Consumers of Mental Health WA (Inc)

Submission to Department of Health (WA)

Sustainable Health Review

1st November 2017

Consumers of Mental Health WA

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1. Introduction

About the Respondents

Consumers of Mental Health WA (CoMHWA) is Western Australia's peak body for and by mental health consumers (people with a past or present lived experience of mental health issues). We are a not-for-profit, systemic advocacy group independent from mental health services that exists to listen to, understand and act upon the voices of consumers. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery and wellbeing.

Request for Feedback

CoMHWA works to uphold the dignity and human rights of consumers, through providing advocacy in leading change with and for consumers.

We appreciate notification of the outcomes of our submission to the Sustainable Health Review in order to understand and communicate the difference made through our work.

Please provide feedback via the contact details on this submission's cover page.

Language

CoMHWA uses the term mental health consumer throughout this submission. Mental health consumers to refer to people who identify as having a past or present lived experience of psychological or emotional distress, irrespective of whether they have received a diagnosis of mental illness or accessed services.

This definition is based on consumers' call for respect, dignity and choice in how we choose to individually identify. As individuals we choose different ways to name and describe our experiences that may confirm or trouble ideas about 'mental illness'.

2. About This Report

CoMHWA welcomes the opportunity to make a submission as part of Department of Health's Sustainable Health Review consultation process. We present key facts and issues affecting both the sustainability and suitability of current mental health services and recommendations for improving outcomes and cost effective care.

We base our submission on:

- Ongoing consultation with consumers in Western Australia on joint priorities for an improved mental health system, including feedback during the development of the ten year plan, statewide consumer, carer and family engagement strategy and pre-election consultation;
- Participation in the South Metropolitan consultative workshop for the Sustainable Health Review;
- Ongoing consumer representation to, and liaison with consumer representatives within, various government agencies including: health service providers, the Department of Health, Mental Health Commission of Western Australia, Office of the Chief Psychiatrist, Health and Disability Services Complaints Office, Licencing and Regulation Unit, Mental Health Advocacy Service and WA Primary Health Alliance;

3. Key Facts and Issues

Comparative Cost of Clinical and Community Support

Public clinical care costs are significantly higher than non-clinical community based care (Fig 1). Despite this, only 5.3% of mental health expenditure in Western Australia is dedicated to community supports and 5.2% to community bed-based supports, with more than 8 times this amount (87% of all expenditure) going to hospital based inpatient and community support equivalents (Fig 2)[1].

[1] Mental Health Commission WA. Annual Report 2015-16..

Figure 1

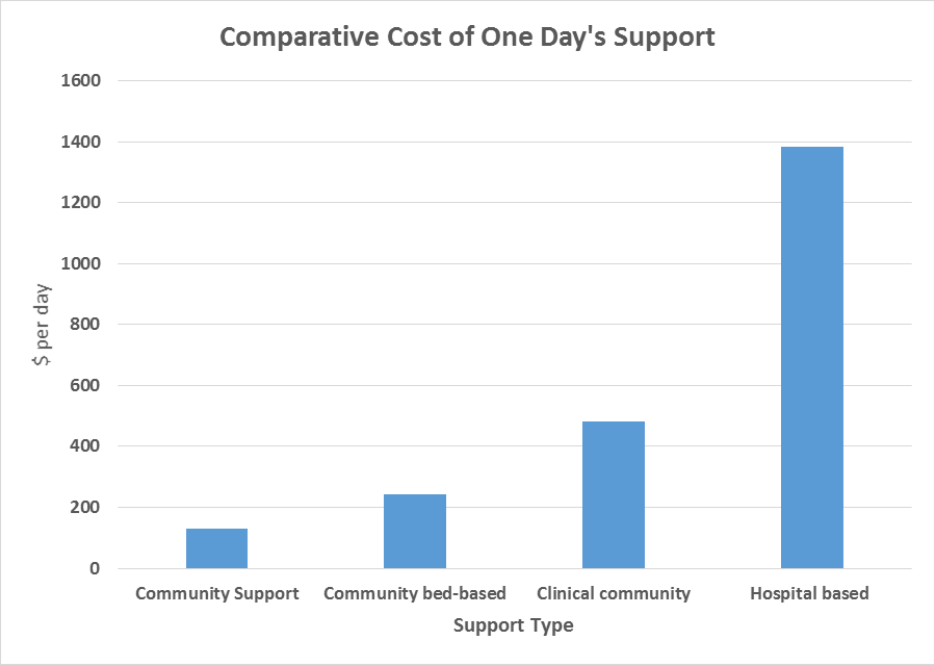
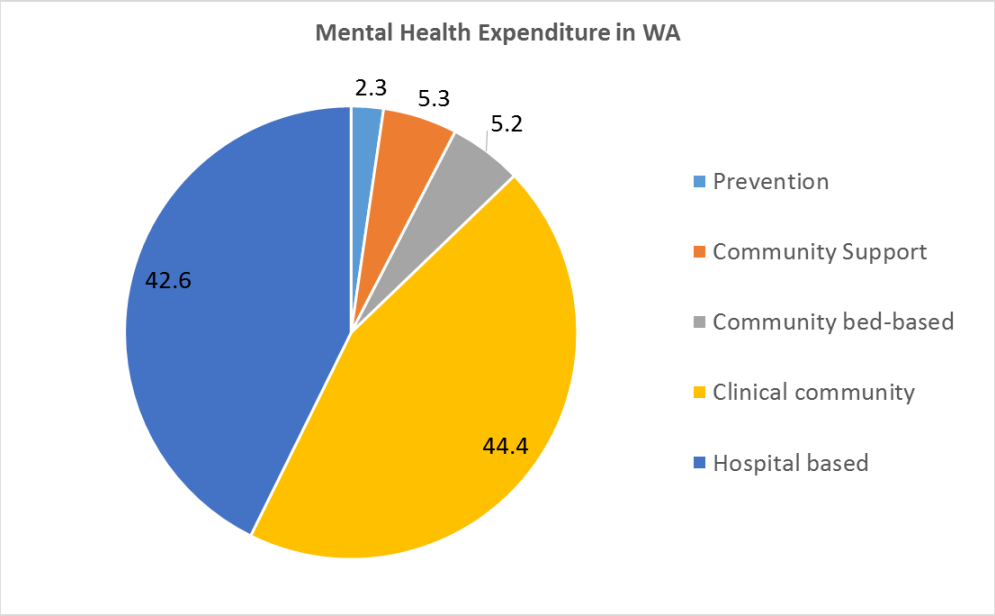


Figure 2



Capacity to Meet Needs In Current System Mix of Services

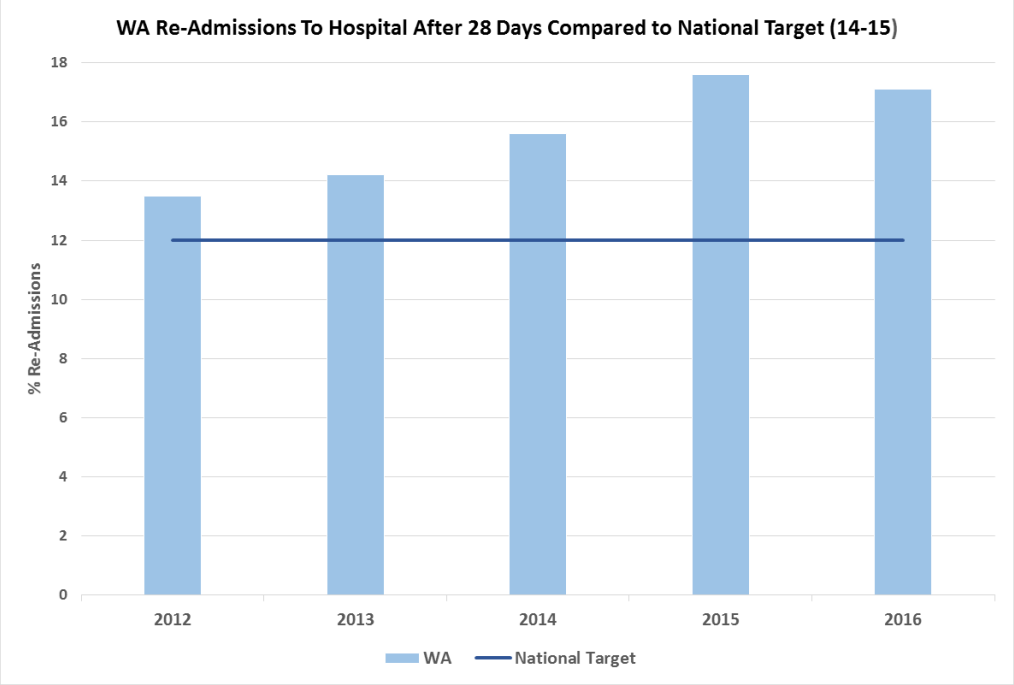
The public mental health system only has a reach of 2.2% of the population[2]. 10.6% of the population report high or very high rates of distress[3]. This means that while around 57,000 people with high/ very high distress can receive support from public clinical mental health

[2] Mental Health Commission WA. Annual Report 2016-17.
[3] Mental Health Commission WA. Annual Report 2015-16.

services (at 87% off expenditure), a further 217,500 people need to rely on private care, GP care or the non-clinical community supports mentioned above. There is $0.46, or 21 seconds, per day of non-clinical community support funded for every person with high or very high rates of distress.

People frequently need re-admitting to hospital for mental health reasons when they don't have adequate post-hospital support in the community. **Re-admission rates are too high and have been rising.** Re-hospitalisation rates within 28 days were 17.2% in 2016-17 compared with a national target of 12%.[4] This means that 17 people of every 100 are re-admitted to hospital within 28 days of discharge. Within the short-term (for those already in hospital or emergency situations) 13 of these admissions could have been prevented by access to step up step down facilities or equivalent intensive post-hospital support[5].

Figure 3[6]



Peer Hospital to Home programs- of which there are two current pilot programs in Western Australia- have been found in repeat studies to prevent hospitalisations and reduce stay length in hospital. A recent Australian pilot achieving an average reduced stay length of 11 days across 64 participants supported, which would represent avoidance of $974,336 in WA

[4] ibid
[5] Rates of re-admission are 17.1% following discharge from hospital but only 4% for people in step up step down services (source, ibid)
[6] Re-Admission rates sourced from Mental Health Commission Annual Reports 2014-15, and 2015-16.

hospital costs[7]. These are also greatly promising for reducing the higher risk of suicide of people recently discharged from hospital and emergency departments.

There is sufficient evidence base for the effectiveness of time limited, intensive community supports in preventing hospitalisation for people discharged from emergency departments (hospital diversion) and those discharged from mental health hospitals (re-hospitalisation avoidance/hospital to home programs). As these are relatively new models, most deploy a contemporary approach of peer-delivered supports and there is strong support among consumers for peer-based staffing of such programs. These programs can offer similar support to step up step down facilities at a lower cost and with a much shorter program establishment timeframe where a person is able to be supported at home (i.e. not homeless/experiencing domestic violence).

However it should also be noted that these brief intervention supports – both accommodation based (step up step down) and community based (hospital to home) are still focused at the crisis stage of people's mental health support needs. It important to consider that the outcomes they achieve reflect the general principle that people who receive adequate recovery supports in their community have a much lower risk of experiencing subsequent mental health crisis and hospitalisation.

Consequently, investment in general community mental health supports for those of us with significant mental health support needs could be expected to prevent hundreds if not thousands of emergency department presentations and hospitalisations per year. It is also critically needed due to the repurposing of Commonwealth funded community mental health programs into NDIS transition services that only people eligible for the NDIS can access (a much smaller population group than before), resulting in the drying up of community support pathways for recovery and hospital prevention.

It is also important to consider mental health in the context of national health performance indicators generally. We are not aware of any specific targeted investment in integrated care to improve the physical health outcomes of mental health consumers, despite our life expectancy being 12-15 years less than the general population. This Submission also discusses issues with the lack of recovery focus of hospital-based care, and the need for services to be designed for achieving better recovery and wellbeing outcomes- outcomes such

[7] Scanlon, J., N. Hancock & A. Honey. 2017. Evaluation of a Peer-Delivered, Transitional and Post-Discharge Support Program Following Psychiatric Hospitalisation. *BMC Psychiatry.* 17: 307.

as being in good physical as well as emotional health, being able to work, have safe and suitable housing, good relationships, live well and contribute as part of community.

The Human Toll of Crisis-Driven/Acute-Focused Care System

The statistics highlighted above clearly indicated that the mental health system is over-reliant on hospital based care with a shortage of alternative supports to prevent and respond to mental health crisis in community settings. This creates serious problems for the human rights, recovery and wellbeing of people affected by mental health issues, with the following statistics of concern for 2016-17:

- There were 52,467 presentations to an emergency department for mental health reasons (5.1%) of all presentations with an average 3.6 hour stay in emergency department[8].
- 19.6% of those presenting to emergency department were admitted to hospital, compared with 35.9% national average, suggesting over-demand for hospital care relative to other states and territories.
- 2,955 people left emergency department prematurely without being adequately assessed, increasing risk of suicide.
- 8,371 individuals had a mental health hospital stay.
- Due to limited resources, people have limited choice about their supports. However, it is worth considering that for half the cost of the average stay length in hospital, a person could be provided with 3 hours of community support every week for six months[9].
- 193 mental health consumers died while under the care of the public mental health system, including 52 suicides, 62 deaths from unnatural or unknown causes (such as accidents and suspected suicide) and a further 79 deaths from physical causes.
- The suicide rate for people under the care of the public mental health system based on the above data is between 73.6 and 161.4 per 100,000, or from 6- 13 times higher than the national rate of suicide (11.8 per 100,000 in 2016)[10].

[8] All data in this section except where otherwise indicated is sourced from:
Office of the Chief Psychiatrist. 2017. Annual Report 2016-17.
[9] Based on hourly cost of community supports, Mental Health Commission Annual Report 2016-17
[10] Suicide Prevention Australia. 28 September 2017. Media Release: Peak Body Reports a National Decrease in Deaths by Suicide.

- An audit of public clinical services found that most involuntary care was provided without the treatment and discharge plans that are required under the Act[11]. This means that the person was being held involuntary without adequate evidence that they are being informed or involved in decisions about their recovery and support needs.
- Risk of receiving involuntary treatment (treatment without informed consent) rose to 26% for people admitted to mental health hospital, compared with 1.75% for those being treated in the community (1.75). 2,193 people were detained involuntary in mental health inpatient services in the past year. A total of 4,041 involuntary hospital or community treatment orders were made[12]. Involuntary incidents of particular concern in 2016-17 were:
    - Electroconvulsive procedures (803 cases),
    - Restraint- the use of bodily or mechanical devices to restrict movement (951 cases), and
    - Seclusion- solitary confinement in a room which a person cannot leave (958 cases).

One family member's story shared with the Mental Health Advocacy Service captures the plight of people with lived experience facing coercive treatment in inappropriate environments, including children who can face hours of physical or mechanical restraint during forced re-feeding for eating disorders (a situation unchanged in the past 20 years in Western Australia):

> *My 15-year-old daughter, Tessa [pseudonym used], at 37 kg approx., walked calmly with me into PMH Emergency five weeks ago. We walked in with the confidence that she would get the appropriate level of care, consistency, nutrition, support and confidence required to return to school life in a couple of weeks/month.*
>
> *Five weeks on, she is now 35.75 kg, miserable/flat and extremely anxious. Today, she didn't have a 'feed' as now she needs 'holding' and there wasn't the staff available to assist.*
>
> *My daughter has not been outside in the sun except for two occasions in the past few weeks where I have been allowed to sit with her for around 15 minutes on each occasion. There are no televisions in the room and I have been informed I cannot bring one in. Is this a punishment?*[13]

[11] Mental Health Advocacy Service. 2017. Annual Report 2016-17.
[12] Mental Health Advocacy Service. 2017. Annual Report 2016-17.
[13] Mental Health Advocacy Service. 2017. Annual Report 2016-17.

Value for People, Value for Money, Requires Radical Recovery Change

Our hospital-based and public health systems, both in Western Australia and at a national level that spends billions of dollars each year providing only a very specific, narrow and often outdated approach to care that does not actually meet people's needs – the need for mental health recovery.

This is not a criticism of any individual staff, nor of any particular services, but instead reflects a health system that does not design for, fund for, understand and respond to mental health in the ways people with lived experience most need it to.

In the old, traditional paradigm of mental illness, mental illness is a disease of unknown but probably organic or neurochemical origin, of poor prognosis, needing long-term or life long medical treatment either to cure the disease or to alleviate symptoms. A disease of the brain, it affects reason as well as volition, and requires emergency life-saving interventions, often done to and upon the person, like a brain-based CPR. Diagnostic, pharmaceutical and other clinical (such as electroconvulsive procedural) interventions become lifesaving, emergency, essential and sufficient. These interventions are also cheaper and quicker to administer in the system compared with those that involve contact time with people (such as psychological, occupational, exercise and complementary/holistic health care programs). Time with the person is not based on the person's desire to talk to someone- a common need at times of human distress- but is generally restricted to when assessments or interventions are administered ('medication time'), with relationship-based care and trust given less value and incentive in the hospital system than routine, performance and compliance. The end result is dehumanised, distant and disempowering care. The majority of people affected by poor mental health have also experienced life trauma, and this relational environment and approach to the person is not supportive of healing and recovery.

By contrast, people with lived experience often have very different and more nuanced views about their mental health- grounded in human experience and relationships, and often about finding renewed capacity to cope after a period of overwhelm in life: *"Mental illness is not a*

failure…it's a beginning. A start to discovering something extraordinary about yourself! You care. That is the greatest gift that anyone can have.[14]"

Figure 4. Concept of Recovery- National Framework

The National Framework for Recovery-Oriented Services provides an alternative vision that reflects many years of lived experience advocacy to promote alternative understandings of mental health[15].

The Framework defines recovery as: "a journey that is a unique and personal experience for each individual. It has often been said to be about: gaining and retaining hope, understanding of ones abilities and limitations, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self. Essentially, the personal view of recovery is about a life journey of living a meaningful and satisfying life."

The National Standards for Mental Health Services require all services to work in accordance with recovery (the Framework was developed to support the Standards), but clinical services are not designed, funded or appropriately staffed to embed recovery approaches to care.

The recovery paradigm also ultimately calls for a diminished role for hospitals in mental health care through provision of community supports- including formal services, informal groups and self-help supports. This is because recovery support is about proactively responding and assisting to the holistic process of restoring good mental health and wellbeing through the role of family and relationships, companionship, friendship, community participation, good physical health and self-care, work and volunteering, study, self-expression and achieving life security (in housing, employment and income).

The success signs of a recovery–focused mental health system for individuals and at population level are outlined by the Mental Health Outcomes Statements, developed by the Mental Health Commission of Western Australia in 2012 (below).

[14] CoMHWA. 2017. Bring Your Voice Report. Participant Quote.
[15] Commonwealth of Australia. 2013. National Framework for Recovery-Oriented Services: Guide for Practitioners and Providers.

Outcome	Outcomes Statements
Health, Wellbeing and Recovery	People enjoy good physical, social, mental, emotional and spiritual health and wellbeing and are optimistic and hopeful about their recovery.
A home and financial security	People have a safe home and a stable and adequate source of income.
Relationships	People have enriching relationships with others that are important to them such as family, friends and peers.
Recovery, learning and growth	People develop life skills and abilities, and learn ways to recover that builds their confidence, self esteem and resilience for the future.
Rights, respect, choice and control	People are treated with dignity and respect across all aspects of their life and their rights and choices are acknowledged and respected. They have control over their lives and direct their services and supports.
Community belonging	People are welcomed and have the opportunity to participate and contribute to community life.

Public mental health services do not report against these Outcomes Statements or any similar recovery measures- so there is no evidence being collected that hospital services are contributing anything to a person's recovery, such as the extent of hope, esteem, capacity to cope, resolution of life issues/problems, restored sense of purpose, and access to supports and help from family, friends and/or community services.

CoMHWA has never received feedback from any person in the public mental health system that they felt they received holistic recovery focused care that would match the Outcomes Statements. Typically, the reasons for this include the lower value and priority placed on allied health services, inappropriate funding rules and stagnant cultures of care. The closer service activities and staffing are to holistic and recovery supports on the continuum, it seems that the less valuable, useful and legitimate they are within the health system. The progressive defunding, closure and sell off of public mental health day programs in Western Australia over the past 10 years is one example, which has further reduced the recovery relevance and role of clinical services by cutting occupational therapy and social work services. The same issues of systemic neglect revealed in the Burdekin report therefore persist for people staying on public mental health hospital wards, with little to do but smoke, sit or sleep watching a

communal TV on mute, bargaining for time off the ward for fresh air, with minimal or no recovery support, in inhospitable and sterile environments.

Hospitals are consequently designed, funded, built and delivered as 'crisis container' systems, that rely on the person being able to cope in the world outside the container- but at this time, without the community support that supports people to cope well. This builds up a juggernaut of unsustainable hospital-based care that contains crisis after crisis, without sustainable or meaningful outcomes for people's health and wellbeing. Even with the most skilled staff, the physical design, staffing and strategies focused on in hospital-based care need radical change to become environments helpful and contributing to recovery, and need to be part of a more balanced system where clinical and community supports are both optimally funded.

4. Recommendations

CoMHWA recommends that rebalanced investment be considered as a matter of priority. Both community support during crisis and more readily available community supports that prevent crisis through sustaining wellbeing are not sufficiently funded, and investment is required that would translate into major cost savings through preventing emergency department presentations and hospitalisations.

Most of our recommendations also suggest peer-based delivery of services. This reflects strong consumer demand for supports by and for people with lived experience of mental health recovery (peers), and the availability of skilled peer workers in Western Australia not matched by the supply of jobs[16].

Recommendation 1

The following services require investment on a **statewide basis:**

- Peer based hospital-to-home and emergency department-to-home programs;

[16] WA Peer Supporters' Network. 2017. Mental Health and Alcohol and Other Drug Peer Workforce Study. Forthcoming publication.

- Co-Response teams, due to their effectiveness in enabling direct to hospital admission (instead of emergency departments), reduced stigma, prevention of hospitalisation and suicide;
- Samaritans Crisis Line (defunding detailed in Hansard questions). This suicide counselling service does not duplicate Life Line as the two services have different protocols for suicide emergency that result in different people using these services.
- Community mental health programs offering longer-term recovery support for those not eligible for NDIS. Core program models that also need state funding streams for NDIS ineligible consumers are included in Table 1 below.
- Evidence-based programs that target improvements in the physical health outcomes of mental health consumers, such as peer health coaching.

Recommendation 2

CoMHWA recommends **increased investment** in health and wellbeing focused community supports. These are not statewide services but are locally based and meet more targeted needs. They are not specifically recovery programs but assist recovery, particularly for people facing economic stigma related barriers to socio-economic participation. Examples are listed in Table 2 below. Recent funding cuts to a number of these services are concerning as a disproportionately high number of people accessing these services are socio-economically marginalised members of the community, which increases vulnerability to situational crisis and hospitalisation.

Recommendation 3

CoMHWA recommends development of a statewide strategy and reform plan for recovery-focused care in hospital, emergency health care and clinical outpatient services. Improving recovery effectiveness of care is likely to reduce length of stays and re-hospitalisations while also improving health and wellbeing outcomes. Example components of this strategy would include:

- Development of a statewide Recovery Charter across all mental health services and services providing emergency mental health care, in partnership with consumers, families and carers;

- Include integration and coordination partnerships for referral and shared clinical-community care with clinical mental health services (hospital and outpatient) as part of models of community mental health program funding;
- Invest in initiatives to build capacity for shared decision-making, self-advocacy and supported decision-making to improve care partnerships;
- Work to understand and address federal funding and other service delivery barriers to implementing recovery-focused care arrangements in clinical settings;
- Hire and deploy peer workers in staff education and recruitment to embed recovery orientation and approaches in staff;
- Rebalance clinical team mixes to enable hire and embedding of peer workers within all clinical teams. Peer Workers bring lived experience of recovery and enable people to receive social and emotional support, assistance with team communication, recovery planning, development of coping strategies, and improved linkage to community recovery supports, tools and strategies in their community.

Recommendation 4

Western Australia does not currently have any of the following service models well established in America as hospital prevention programs and has a need to establish and evaluate pilot programs for the following options:

- Peer Respite Centres: Voluntary respite centres (models include cafes, day centres and short-stay accommodation) as alternatives to hospital run by peer workers, that provide intensive peer support and a safe space for people in emotional distress and at risk of hospitalisation or suicide.
- Peer-Led Suicide Support Groups: Alternatives to Suicide groups and Lifeline's Eclipse model are two models using group-based peer support to enhance safety, support and recovery for people at risk of suicide.

Table 1. Community Mental Health Program Models
Free or affordable community recovery supports for people with lived experience of mental health issues.
Key models include:

Personal Helpers and Mentors Program: Longer-term recovery focused flexible outreach support for people with recovery needs in areas of community participation, relationships, work and study, housing, self-care or coping with stress. Incorporates individual and group recovery programs, with a strong focus on building community connections, referrals to supports and achieving personal recovery goals.

Partners in Recovery program: Shorter-term linkage and coordination to services and supports, for people with multiple unmet needs and falling through the gaps of supports (e.g. at or at risk of homelessness, leaving out of home care).

Carer Respite Program: Recovery focused carer respite including breaks and wellbeing support for carers, and recovery support for consumers.

Peer-Led Recovery Centres: Community centres providing flexible, community-based peer support, individual and group recovery planning and support, social and community connection, and access to broader community services (e.g. warm referral to employment, health care, recreation services), e.g. *Brook Red*.

Peer Support Groups: Provide regularly social and emotional support for people with lived experience, by people with lived experience.

Table 2. Inclusive Health and Wellbeing Community Supports

Provide affordable community services that contribute to better mental health and wellbeing across domains such as housing, income, physical health, social connection and community belonging.

Key models include:

- Emergency relief and aid services, community legal and advocacy services;
- Companionship, befriending and community linkage services (e.g. Inclusion WA, Befriend WA, Compeer, Community Connections);
- Healthy lifestyle groups, programs (e.g. Tobacco Smart, Holistic Health, HeartBeat- all of which have been defunded);
- Community arts and recreation groups and programs (e.g. Spirit of the Streets Choir- now defunded, DADAA hostel art group- defunded);

- Community hubs for specific groups with peer support elements (e.g. Lorikeet, Tuart Place, Men's Shed)
- Community centres (e.g. Gowrie, Jacaranda, St Patricks Community Centre);