsibility to appropriately resource the mental health sector.

All Australians should have timely access to quality mental and physical health services. A positive human rights-based approach is required by government to achieve this outcome. The substantive work of previous inquiries in Australia has established that chronic underfunding of mental health services causes dysfunction across all levels of the mental health system ranging from acute care to preventative services. Substantial reform is required by government to design a quality mental health system which is integrated between all levels of service delivery and across numerous social sectors. Reform will need to be accompanied by a substantial increase in funding to the mental health sector to achieve meaningful change to the lives of people living with severe mental ill health and their families.

Investment into a recovery oriented mental health system which is responsive to the demand for mental health services and intervenes early when people are at risk of developing mental health issues is both cost effective and humane. Evidence demonstrates that when people at risk of developing mental health conditions can link to services early, outcomes are improved, people are able to recover quickly, and the effects of enduring mental illness are often avoided entirely.²¹ When services provide responsive recovery-oriented care within the community to people who have moderate to severe mental illness, outcomes are improved, people are able to improve their quality of life and hospitalisations are avoided.²²

In 2014 the National Mental Health Commission recommended that a larger proportion of mental health funding be realigned to preventative and community mental health services order to implement an ‘integrated stepped care model’ across the mental health system.²³ ‘Stepped care’ refers to a framework of service delivery wherein a spectrum of services are provided to match individuals level of need, ranging from preventative programs to address whole-of-community needs to acute care services designed to respond to crisis situations. The contributing lives review’s model of ‘stepped care’ emphasises the need for integrated care pathways and better coordination of care for individuals with moderate to severe mental ill health and/or complex needs.

¹⁸ United Nations General Assembly (2017), Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ A/HRC/35/21

¹⁹ Patel et al. (2018), ‘The Lancet Commission on global mental health and sustainable development’, The Lancet, Vol. 392, No. 10157

²⁰ ibid.

²¹ McGorry, G. & Mei, C. (2018) ‘Early intervention in youth mental health: progress and future directions’, Evidence Based Mental Health, Vol. 21, No. 4

²² ibid.

²³ NMHC (2014) op. cit.

In response to the contributing lives review, the Australian government is in the process of phasing in a ‘new wave’ of mental health reforms.²⁴ Successful implementation will require greater investment in community mental health services and not a zero-sum reallocation of funding. These concerns were expressed by the NMHC in its submission to the Productivity Commission Inquiry into Mental Health;

“In order to achieve [a reallocation of funding] while maintaining a seamless provision of service delivery to meet current need, this requires, initially, a greater investment in community based prevention and early intervention approaches, which – over time – would should see a shift in demand towards lower cost activities with less reliance on high cost activity and interventions (hospital based care; welfare support).”²⁵

An Acute System Under Pressure

Multiple inquiries have expressed concern that the bulk of mental health funding in Australia remains concentrated in services which provide acute care. For instance, in 2014 the National Review of Mental Health Services entitled “Contributing Lives” noted that;

“The greatest level of funding goes into high cost areas such as acute care, the criminal justice system, and disability support, indicating that the system has failed to prevent avoidable complications in people’s lives.”²⁶

The result is that individuals to need to wait until they become acutely unwell or experience a mental health crisis before they are eligible to receive support. Acute care delivered in the absence of discharge to ongoing care and management of complex mental health issues in the community does little to support long term positive outcomes for individuals experiencing mental ill health. This contributes to a *cycle in and out of hospital* for many people living with severe mental illness and places considerable stress on the acute care system. Increasing numbers of mental health presentations to emergency departments and high rates of hospital readmissions are indicators that community mental health services are lacking.

In the context of a limited funding environment, there will always be pressure to direct the bulk of funding and services to acute care to manage the risks associated with acute mental illness. While it is important to support people living with mental illness and their families to be safe, a system that is primarily driven by risk management and crisis response (rather than recovery oriented treatment or support), will always fail to deliver the longer-term outcomes which enable people to live meaningful lives and to enjoy full participation in the community of their choice on an equal basis with others.

Inpatient hospitalisation is an expensive and highly restrictive form of mental health care. The national minimum dataset suggests that many people experience improvements in their mental health immediately following an inpatient admission. However, in 2016-17, 23.8% of inpatient admissions resulted in no significant change in clinical outcomes and an additional 4.8% of admissions resulted in significant deterioration.²⁷ The widespread use of involuntary treatment and restrictive practices in inpatient settings (instead of slower engagement practises), causes further harm and continues to traumatise individuals, hindering recovery. Providing adequate access to community-based care will

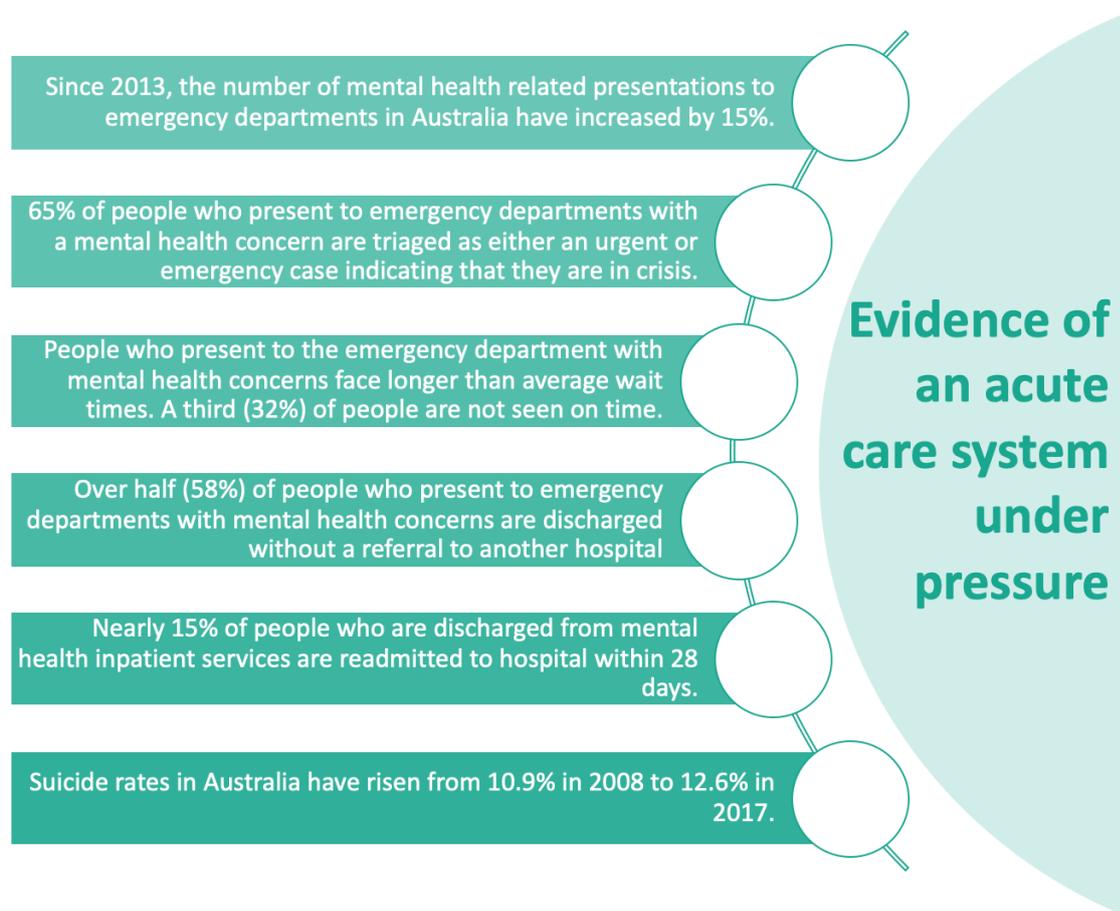
²⁴ ibid.

²⁵ NMHC (2019),

²⁶ The National Mental Health Commission (NMHC) (2014), ‘Contributing Lives, Thriving Communities; the Report of the National Review of Mental Health Services’, The National Mental Health Commission Canberra.

²⁷ AIHW (2019), ‘Key Performance Indicators for Australian Public Mental Health Services Tables’, AIHW, Canberra.

work towards meeting Australia’s human rights obligations to avoid the use of restrictive practices including involuntary mental health treatment, seclusion and restraint.



The Underlying Determinants of Mental Ill Health

The relationship between mental illness and disadvantage is complex and multidirectional. Multiple forms of disadvantage are determinants of mental ill health, likewise discrimination and stigma, combined with the symptoms of mental ill health can impair peoples’ ability to exercise their social, economic and political rights. International law requires states to address the underlying social determinants of mental ill health such as freedom discrimination, supportive family environments and access to basic needs including quality housing.³⁴ Likewise states have a responsibility to enable people with a mental illness to participate fully in the society and to exercise their fundamental rights and freedoms.

²⁸ AIHW (2019), ‘Mental Health Services Provided in Emergency Departments Tables 2017-18’, AIHW, Canberra

²⁹ The Australasian College for Emergency Medicine (2018) ‘The Long Wait: An Analysis of Mental Health Presentations to Australian Emergency Departments’ Australasian College for Emergency Medicine, Melbourne

³⁰ *ibid.*

³¹ *ibid.*

³² AIHW (2019), ‘Key Performance Indicators for Australian Public Mental Health Services Tables’, AIHW, Canberra.

³³ ABS (2018) ‘Causes of Death, 2017’, cat no. 3303.0, ABS, Canberra

³⁴ United Nations General Assembly (2017) *op. cit.*

The Missing Middle

People living with a mental illness in Australia experience multiple forms of disadvantage including discrimination, stigmatisation, poverty, poor physical health, low employment rates and high rates of homelessness and incarceration.

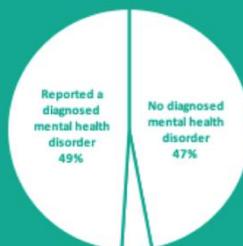
As a cohort people with mental illness experience multiple forms of disadvantage

People living with mental illness are 3 to 9 times more likely to be in prison than the general population.³⁸

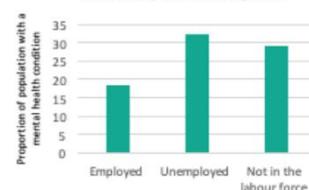
1 in 3 people seeking support from specialist homelessness services have a mental health condition.³⁹



HIGH RATES OF MENTAL ILLNESS AMONG PRISON ENTRANTS⁴⁰



PEOPLE LIVING WITH MENTAL ILLNESS ARE LESS LIKELY TO BE EMPLOYED⁴¹



The life expectancy of people living with mental illness is between 10 to 25 years shorter than the general population.⁴²

Only 1 out of 4 people with a psychosocial disability aged 18-64 are employed,



Compared to 8 out of 10 people who do not have a disability.⁴⁵



AN INCREASING NUMBER OF PEOPLE WITH A MENTAL HEALTH CONDITION ARE ACCESSING SPECIALIST HOMELESSNESS SERVICES⁴³



Compared to the general population, people living with mental illness are more likely to be a victim of a violent crime, bullying or harassment.⁴⁴

The disadvantages experienced by people living with mental illness are exacerbated by inadequate access to quality mental health services, especially community-based care. The 'missing middle' is a term that has been used to describe the gap between low intensity services and hospital provided services⁴³ even though it is clear there are not enough acute in-patient beds either. There is an emerging cohort of people who live with moderate to severe mental ill health and do not present with the acuity of symptoms required for hospital admission. This population often experience complex biopsychosocial issues associated with chronic mental illness such as poor physical health, disability, poverty, unemployment and homelessness. Due to the level of complexity, primary care services do

³⁵ McCausland, R., Johnson, S., Baldry, E., Cohen, A. (2013) 'People with mental health disorders and cognitive impairment in the criminal justice system Cost-benefit analysis of early support and diversion.', the University of New South Wales & PWC

³⁶ AIHW (2019), 'Specialist Homelessness Services 2017-2108 Tables', AIHW, Canberra

³⁷ AIHW (2018), 'The Health of Australia's Prisoners', AIHW, Canberra

³⁸ ABS (2016) 'Survey of Ageing Disability and Carers Disability Tables', ABS, Canberra

³⁹ Erlangsen et al. (2017) 'Cause-specific life-years lost in people with mental disorders: a nationwide, register-based cohort study' The Lancet Psychiatry, Vol 4, 937-945

⁴⁰ AIHW (2019), 'Specialist Homelessness Services 2017-2108 Tables', AIHW, Canberra

⁴¹ NSWMC (2014) 'Mental Health and the Justice System', MHCNSW, Sydney, available at <https://nswmentalhealthcommission.com.au/mental-health-and/the-justice-system>

⁴² ABS (2016) 'Survey of Ageing Disability and Carers Disability Tables', ABS, Canberra

⁴³ NMHC (2014) op cit.

not adequately meet the needs of this cohort. Likewise, MBS funded allied health services, which are capped at 12 sessions per year, do not provide the intensive care and case management required.

Access to care coordination is critical to address complex disadvantage typically experienced by people with chronic, severe mental ill health. There are several successful examples which have provided coordinated care to individuals who fall into the 'missing middle'. The NSW government is piloting the LikeMind project in three LHDs across NSW. LikeMind is designed to provide coordinated care and case management to individuals living with moderate and/or enduring mental illness by coordinating their access to other social services including; health, housing, disability and alcohol and other drug services. LikeMind involves the co-location of multiple social services in one location and, as of December 2017, has provided support to 2000 people.⁴⁴ Other models of community based mental health supports for people with moderate or enduring mental ill health include Regional Mental Health and Wellbeing Hubs in Queensland which provide a range of co-located services and the Safe Haven Café model in Victoria which provides peer support and other resources in a safe therapeutic environment.⁴⁵ The Safe Haven Café model has been shown to reduce the likelihood that consumers need to access acute mental health services such as emergency departments and inpatient units.⁴⁶ Unfortunately, these programs are sporadically available and receive a very small portion of overall mental health funding.

Providing services to fill in the 'missing middle' also requires investment across multiple social service sectors including; disability, justice, education, housing and employment. Numerous inquiries have noted a lack of specialised services which have the capacity to support individuals experiencing mental illness across the social services sector including; homelessness services, alcohol and other drug services, social support payments, employment services and the criminal justice system;

Housing and Homelessness Services;

The symptoms of mental illness (such as difficulties with daily living tasks and poor regulation of behaviour) often impact upon individuals' ability to secure and maintain suitable housing. Up to 16% of people living with a mental illness live in unsuitable housing.⁴⁷ A third of people accessing specialist homelessness services have a mental health condition.⁴⁸

Suitable housing is an important protective factor in promoting long term recovery for people experiencing mental ill health. In the absence of suitable accommodation in the community, places individuals with complex needs at risk of detention in inpatient mental health services (and sometimes the criminal justice system). Up to 30% of people in inpatient facilities could be discharged if appropriate housing and community services were available.⁴⁹

NSW has implemented several programs which support individuals with a mental illness to maintain accommodation in the community including HASI (Housing and Accommodation Support Initiative) and CLS (Community Living Supports). Both programs are similar in the types of support which consumers receive. An evaluation of HASI found that the program reduced hospital readmission and length of stay, improved mental health, independence in daily living, social participation and involvement in education or work and increased the likelihood that consumers maintained stable

⁴⁴ The Mental Health Coordinating Council (MHCC) (2019) 'Mental Health Matters', MHCC, Sydney

⁴⁵ Ibid

⁴⁶ Ibid.

⁴⁷ Productivity Commission (2019) 'Draft Report – Mental Health', Productivity Commission, Canberra

⁴⁸ AIHW (2019), 'Specialist Homelessness Services 2017-2108 Tables', AIHW, Canberra

⁴⁹ Productivity Commission (2019), *op. cit.*

accommodation.⁵⁰ Both HASI and CLS programs are currently operating at full capacity and typically have long wait lists in most regions.

Alcohol and Other Drug Services;

Comorbid substance dependence is extremely common in people living with mental illness with estimated rates ranging between 47% to as high as 100%.⁵¹ In spite of these figures, both mental health and AoD services often lack expertise and specialised models of care to support individuals experiencing comorbid mental illness and substance dependence and therefore exclude them from *all* services. In 2005, the Human Rights Commission reported that ‘persons with comorbid mental health and substance abuse problems are commonly picked up by the criminal justice rather than the mental health system.’⁵² In 2014, the National Mental Health Commission identified a lack of mental health support in alcohol and other drug services as a significant gap in mental health service delivery.⁵³ A lack of capacity across both the mental health and alcohol and other drug service system results in individuals with the most complex needs being turned away by services. Additional investment in services which provide specialised models of care suitable for individuals with a dual diagnosis is critical to ensure individuals with the most complex needs have timely access to support.

Social Support Payments;

Amendments to the Disability Support Pension (DSP) in 2012 and 2015 have raised the bar for individuals with a disability to be eligible for the Disability Support Pension which is paid at the highest rate of payment (\$933.40 per fortnight for a single person). The complexity of the application process was already a significant barrier for people with a psychosocial disability to access DSP, requiring extensive documentation and medical evidence. Amendments to the DSP have corresponded to massive increase of people with a disability who receive Newstart, which is paid at a lower rate (\$559.00 per fortnight for a single person) and places additional requirements on recipients to meet ‘mutual obligations’ in order to receive the payment. This has the effect of pushing already disadvantaged individuals further into poverty and can impact upon their ability to afford housing.

The Justice System;

People living with a mental illness are over-represented in the justice system, often as a consequence of inadequate access to mental health services, disability and housing supports. For instance, several pilot programs have demonstrated that investment in mental health and alcohol and other drug services can be effective in diverting people away from the criminal justice system.⁵⁴ Recent media coverage of several tragic stories where individuals experiencing a mental health crisis were turned away from emergency departments and were subsequently involved in violent crimes also highlight this point. Despite this there is still no legal priority to divert even people who have offended purely and only because of their experience of mental illness to treatment over punishment.

Targeted Prevention and Early Intervention for Disadvantaged Groups

Population groups which experience higher rates of mental ill health in Australia include;

- People living in rural or remote areas,
- People from lower socio-economic backgrounds
- Aboriginal and Torres Strait Islander People.⁵⁵

⁵⁰ Purcal, C., Zmudzki, F., Hill, T., Giuntoli, G., Fisher, KR., O’Shea, P. (2019), Evaluation Plan Housing & Accommodation Support Initiative Plus (HASI Plus), (SPRC Report 1/19). Sydney: Social Policy Research Centre, UNSW Sydney.

⁵¹ Productivity Commission (2019) op cit.

⁵² AHRC (2005) op cit.

⁵³ NMHC (2014) op cit.

⁵⁴ KPMG (2018) ‘Maranguka Justice Reinvestment Project Impact Report’ KPMG, Sydney.

⁵⁵ Meadows, G., Enticott, J., Inder, B., Russell, G.M. & Gurr, R. (2015) ‘Better access to mental health care and the failure of the Medicare principle of universality’, Medical Journal of Australia. 2015; 202

These groups have disproportionately poor mental health and wellbeing outcomes and lower access to Medicare Benefits Schedule (MBS) funded allied mental health care.⁵⁶ This indicates that the bulk of investment in low intensity supports has not reached the communities where it is most needed. The MBS is the largest program which specifically provides support to individuals experiencing milder mental health concerns. However, there are a limited number of bulk billing allied mental health professionals and the cost gap-payments is prohibitive for many. Workforce shortages in rural and region areas also contribute to a lack of access to MBS funded mental health services.⁵⁷

Early access to timely treatment when mental health concerns first arise reduces the likelihood that an individual develops chronic or severe mental ill health and, in some cases, can prevent mental illness in the first place. It is therefore essential that communities at the highest level of risk of developing mental ill health have timely access to appropriate mental health supports. PHN commissioned services (such as headspace) which provide free allied mental health care and outreach services are critical to ensure that mental health support is available to disadvantaged groups. At present, this type of service represents a small portion of overall spending on low intensity supports.⁵⁸

Families and carers are also a population group that experiences significant disadvantage in terms of mental and physical health. For instance one study found that families and carers experience the lowest level of wellbeing within population sub groups based on 13 years of the Australian Unity Wellbeing Index.⁵⁹

Families and Carers

Where appropriate mental health supports aren't available, friends, family members and carers often attempt to support people experiencing mental illness. In many cases, with very little training or education in mental health and without support, supervision or advice from skilled professionals. The limited availability of community mental health supports places carers in the predicament where setting healthy boundaries is challenging. Without appropriate access to community supports people are placed in the unenviable predicament where they are reliant on family and friends to stay safe, maintain accommodation, take medication, complete daily tasks, regulate their emotions and afford the basic costs of living. This places significant strain on families and care networks and can interrupt carers' ability to participate in education, employment and social commitments.

Carer supports are highly valued by carers and have multiple positive outcomes including;

- Improved mental health and wellbeing
- Improved quality of relationship with the care recipient
- Increased knowledge and skills related to the caring role
- Social connection to other carers in similar situations⁶⁰

Carer respite also provides opportunities for carers to participate in employment, voluntary work, education and recreational activities.

Funding to mental health carer services has faltered significantly in the context of the transition to the NDIS. Mental Health Carer Respite, which previously received \$62 million annually, has been defunded and not replaced by anything like an equivalent. This program previously funded a wide range of

⁵⁶ Meadows, G., Enticott, J., Inder, B., Russell, G.M. & Gurr, R. (2015) 'Better access to mental health care and the failure of the Medicare principle of universality', *Medical Journal of Australia*, 202(4): 190-194

⁵⁷ Commonwealth of Australia (2018) 'Report of the Senate Inquiry into Accessibility and quality of mental health services in rural and remote Australia', Commonwealth of Australia, Canberra

⁵⁸ Productivity Commission (2019) op. cit.

⁵⁹ Kemp, B., King, S., Paleologos, Z., Bellamy, J. & Mollenhaur, J. (2016) 'Carers; Doing it tough, doing it well', Anglicare, Sydney.

⁶⁰ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016) 'Transitioning Australian Respite', Social Research and Policy Centre, UNSW, Sydney

respite services on the basis of carer needs which supported carers to spend time devoted to their own wellbeing. An evaluation of the program demonstrated that it was highly valued by carers and that carers who participated in the program felt that it had supported them to develop improved coping strategies, reduce stress and anxiety, better utilise strategies to support their own wellbeing and better manage their caring role.⁶¹

In pace of respite services, the Commonwealth Government has funded Integrated Carer Support Services (ICSS). The ICSS is intended to provide a range of tailored support services through the Carer Gateway and is intended to match carers with an appropriate level of support based on an assessment of needs. Although the service is intended to provide for a diverse range of carers, funding has not been specifically allocated to provide specialised services to mental health carers. This is of concern, given that mental health carers typically provide specialised supports due to the distinctly different nature of their caring role. Furthermore, given the amount of funding dedicated to the program (\$85 million over three years), it is unlikely that the program will provide the same level of specialised support that mental health carer respite provided.

Freedom from Inhuman or Degrading Treatment

Mental health inquiries have raised serious concerns around the quality of mental health services in Australia, particularly with regard to acute care services as well as involuntary care delivered in the community. The 1993 HEROC report found that the rights of people were frequently ignored or abused in inpatient mental health care.⁶² The 2005 'Not for Service' report by the AHRC expressed concerns of numerous carers, consumers and other stakeholders around human rights abuses and restriction of freedom of people living with mental illness, especially in inpatient care. The report noted that;

“An inability to access services prior to the need for acute care also meant that many consumers were not able to select the most appropriate option in the most empowering setting. Deteriorating mental health and the need for acute care often resulted in the need for sedation, restraint and seclusion; the maximum restriction of rights. Some consumers entered the criminal justice system due to an inability to access treatment and support services, also reflecting a maximum restriction of rights.”⁶³

More recently the inquiry into the use of seclusion, restraint and observation in NSW Health Facilities noted the absence of predictable therapeutic programs and inconsistent delivery of care planning across mental health facilities in NSW. The absence of consistent supportive, person-centred care and a therapeutic environment which treats people with lived experience with dignity and respect can further traumatise and trigger individuals and contributes to overuse of the most restrictive forms of 'care'.⁶⁴

The use of coercive involuntary treatment underpins mental health and guardianship laws in Australia. Seclusion and restraint of people living with mental illness occurs in multiple contexts across Australia including in; mental health, age care, education, disability and criminal justice. There is no one single policy, law or governance structure for the definition, use, monitoring and reporting of seclusion and restraint across different settings Australia. Instead, there are multiple policy frameworks which

⁶¹ Carers NSW (2015) 'Carers NSW Mental Health Respite Carer Support Evaluation 2015', Carers NSW, Sydney

⁶² Australian Human Rights Commission (AHRC) (2005) 'Not for Service; Experiences of Injustice and Despair in Mental Health Services in Australia', Australian Human Rights Commission, Sydney.

⁶³ Ibid.

⁶⁴ Wright, M. 'Review of Seclusion, Restraint and Observation of Consumers with a Mental Illness in NSW Health Facilities' NSW Health, Sydney

imperfectly and inconsistently govern and monitor the use of seclusion and restraint in different settings and in different states. In NSW, the use of involuntary treatment on people living with mental illness is primarily governed by the following legislation;

The Mental Health Act (2007)	The Guardianship Act (1987)
<ul style="list-style-type: none"> • People who are determined to be a 'mentally ill' or 'mentally disordered' person can be detained under the act at a mental health facility for treatment if they are at 'serious risk of harm to themselves or others.' • Involuntary treatment in the community can be administered under the act when the NSW Mental Health Tribunal determines that there is 'no other care of less restrictive kind, that is consistent with safe and effective care.' This includes administering medication. 	<ul style="list-style-type: none"> • Under the Guardianship Act (1987) the NSW Civil and Administrative Tribunal may appoint a guardian for a person who 'because of a disability, is totally or partially incapable of managing his or her person.' • Guardians can be granted broad decision making powers over multiple aspects of an individual's life including financial decisions, accommodation arrangements, health and disability care decisions and consent to medical treatment.

Involuntary Treatment

Article 14 of the Convention on the Rights of Persons with Disabilities states that;

States Parties shall ensure that persons with disabilities, on an equal basis with others:

- a) Enjoy the right to liberty and security of person;*
- b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.⁶⁵*

The committee on the Rights of Persons with Disabilities has expressed the complete prohibition of involuntary detention based on disability and the complete elimination of forced treatment.⁶⁶ In 2013, the committee recommended that Australia;

"Repeal all legislation that authorizes medical intervention without the free and informed consent of the persons with disabilities concerned, committal of individuals to detention in mental health facilities, or imposition of compulsory treatment, either in institutions or in the community, by means of Community Treatment Orders."⁶⁷

In contrast, the United Nations Human Rights Committee has interpreted article 14 as follows;

"The existence of a disability shall not in itself justify a deprivation of liberty but rather any deprivation of liberty must be necessary and proportionate, for the purpose of protecting the individual in question from serious harm or preventing injury to others. It must be applied only as a measure of last resort and for the shortest appropriate period of time, and must be accompanied by adequate procedural and substantive safeguards

⁶⁵ United Nations (2006) 'Convention on the Rights of Persons with Disabilities', United Nations, New York

⁶⁶ United Nations (2017) 'Mental Health and Human Rights; Report of the United Nations High Commissioner for Human Rights', GE.17-01400(E)

⁶⁷ United Nations Committee on the Rights of Persons with Disabilities (2013) 'Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session', CRPD/C/AUS/CO/1

*established by law. The procedures should ensure respect for the views of the individual and ensure that any representative genuinely represents and defends the wishes and interests of the individual.*⁶⁸

The evolving debate around involuntary treatment at an international level demonstrates that is a complex area which raises numerous ethical dilemmas for all involved in the provision of involuntary care. MHCN notes that many carers support the use of involuntary treatment in circumstances where an individual is at risk of serious harm and there are no appropriate options to provide care in a less restrictive environment. Many carers view involuntary treatment as necessary to ensure their own safety, as well as the safety of their family. Likewise, many carers view guardianship as necessary to support the wellbeing of people living with mental illness when the symptoms of ill mental health interfere with their capacity to make informed decisions.

There is some debate among consumers and carers as to whether involuntary treatment should be used and if so under what circumstances. However, there is general agreement that particular care needs to be taken to ensure the highest quality of treatment for people subject to involuntary care, due to the substantial power imbalances involved. No person should be forcefully subjected to poor quality or abusive treatment which makes them worse and inflicts additional trauma.

Regardless of interpretation of Article 14 there is widespread consensus that Australia has an obligation to minimise the use of involuntary mental health treatment and promote the least restrictive form of care. This can be achieved by;

1. Improving access to voluntary treatment in the community to reduce the demand for acute care services as previously discussed.
2. Promoting a therapeutic environment (including the use of trauma informed care, recovery oriented practices and a person-centred approach) across all inpatient mental health services.
3. Promoting a person-centred approach which is free from stigma increases the likelihood that consumers consent to receive treatment in the first instance.

Substitute Decision Making

Article 12 of the convention on the rights of persons with a disability states that;

2. *States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
3. *States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*
4. *States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.*⁶⁹

As stated previously many carers consider some mechanism of guardianship to be necessary when as a result of disability, individuals lack capacity to make informed decisions. Article 12 implies that states have a responsibility to provide support to people with disabilities so that they can exercise their legal capacity where ever it is possible for them to do so. It also indicates that any laws which relate to the legal capacity of individuals with a disability are subject to appropriate safeguards to prevent abuse.

⁶⁸ United Nations Human Rights Committee (2014) 'International Covenant on Civil and Political Rights General Comment No. 35', CCPR/C/CG/35

⁶⁹ United Nations (2006) 'Convention on the Rights of Persons with Disabilities', United Nations, New York

In 2017, the NSW law reform commission undertook a review of the NSW Guardianship Act (1987). MHCN made several submissions to the review of the Guardianship Act which expressed concerns including that;

- The current Guardianship Act allows for service providers to be appointed as enduring and financial guardians and this represents a significant conflict of interest especially in cases where the service provider is paid to deliver services to the individual who is subject to the guardianship order.
- There are several cases where the NSW Trustee and Guardian has excessively prioritised financial asset preservation or generation and savings to the detriment of other considerations such as the standard living of people under guardianship orders and had a very limited capacity to oversee the adequacy of support for the person under guardianship.
- Mechanism to review and alter guardianship orders under the current Guardianship Act are complex and time consuming. There is little flexibility in the guardianship orders to respond to the needs of people who experience fluctuating decision making capacity such as people living with mental ill health.⁷⁰⁷¹

The Law Reform Commission's report was a substantive piece of work based on the results of numerous consultations and 220 public submissions. Key recommendations of the review included;

- That an "Assisted Decision Making Act" which provides a framework for assisted decision making replace the current Guardianship Act which provides only substitute decision making. The new act would include options formal supported-decision making arrangements as part of 'a suite of assisted decision making options'.
- As opposed to the Guardianship Act where decisions are based on the "person's welfare and interests" the new act should require that "a person's will and preferences are given effect wherever possible." The "Assisted Decision Making Act" should also include provisions which recognise that decision-making ability can fluctuate over time.
- That an 'office of the public advocate' be established to 'to advocate for people in need of decision-making assistance, mediate decision-making disputes, provide information, advice and assistance about decision-making and investigate cases of potential abuse, neglect and exploitation.'⁷²

At present the NSW Guardianship Act is not fit for purpose. The lack of options for people with a disability to access supported decision making does not comply with article 12 of the Convention on the Right of People with Disabilities. The NSW government should, in consultation with people living with disabilities and their families and carers, act to implement the recommendations of the law reform commission review in a timely manner.

Seclusion and Restraint

Article 17 of the Convention on the Rights of People with disabilities states that;

*Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.*⁷³

The United Nations Principles for the protection of persons with mental illness and the improvement of mental health care adopted by the general assembly in 1991 states that;

⁷⁰ MHCN (2016) 'NSW LRC Guardianship Review MHCN Submission Question Paper 2 & 3', MHCN, Sydney

⁷¹ MHCN (2016) 'NSW LRC Guardianship Review MHCN Submission Question Paper 1' MHCN, Sydney

⁷² The Law Reform Commission (2018) 'Report 154: Review of the Guardianship Act', Law Reform Commission, Sydney

⁷³ United Nations (2006) 'Convention on the Rights of Persons with Disabilities', United Nations, New York

Physical restraint or involuntary seclusion of a patient shall not be employed except in accordance with the officially approved procedures of the mental health facility and only when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose.⁷⁴

The Special Rapporteur on Torture has called for an absolute ban on the use of seclusion and restraint stating that;

“there can be no therapeutic justification for the use of solitary confinement and prolonged restraint of persons with disabilities in psychiatric institutions... Moreover, any restraint on people with mental disabilities for even a short period of time may constitute torture and ill treatment... The environment of patient powerlessness and abusive treatment of persons with disabilities in which restraint and seclusion is used can lead to other non-consensual treatment, such as forced medication and electroshock procedures.”⁷⁵

In 2013, the Committee on the Rights of Persons with Disabilities noted the use of restrictive practices such as chemical, mechanical and physical restraints recommended that Australia;

‘take immediate steps to end such practices, including by establishing an independent national preventive mechanism to monitor places of detention — such as mental health facilities, special schools, hospitals, disability justice centres and prisons —, in order to ensure that persons with disabilities, including psychosocial disabilities, are not subjected to intrusive medical interventions.’⁷⁶

According to the World Health Organisation;

‘There is no evidence-based research that supports the idea that seclusion or restraints are therapeutic. Seclusion and restraints cause physical, emotional and mental harm. Also, the psychological impact and trauma of seclusion and restraint is profound and long-lasting.’⁷⁷

Article 17 suggests that governments have an obligation to proactively promote a therapeutic environment and respectful culture across all service settings which acts to minimise the use of seclusion and restraint and actively promote the dignity of individuals with lived experiences of mental illness. Critically, people with a lived experience of mental health services need to be involved the conversation around the regulation of seclusion and restraint and be empowered as active participants in designing services and policy to prevent the use of seclusion and restraint and promote less restrictive forms of care. There also needs to be formal mechanisms for monitoring which are effective, provide avenues for redress to people who have experienced human rights abuses at mental health services and to support a culture of continual quality improvement.

Access to supportive, trauma informed, therapeutic care which upholds the dignity of people living with mental illness can prevent behaviour which leads to the use of seclusion or restraint. For instance, care planning engages consumers and carers as partners in managing their behaviour and avoiding triggers. Both the 1993 HEROC review and the 2005 AHRC review indicated that under-resourcing of

⁷⁴ United Nations (1991) ‘Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care’, United Nations General Assembly resolution 46/119

⁷⁵ United Nations (2013) ‘Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, A/HRC/22/53

⁷⁶ United Nations Committee on the Rights of Persons with Disabilities (2013) ‘Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session’, CRPD/C/AUS/CO/1

⁷⁷ World Health Organization, Department of Mental Health and Substance Abuse (2017) Strategies to end the use of seclusion, restraint and other coercive practices – WHO Quality Rights training to act, unite and empower for mental health. Geneva: World Health Organization.

inpatient mental health services often jeopardised patient safety and contributed to a culture which overwhelmingly focused on safety, security and risk management as opposed to therapeutic care.^{78,79}

The recent ‘Review into Seclusion Restraint and Observation in NSW’ did not find a ‘single convincing example of a purposeful and predictable therapeutic program’ in mental health facilities in NSW and noted that inclusive care planning with carers and consumers was inconsistently delivered across all hospital mental health services.⁸⁰ The report details serious concerns around the quality of acute mental health services in NSW including that;

- a stigmatising and discriminatory culture was pervasive across all levels of the workforce,
- that there were staff with insufficient skills and mental health knowledge working with mental health consumers,
- that the overuse of ‘safe assessment rooms’ in emergency departments was traumatising to many consumers and;
- that many mental health units bear a resemblance to custodial settings.⁸¹

Previous inquiries highlight that the prevention of seclusion and restraint requires governments to proactively provide access to less restrictive care throughout a person’s journey through the mental health system, rather than reactively engage in de-escalation and risk management once inadequate access to therapeutic care has contributed to a person becoming so unwell that they pose a risk to themselves or others. The NSW governments response to the review of seclusion and restraint has significant promise, in that it seeks to address each of the nineteen recommendations made by the report.⁸² The substantial overhaul of culture, service design and policy required to achieve meaningful outcomes in this area will require ongoing monitoring of outcomes and investment of resources into the mental health system.

A Transparent and Accountable Rights Based System

According to the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health;

“Accountability for the enjoyment of the right to mental health depends on three elements: (a) monitoring; (b) independent and non-independent review, such as by judicial, quasi-judicial, political and administrative bodies, as well as by social accountability mechanisms; and (c) remedies and redress.”⁸³

Consumers, carers, professional bodies and government inquiries have expressed considerable concern around poor accountability within the mental health system and government for quality mental health care. For instance, the Human Rights Commission noted in 2005 that there was a; *‘lack of accountability for mental health spending, service deficits and critical incidents in the mental health sector.’* Likewise, the Senate Select Committee on Mental Health in 2006 reported stakeholder concerns about the level of accountability at a systemic level. These concerns were echoed by the National Mental Health Commission in 2014 which noted that *‘The Commonwealth’s major*

⁷⁸ HEROC (1993) op. cit.

⁷⁹ AHRC (2005) op. cit.

⁸⁰ Wright, M. (2018) op. cit.

⁸¹ ibid.

⁸² NSW Health (2018) ‘Mental Health Safety and Quality in NSW: A plan to implement recommendations of the Review of seclusion, restraint and observation of consumers with a mental illness in NSW Health facilities.’ NSW Health, Sydney.

⁸³ United Nations General Assembly (2017), Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ A/HRC/35/21

programmes reward volume of activity and funding of one-off patient interactions, with no accountability for effective achievement of outcomes.' Likewise, the NSW Mental Health Commission, in 2018, noted that *'it remains essential that the NSW Ministry of Health and the LHDs (and Specialty Health Networks) make a major step in improving their reporting [of mental health service outcomes] to the community.'*

Remedies or Redress for Negligent Mental Health Care

The mechanisms by which individuals can seek redress or compensation for negligent, incompetent or abusive mental health service provision are not fit for purpose. In NSW the Civil Liability Act (2002) and the Mental Health Act both include clauses which limit the liability of government services and health care professionals for negligent mental health treatment;

The NSW Civil Liability Act (2002)

- The NSW Civil Liability Act (2002) limits opportunities for people with lived experience of mental illness and their families to legally hold professionals and services accountable for negligent mental health care. The Civil Liability Act in NSW was amended in 2003 to reduce possible claims against 'public authorities' including public mental health services and their employees.
- Section 43 of the NSW Civil Liability Act was amended to state that *"Any act or omission involving an exercise of, or failure to exercise, a special statutory power does not give rise to civil liability unless the act or omission was in the circumstances so unreasonable that no authority having the special statutory power in question could properly consider the act or omission to be a reasonable exercise of, or failure to exercise, its power."* The effect of this clause is to raise the threshold of liability so high as to be impossible to hold public authorities liable for negligent practice.
- The amendment also added section 54A, which specifically states that no damages may be awarded for losses resulting from negligent care which results in a mentally ill person committing a violent offense.

The Mental Health Act (2007)

- Section 191 states that any police officer, ambulance officer, health care professional and NSW staff member who *'in good faith, exercises a function that is conferred or is imposed on that person by or under this Act or the Mental Health (Forensic Provisions) Act 1990 is not personally liable for any injury or damage caused by the exercise of that function.'*
- Sections 3, 68 and 194 of the act outline the objectives of the health system and the general principles which should be considered when administering involuntary treatment. This includes the principle that 'people should receive the best possible care and treatment in the least restrictive environment' and that people should receive 'timely and high quality care'.
- However, section 194 states that *'The provisions of sections 3, 68 and 105 are intended to give guidance in the administration of this Act and do not create or confer on any person, any right or entitlement enforceable at law.'*

The effect of these clauses is that in practicality it is very difficult, if not impossible to hold government, public mental health services and their staff members legally responsible for poor mental health treatment. Although people with lived experience of mental illness have some formal avenues for complaint in NSW via the official visitor's scheme and the Health Care Complaints Commission, these

resolution mechanisms primarily rely on negotiation or revocation of practitioners' license in the absence of options for legal action.

For instance, the Official Visitors Scheme is legislated for in the NSW Mental Health Act (2007). Official Visitors are employed to routinely inspect Local Health District emergency departments, acute and community mental health services. Official visitors can investigate complaints from patients, their families or staff members and in many instances, will seek to negotiate a solution between relevant parties or to improve service practice to align with safety and quality standards. Official visitors can report serious issues to the Principal Official Visitor or the Minister for Health or in very extreme cases refer a matter to police in the case of criminal misconduct.

Likewise, the Health Care Complaints Commission often mediates between the health service, patients and family members in order to reach a resolution which is amiable for all parties involved. The Health Care Complaints Commission has additional powers to revoke a health practitioners licence or impose restrictions on their practice in cases of serious misconduct. In extreme cases involving criminal negligence the Health Care Complaints Commission will refer matters to the police. There are some indicators that the Health Care Complaints Commission is under resourced to handle the volume complaints that it receives. Of the complaints received in 2017-18, the commission assessed only 54.7% within the statutory timeframe of 60 days.⁸⁴

Negotiation is appropriate where both sides are able to act in good faith and are equitably empowered to work collaboratively to improve future service delivery. In situations where people with lived experience of mental illness have been subjected to human rights abuses or, where services have a culture of stigmatisation and disempowerment of people with a mental illness or, where negotiations have failed, legal or disciplinary action may be more appropriate. In the absence of appropriate accountability mechanisms, many people with lived experience of mental illness report fear that they will be punished for making a complaint due to power imbalances inherent in involuntary treatment. Likewise, carers are often concerned that if they complain it may have a negative impact on their loved one's treatment.

It is imperative that stronger legal mechanisms are made available to people who have experienced negligent mental health treatment. Especial attention should be given to providing avenues for people who are subject to involuntary treatment to seek redress in cases where the treatment provided was negligent or inappropriate.

Accountability to Uphold Rights of People with Lived Experience

There is no enforceable legal obligation for government to provide high quality mental health care in Australia or to consider the impact of policy decisions on the rights of people living with mental illness and their carers and family members. Accountability of government and services underpins a robust system of human rights protection. This requires that responsibility for providing mental health care is negotiated upon, clearly defined and legislated between all levels of government. Accountability also requires government to have in place transparent and effective mechanisms for monitoring and reporting on progress towards the implementation of the right to mental health as well as other human rights.

⁸⁴ Health Care Complaints Commission (HCCC) (2018) 'Annual Report; 2017-2018', HCCC, Sydney.

State and federal government responsibilities in providing mental health care not clearly defined, leading to fragmentation of the mental health system, significant gaps in mental health service provision as well as costly duplication of services. For instance, the National Mental Health Commission noted in 2014 that;

“The largest areas of duplication between the Commonwealth and the states and territories appear where there is a lack of clarity of roles and responsibilities: community mental health services and non-clinical community support services, where too often both levels of government make decisions about programmes and services without proper engagement, planning and co-design of services.”⁸⁵

The result is a system which fails to follow and support individuals living with mental illness throughout their journey of recovery. As noted previously in this report, clearly defined responsibilities between all levels of government is critical to implement a stepped care model of service delivery. Stepped care requires that government be accountable for the mental health system as a whole. This encompasses both the provision of discrete services as well as planning and funding coordinated pathways between services so that individuals are supported to navigate the mental health system and receive timely access to the appropriate level of care.

In addition to clearly defined and legislated responsibilities for government to provide mental health care, transparent reporting of mental health service data is a critical element of accountability. Meaningful, publicly reported data is critical to enable active community participation in issues which impact upon their human rights such as mental health care. Publicly reported data that matches government policy and funding decisions to a set of agreed upon outcomes is critical for the public to be able to participate in a meaningful debate on public policy. Numerous mental health inquiries have noted inadequate and inconsistent data collection on mental health service outcomes in addition to a lack of transparent reporting mechanisms to make data available to the public. The ‘Not for Service’ report published by the Australian Human Rights Commission in 2005 noted a *‘lack of accountability for mental health spending, service deficits and critical incidents in the mental health sector.’⁸⁶*

The 2014 NMHC review expresses concern that there is a lack of consistent reporting on mental health outcomes and that multiple complex reporting and monitoring structures create substantial ‘administrative red tape’ for services. Differences between state and federal jurisdictions in reporting structures in terms of geographical boundaries, definition of outcome measures and reporting structures exasperate this problem. The report notes that *‘Data that is provided should be reported once and used often—but too much data currently provided is not used strategically or to inform future policy decisions.’⁸⁷*

More recently, the NSW Mental Health Commission has expressed concerns that the new activity based funding model for healthcare services incentivises volume of admitted activity, rather than promote a focus on better outcomes.⁸⁸ Although some outcome data for mental health services are collected in NSW and used as KPIs and for benchmarking of services including the Health of the Nation Outcome Scales (HoNoS), Life Skills Profile (LSP) and the ‘Your Experience of Service Survey’ (YES), the activity based funding model ties funding to outputs (i.e. the number of National Weighted Activity Units). The commission expressed the need for *‘broader, deeper and stronger performance reporting and benchmarking in NSW’ to ‘drive quality and value.’⁸⁹* The commission recommended that outcome data should be published in a way format that is readily accessible to the public. Although the results of the YES survey are publicly reported on, detailed KPI and critical incident data in NSW is

⁸⁵ NMHC (2014) op. cit.

⁸⁶ AHRC (2005) op. cit.

⁸⁷ NMHC (2014) op. cit.

⁸⁸ MHCNSW (2017) ‘Review of transparency and accountability of mental health funding to health services’, MHCNSW, Sydney

⁸⁹ MHCNSW (2017) op. cit.

not readily available to the public which limits meaningful public discussion and impacts upon public trust in the mental health system.

Concluding Remarks

Decades of mental health inquiries document a systemic failure to implement the substantial reforms intended to address systemic human rights abuses of people with lived experience of mental illness. While there have been many positive examples of innovation and of substantial cultural change led by both mental health services and policy makers, the mental health system as a whole remains chronically underfunded, fragmented, complex and difficult for people with lived experience to navigate. This significantly impacts upon quality of life for people with lived experience of mental illness, often contributing to a long-term cycle between chronic mental ill health, crisis and hospitalisation. It also the impacts quality of life of their families and carers who will often step in to provide care when the system fails to do so. This comes at a cost to families in terms of financial prosperity, career and educational opportunities and physical and mental wellbeing.

Fortunately, decades of mental health inquiries have also provided evidence-based solutions which governments can rely on in order to implement meaningful mental health reform. The work of past inquiries has made a convincing case that a significant increase in mental health funding is a prerequisite to achieving meaningful change. This key recommendation has been largely ignored and mental health funding as a proportion of overall health funding has remained stagnant for the past two decades.

Reforms which have curtailed funding from one part of the mental health system to fund new services, typically undermine existing infrastructure and do not improve access to services overall. Rather than repeat failed attempts to creatively reorganise a cash strapped service system, government needs to commit substantial resources to structural reforms which action the recommendations of previous inquiries.

Accountability is critical in progressing the right to the highest attainable standard of mental health. Accountability needs to encompass accountability of governments for the mental health system as a whole rather than for the delivery of services in siloes. This requires a robust system of accountability, monitoring and public reporting on outcome measures which are agreed upon across all levels of government. A framework for accountability needs to empower people with lived experience of mental illness or caring to participate in designing a mental health system which is accountable for upholding their rights. A framework of accountability should also encompass legal mechanisms for redress when people with lived experience of mental illness or caring are subject to human rights abuses (such as negligent or inaccessible mental health treatment). Only then can Australia claim to honour its human rights obligations to every member of our society through decisive and realistic actions.

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