Mental Health Carers NSW Inc.

Response to the inquiry into Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales

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Mental Health Carers NSW

About Mental Health Carers NSW (MHCN)

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience severe and persistent mental distress in NSW. It is a community-based, non-government organisation that provides systemic advocacy, capacity development and education for the carers, family, friends, and kin of those experiencing mental distress across NSW. There are currently 2.7 million unpaid carers in Australia, 39% of whom provide more than 40 hours of care per week[1]. Due to the demands of their full-time caring role, carers are at a high risk for developing mental health issues. We work to ensure the voices of mental health carers in NSW are represented and heard in policy and service reform processes to ensure they are recognised, and their rights upheld. We endeavour to empower mental health carers across the state to become champions for mental health reform and advocacy. MHCN also undertakes systemic advocacy for psychosocial disability issues to non-Health state government services under the Disability Advocacy Futures Program funded by the Department of Communities and Justice, reflecting that 80% of necessary supports do not relate to 'treatment'.

Focus group

MHCN held a focus group on Tuesday 22nd of August wherein MHCN consulted with carers from across NSW to ensure the views expressed in this submission directly reflect the current needs and experiences of the NSW community. In line with MHCN lived experience engagement policies, carers who attended the focus group were paid for their contribution. We also discussed issues and recommendations with participants in our regular "Mental Health Carer Connections Meeting" (25 August), and our ""Carers of Forensic and Corrections Patients Network" (29 August).

Introduction

This submission provides MHCN's views on the capacity of NSW community and outpatient mental health supports to meet the needs of people with lived or living experience of serious and persistent mental distress and/or illness diagnosis (consumers) and their families, friends, kin and carers.

Thank you for the opportunity to contribute to improving the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales. In our submission, MHCN will address (1) access to mental health services, (2) capacity of services; appropriate and efficient allocation of mental health care workers, (3) navigation of mental health services, (4) the use of Community Treatment Orders under the *Mental Health Act 2007*, (5) and the use of emergency services to respond to crisis.

The Policy and Advocacy Team from MHCN would be honoured to give evidence as witnesses for the committee.

[1] Barrett, C & Crameri, P (2015). *An Extra Degree of Difficulty*, La Trobe University.

Executive Summary

There needs to be a massive reform of community mental health services including, you know, the resourcing and funding of those. They need to knock it all down and start again. ***We don't need more fancy hospitals; we need appropriate services****." Carer, 2023*

Our continuous engagement, and specific consultations on this matter with carers, have found that there is inadequate access to an inadequate mental health 'system' that lacks the scale to deal with the scope of the population's need for mental health services in the community. The fragmented system is hard to navigate, tracks needs and delivers support poorly across settings, relying excessively on medication and coercive and emergency responses due to the inadequate planning and resources for follow-up and coordination. This leaves overburdened service providers hard pressed to deliver adequate, empathic support, let alone time to identify, engage and support families and carers in their caring role and in looking after their own wellbeing.

The fundamental principles and culture of the 'medical model' upon which NSW mental health systems are based pose the ultimate barrier to genuine progress, which only embracing the 'psychosocial' model of mental health and recovery will address. Despite the wide range of changes made to Community Mental Health since its inception, the issues reported by 'consumers' (of mental health services) and carers continue to centre on the harms they experience from interacting with a discriminatory, deficit based, and risk focused system that remains intent on control rather than recovery and is too poorly resourced to provide appropriate personalised services to individuals and to meet the true scale of community need.

Community mental health programs in NSW were developed in response to an urgent need for mental health services in the community. Due to this responsiveness, the current NSW mental health landscape remains underpinned by the same principles that caused the 'asylums' of yesteryear to inflict harm. Without critical reflection on these principles, services have continued to control or separate out people exhibiting behaviour that is considered 'abnormal', rather than identifying and addressing the causes and impacts of their distress and related behaviours. As a result, services are used to control people with perceived mental illness for the benefit of the community, rather than for the wellbeing of the consumer. In practise, these principles are displayed through a continued reliance on the medical model and excessive use of coercive means which breach human rights, such as restraint, seclusion, and involuntary treatment. Too often this devalues and denigrates difference rather than truly supporting the diversity and equality of all members of our community to take their rightful place.

These principles, and the subsequent service culture they foster, maintains legitimacy because health systems continue to direct resources and funding toward unchallenged, harmful systems which impose control on the vulnerable instead of supporting their genuine recovery. Too often mental health carers, families and friends are left to cover the gaps or deal with the dreadful outcomes the system 'achieves' for the people they love. **As such, we implore you to carefully consider the values and principles of the mental health systems that this NSW parliament wishes for our communities.**

In the following submission we have suggested some alternative approaches to community and outpatient, and crisis-responses linking to inpatient, mental health systems based on the principles of dignity and choice which will direct resources toward building mentally healthy communities. Resourcing community alternatives to existing restrictive services, including inpatient units and

Community Treatment Orders, will allow the NSW parliament to generate a new culture in community services based on principals of human rights.

We see this inquiry as an opportunity to re-set the direction so as to develop more robust systems of support in communities which can prevent crisis, facilitate recovery, and foster wellbeing. Community and outpatient mental health services can and should be distinctly designed to deliver person-centred, trauma informed, proactive and preventative mental health care that can trace and address consumer's and carer's needs in the community.

The issues and recommendations in this submission are inextricably linked with one another; with the overall resourcing and delivery of mental health and social services in NSW; and with the current understandings of the causes of mental distress. The following recommendations are required so the culture developed in the 'asylum' era can be practicably dismantled and appropriate supports based on least restrictive care and support for maintaining or recovering the capacity for responsible autonomy, (no matter how you perceive the world), are developed and implemented instead.

recommendations

1. A wide-reaching media and public education campaign must be developed and delivered to educate the community on how to identify different types mental health crisis and which available crisis service is appropriate to contact for different mental health presentations.
2. Implement improved and increased education and training for GPs and an effective mental health information system supporting GP referrals.
3. Develop the legal and technological infrastructure requirements for to support shared care between in-patient and community mental health services, and primary care providers, like GPs, including funding for liaison staff to support collaboration and care co-ordination and between the various service providers both with and on behalf of the person.
4. The Ministry of Health must develop and implement a strong anti-stigma education campaign among NSW Health service staff.
5. The Ministry of Health must fund the implementation of the Agency for Clinical Innovation's Framework for Change to implement Trauma-informed care in mental health services across NSW.
6. The Ministry of Health must develop of much stronger supports for carers, particularly the family, friends and kin of people who experience serious mental health concerns and for those whose loved ones are at high risk of discrimination and trauma.
7. Fully funding and resourcing the existing unmet need in the community and outpatient mental health system would ensure services have capacity to accept consumers who would otherwise been refused support due to lack of available service capacity.
8. Peer delivered service navigation and case coordination support services which cross funding and sector boundaries must be developed and funded especially in regional areas, and for culturally and linguistically diverse and First Nations communities.
9. The Mental Health Act should be amended to strengthen the protection of the rights of consumers and carers and to ensure adequate supervision and review of clinical decision making in accordance with the law and human rights principles when imposing involuntary treatment including under CTOs. This includes (and is not limited too) the following changes:

a. Ensuring involuntary treatment in the community under CTOs:
    i. is justified and the treatment delivered is effective,
    ii. medication is discontinued or changed if it is not effective,
    iii. is proportionate relative to harms prevented and side effects experienced,
    iv. genuinely represents the least restrictive care,
    v. is supported by counselling, therapy, counselling, rehabilitation and other services.
b. Ensuring second opinions are available on demand to challenge (or uphold) clinical evidence provided to the Mental Health Review Tribunal by the treating team about the matters in 'a.' above
c. Requiring that all CTOs to include details on the obligations of the declared community mental health service; such as a Care Plan that outlines how the service will meet its obligations under the CTO
d. Requiring that when a consumer is admitted to a mental health facility following a breach of a CTO they should be subject to the same provision of the Mental Health Act (2007) as any new admission – that is, two authorised medical practitioners must examine the person to determine that they should continue to be detained and they should be bought before the Mental Health Review Tribunal to confirm the lawfulness of the detention as soon as possible.
e. Ensuring consumers, carers, and any treating doctors involved in a person's care are given copies of the treatment plan, as well as information about healthcare professionals and patient's and carer's rights and responsibilities.
f. Imposing an obligation that all CTO 'breach' events must be recorded as an incident in the Health incident reporting system and reviewed by senior management, triggering an automatic requirement for a second opinion to be provided to review the treatment regime imposed.
g. Stipulating that data must be collected by the Ministry of Health about the number of breach orders issued by all community mental health services and published annually.
h. Mandating that the carer of a person is notified of an upcoming hearing and notified in sufficient time to attend the hearing.

10. To minimise the number of Police responses to mental health crisis in favour of appropriate mental health crisis response teams, and to improve those responses when they do occur, the NSW Government must:
    a. Develop and implement more effective and proportionate non-lethal means of de-escalation, and potentially lethal responses only implemented if there is an immediate and proportionate risk of serious injury or death.
    b. Track the number of injuries and deaths of mental health consumers and report these figures as a Key Performance Indicator of NSW Police.
    c. Fully develop and fund The Police, Ambulance, Clinical, Early Response (PACER) program trail across all NSW LHDs, especially in regional areas.
    d. Ensure all Police in NSW receive robust mental health training, especially in no-violent de-escalation techniques and the use of minimum force in physical restraint, as well as significantly more support for their own mental wellbeing.

1 access to mental health services

Carers have expressed frustration through multiple avenues, including directly to the Minister for Mental Health in NSW, regarding their loved ones being denied or refused access to both inpatient and community services in times of critical need, a situation that would not be tolerated in any other area of medicine. Carers frequently tell MHCN that this refusal of service only serves to further endanger the individual seeking services, and the family and carers who are suddenly required to fulfil the unmet service needs of their loved ones. Many of the following access issues were identified and reported in the landmark 'Not for Service'[i] report of 2005 and in many reports, inquiries and reviews subsequently.

Lack of information prohibits access

Due to a broad lack of awareness and understanding of the different mental health crisis services available in NSW the first hurdle Australians must face is a lack of information about the services available to support mental health in the community, and a lack of information about what services to contact depending on the severity of the current situation. This impacts both community members and primary care providers like GPs whom they rely upon to refer them to appropriate supports.

Carers of a loved one experiencing greater distress, such as suicidality or symptoms of psychosis, find themselves lacking adequate information about crisis services and how to access them. Several spaces of service for such crisis exist such as Acute Care Service [ii](situated in South Eastern Sydney Local Health District, as a community-based team) Safe Haven [iii](new Suicide Prevention specific drop-in centres), and the Mental Health Line[iv]. However, the broad lack of awareness among the public, and conflicting information about which service is most appropriate to access in different circumstances (such as their purpose, scope, hours of operation, and contact information) leads to confusion about where to turn in times of crisis.

This conflicting information can be delivered by the crisis services themselves, each assessing the severity of the situation differently and advising carers to contact a different service, who will in turn advise the carer to contact the original service.

There was a nation-wide triage standard … and I do think that we need something state-wide, nation-wide for, ah, for mental health, so that when mental health patients are assessed or triaged … there is some sort of level of accountability and a standard which they, um, which they must reach. At the moment it's a little bit whimsical." Carer, 2023

As a result, carers are often forced to seek emergency services when mental distress presents as crisis. This places unnecessary pressure on police, ambulance, and hospital emergency departments which are ill-equip to handle mental health crisis alongside other presenting emergencies [see 5. The use of emergency services to respond to crisis].

Crisis requiring emergency response can often be avoided itself, when other services are accessible before a person's distress reaches crisis point. A robust resourced local community mental health service should act as this earliest point of access and must ensure that no individual seeking support is turned away. Service planning which seeks to fill the gaps in what existing services can deliver will be ineffective; instead the committee must examine what individuals need and how the NSW Government can plan to meet that.

recommendation

1. A wide-reaching media and public education campaign must be developed and delivered to educate the community on how to identify different types of mental health crisis and which available crisis service is appropriate to contact for different mental health presentations.

Conflicting information and inconsistent care prohibits access

Most factsheets, brochures, informational advertisements, and community education platforms state that a General Practitioner (GP) is the first port of call, as they can refer consumers and carers to the specialists and services needed for someone experiencing mental illness symptoms or crisis. Carers have told MHCN that this approach often fails to produce positive outcomes for a range of reasons.

> *"I live in the country, so your first port of call is your GP, and the GP just said ' forget about it, (they're) a lost cause; I don't know what to do with (them), don't bother bringing (them) here'. That was the reaction I got from my GP. So they need better information or better education."* Carer 2023

> "*We actually had a very, very good GP, he saved our (consumer) I would say… But, he was unable to convince the psychiatrist in the local health district or the psychiatric nurses that there was a problem. We collectively struggled along for a long time, before, before we could even get (the consumer) in. … Even those (GPs) can be dismissed by, as he calls it, the big boys within the hospital system. So we have to support our GPs … with getting them into a place where other doctors are forced to listen to them."* Carer, 2023

While General Practitioners (GPs) continue to play a leading role in mental health treatment in the community, many GPs across NSW, especially in regional areas, are still unfamiliar with mental health issues and the available services for specialised treatment. GPs around NSW are often unable to adequately assess mental health presentations and provide referrals to community members in need or are unable to progress these referrals if community mental health services are too under resourced to consider new clients. These issues are only exacerbated in regional and rural areas where fewer GPs and mental health specialists are located. If the advice from NSW Health is to contact a GP upon first experience or observation of mental distress, then this contradiction must be resolved; between the role of GPs as outlined by NSW Health, and what GPs are trained to do and resourced to deliver.

Similarly, people presenting to emergency departments in crisis are not followed up if in the community if they are not admitted by specialist mental health services, nor having their primary healthcare provider, their GP, advised. If people are admitted, there is often little engagement with GPs or carers who will take over care when planning discharge.

Mental Health Carers and GPs are not adequately resourced to provide care co-ordination as is required in the current system wherein care co-ordination is not prioritised. Shared care arrangements have been 'piloted' in various places, such as Central Easter Sydney Primary Health Network[v], which have the potential to greatly increase the efficiency and impact of care for both the physical and mental health of people accessing community mental health services. To be effective, shared care programs require liaison staff, protocols, legal and infrastructure requirements, and a platform to allow sharing of confidential medical information concerning patients between NSW Health and primary care services.

With no existing funding or resources dedicated to shared care consumers, carers and clinicians must repeatedly solve these problems on a case-by-case basis, leading to inconsistencies of care under the same model.

recommendations

2. Implement improved and increased education and training for GPs and an effective mental health information system supporting GP referrals.
3. Develop the legal and technological infrastructure requirements for to support shared care between in-patient and community mental health services, and primary care providers, like GPs, including funding for liaison staff to support collaboration and care co-ordination and between the various service providers both with and on behalf of the person.

Head to Health phone and in person services may offer an alternative entry pathway for those with lower levels of support need, where alternatives to a medicalised approach, such a psychology and psychotherapy, are considered appropriate. However, this service would not practicably support consumers with higher levels of distress and their carers, as the Head to Health service model[vi] only offers an alternative pathway to the existing treatment pathways beginning with GPs and community mental health services, which remain to under resourced to meet demand.

Stigma and discrimination prohibit access

An extremely common experience amongst carers consulted by MHCN was the devastating harm to lives and livelihoods caused by disabling or discriminatory comments made by clinical and allied mental health staff. A culture of dehumanising people experiencing mental distress and their families is pervasive within clinical mental health systems. The behaviour and comments of GPs, nurses, and doctors which express a lack of compassion for distressed people and their loved ones can have truly devastating consequences in our community.

> *"I did have a friend who committed suicide because he went to the doctor (GP) and they just said 'oh you just need a job'. A week later he (died) … that's what it's like in the country"* Carer, 2023

> *"We were told that the person I was caring for 'looked like (they) didn't need any help'. … (the consumer) has just come out after 6 weeks of being in an involuntary patient at a level 6 hospital … Yes (the consumer) has worked professionally for like 25 years … but that doesn't mean (they're) is any less disabled."* Carer, 2023

> *"Both of my children identify as LGBTQI. Community mental health have suggested to me that they have both been sexually abused to make them LGBTQI . Horrific!"* Carer, 2023

> *"A lot of it is not so much funding, its attitude."* Carer, 2023

Carers and advocates continue to report significant incidents of discriminatory comments and behaviour in among staff at community and outpatient mental health services, which can have devastating impacts upon people accessing these services and their families and loved ones.

It has been evidenced through countless recollections of lived and loved experience that when consumers and carers face this sort of discrimination or degradation from staff in mental health services, those people are far less likely to engage with services any further. Stigma and discrimination, such as the above, makes mental health service spaces unsafe and inaccessible for those who require them. As a result, the unpaid work of providing support falls to carers once more.

In the light of the recommendations of the 2017 'Review of Seclusion Restraint and Observation in NSW Mental Health Services'[vii], the Agency for Clinical Innovation developed 'Trauma-informed care in mental health services across NSW A framework for change'[viii], however no funding has ever been dedicated to the ongoing implementation of this Framework, which amounts to an enormous change management process across NSW Local Health Districts demanding personnel and other resources to be dedicated to it. Entailed within this implementation would be work on stigmatising attitudes towards people who experience mental health concerns and their families and carers.

recommendations

4. The Ministry of Health must develop and implement a strong anti-stigma education campaign among NSW Health service staff.
5. The Ministry of Health must fund the implementation of the Agency for Clinical Innovation's Framework for Change to implement Trauma-informed care in mental health services across NSW.
6. The Ministry of Health must develop of much stronger supports for carers, particularly the family, friends and kin of people who experience serious mental health concerns and for those whose loved ones are at high risk of discrimination and trauma.

2. Capacity of services; appropriate and efficient allocation of mental health care workers

The capacity of community and outpatient mental health services is directly linked with the allocation of workers, and the resources provided to allocate enough appropriate workers to community mental health service. Community and outpatient services have been systemically under resourced in NSW as funding has been moved or otherwise directed to different areas of mental health service delivery including, but not limited to, inpatient mental health services, Community Managed Organisations (CMOs), and due to the perceived coverage granted by the National Disability Insurance Scheme (NDIS).

Lack of service capacity prohibits access

In addition to a lack of information and conflicting information, all mental health services delivered in the community, including the services that are considered 'crisis support services' are far too under resourced to meet community need. Even consumers in crisis who attend Emergency Departments are often refused support and discharged without linkages to appropriate community mental health services for follow up, creating a significant gap in service delivery for those in urgent need. As a result, consumers and carers are left without access to free or low-cost clinical community mental health services. NSW community and outpatient services appear to constantly lack capacity and resources to support consumers in need of these services. Consumers and their families are then seemingly placed on a waitlist without even being considered for triage.

> *"I've recently tried to get extra support for my (consumer) with (their) psychiatrist and psychologist in the community, um, but just get emails saying, 'we'll contact you if an appointment comes up'. So, they don't actually call you to assess the situation, triage it in anyway, so I am just waiting and waiting, and there's no communication."* Carer, 2023

Alternatively, consumers who present to a NSW Health community mental health team may be triaged and be immediately recommended to seek support elsewhere, either by being urgently taken to an inpatient unit, or are discharged with little indication of what services would be available to the

consumer and their carers. Some services that lack capacity will recommend consumers and carers contact another service; that second service will then refer consumers and carers back to the first service.

> *"Community mental health and hospital are bouncing the person around, basically pushing responsibility onto each other."* Carer, 2023

This action of 'shifting responsibility' nullifies the concept of 'no wrong door', a healthcare principal wherein services are required to ensure that every consumer is admitted into an appropriate service before they can be discharged from the service they first presented to. The decision to refer people on past triage appears, to carers, to have little to do with the needs of the person; instead, decisions appear to reflect the capacity of the service and the level of advocacy that can be mustered on behalf of the consumer. Consumers who cannot or do not forcefully advocate for their acceptance into the service, or consumers who do not have the support of unpaid carers who can forcefully advocate for them, are frequently discharged without receiving any support despite articulating the urgency of their distress.

> *"(the consumer) died in 2016 because (the consumer) was trying to get help from public inpatient units, public psychiatry, and even private psychiatry … There were a number of times when (the consumer) was admitted for one either night and then discharged, or not admitted at all, and (the consumer) ended up taking (their) own life because (they) didn't get access to help that (they) needed."* Carer, 2023

Shifting responsibility without facilitating a referral and handover means that consumers continue to fall through these gaps, which can result in loss of life. Often the work of ensuring a consumer is seen by appropriate specialists and able to have their support needs met falls to carers; carers are forced to take on the work that NSW health services lack capacity to complete despite carers having not the training, time, money, or legitimacy to complete this work.

Carers and consumers continually advocate for alternatives to inpatient services which this cannot be realised until resources are redirected to a NSW wide, free, community and outpatient mental health system that delivers strategic, bespoke, person-centred and trauma-informed care to meet consumers and their families where they are. Fully resourced services in the community have a greater chance to provide preventative care and reducing incidents of crisis and the need for crisis response.

> *"Capacity is not just in front-line, but being able to strategize and coordinate services to cater for complex and individual needs … but this kind of thinking is incompatible with the crisis-driven nature of mental health services."* Carer, 2023

Notably, carers repeatedly shared stories of seeking any support outside of regular business hours and finding that there are no supports available.

> "*When I was struggling with my (consumer) I found weekends were a black hole. You could not get support anywhere. And you still can't."* Carer, 2023

As a result, carers are forced to take on the responsibility of becoming a crisis service to their loved one. This can not only place carers own wellbeing at risk and make the role of provide unpaid care unsustainable, but it also places consumers at a significant disadvantage in their recovery journey when they are unable to receive timely, appropriate support using the least restrictive practises possible.

Lack of service integration prohibits access

The under resourced community and outpatient mental health services lack capacity to support consumers with even minimally complex support needs. This may include; consumers who experience significant symptoms but are not distress or crisis; or consumers who require psychical health support as well as mental health support, such as nutritional support; and consumers who require subsidised clinical care from local community mental health teams and also require psychosocial or other supports through private networks, such as NDIS.

> *"We cannot access public mental health nurses, community nurses, in this area if we are a private patient of a psychiatrist."* Carer, 2023

> *"because (the consumer) is also an NDIS participant (NSW Health services) put (the consumer) in that category… so there's kind a bit of argy-bargy between community mental health and the NDIS as to whose doing what, and so we fall through that massive crack."* Carer, 2023

> *"We asked for a dietician, not available, exercise physiologists, not available. Um, (the consumer) got prediabetes because of the medication, and we weren't told about the free diabetes clinic; their funds were exhausted as a result of trying to access private treatment. And even when we told them that, when we told community mental health, that um, they didn't even tell us about the free diabetes clinic, we had to find out about that on our own."* Carer, 2023

Consumers with complex needs who do not neatly 'fit' into one category of service, and who require a range of services, and frequently prohibited from accessing multiple services at once. Many community mental health patients who engage with programs beyond those offered in their local NSW Health community mental health team, such as dieticians or social services through NDIS, are immediately pushed to transition out of the community mental health services that they continue to rely on for clinical care.

> *"In hospital (the consumer) accesses art therapy and is able to engage with that medium of therapy. Community health doesn't offer art therapy. Um, so, I've sought a private art therapist that the hospital recommended… However now community health team are … saying 'well, because you're accessing private services were going to have to discharge you."* Carer, 2023

As such, the dream of integrating NSW Health community and outpatient mental health services with general practice health, and other mental health and social services, remains unrealised. Instead, the work of care co-ordination across multiple services is shifted to carers who lack the appropriate information, time, money, and legitimacy to complete this work.

> "*When you're caring for someone in crisis and are, probably, in crisis yourself, and you're new to the system, you don't know what supports is available, you don't know the range of options that there are, or really what even support looks like,* ***you just know you and your little family are drowning*** *and you need help."* Carer, 2023

Unpaid carers consistently take on the care co-ordination work of under resourced services to try to meet the complex needs of their loved one. This care co-ordination is often required to meet the shortfalls of community and outpatient mental health services who offer limited supports, limited by either funding allocation or geography. Community mental health services are required by the NSW Health Policy Guideline (GL2021_006)[ix] to ensure that screening for physical health needs is

undertaken on a regular basis. Despite this, carers consulted by MHCN were unaware if these screenings took place or resulted in the physical health needs of their loved one being met.

Additionally, community and outpatient services are seen to punish a carers proactive care co-ordination by removing access to NSW Health services. Consumers access to healing in the community is removed as soon as they begin to utilise different services with different programs with different support offerings. Despite all attempts at 'service integration' in NSW, the mental health service landscape appears to be more siloed than ever before.

recommendation

7. Fully funding and resourcing the existing unmet need in the community and outpatient mental health system would ensure services have capacity to accept consumers who would otherwise been refused support due to lack of available service capacity.

3 navigation of mental health services

"I remember when I was looking after my (consumer) … ***it was an absolute baptism of fire.*** *We went in not knowing anything about any of these systems; we knew nothing about the Mental Health Act, Community Treatment Orders, community mental health – who it was and what it offered, you know, what supports were available at NSW Health. None of those services were offered to us and we don't know why*." Carer, 2023

"It was that kind of peer approach, someone coming up to you and navigating you, I believe, was vital and is missing in the system." Carer, 2023

Currently, service navigation in NSW is also severely under resourced. Carers told MHCN that service navigation in community and outpatient services is rare. Social workers or case managers in NSW Health systems are unable or unwilling to dedicate time to supporting service navigation. Such support is more likely found in Community Managed Organisations, but incomplete information and unrealised service integration remains a barrier for peer workers and other staff attempting to support consumers and carers with service navigation.

recommendation

8. Peer delivered service navigation and case coordination support services which cross funding and sector boundaries must be developed and funded especially in regional areas, and for culturally and linguistically diverse and First Nations communities.

4 the use of Community Treatment Orders under the Mental Health Act 2007

A range of legal and medical issues permeate the use of Community Treatment Orders (CTO's) in NSW, and a full reformation of the current system is urgently needed. As recently as 2022, consumers have described the use of CTOs as 'lazy medicine'[x], wherein a coercive, biomedical, medication-only approach continues to be preferred by legal and medical professionals despite this model being repudiated by medical research and human rights imperatives.

"There's a massive problem within the legal system, um, that suggest that people who have offended, um, it could be, you know, because their judgement was clouded because of mental health reasons. It, ***it incorrectly assumes that, um, medication is going to stop them from reoffending … when in fact it's far more complicated than that****."* Carer, 2023

Improving the social determinants of health across all communities, especially the most vulnerable social groups in NSW, is the best preventative approach to decreasing experiencing of mental distress across the community[xi] and reducing the need for CTOs. The best alternative to the use of coercive and restrictive practises is providing dignity and choice through a non-hierarchal support service that offers clinical, social, and alternative treatments in person-centred community mental health services upon first presentation[xii].

Clinical treatment under Community Treatment Orders

The growing consensus is that experiences of mental distress are socially determined, yet CTOs continue to progress the narrative that distressing experience and behaviours are the result of biological factors which must be repaired through medication use. CTOs do not reflect a holistic, person centred approach to mental health care and fail to provide social supports to the consumers and their families in the system.

> *"…treatment consists of antipsychotics, it doesn't take into account any other type of, like, treatment option, um, which is devastating because they cause, like, very serious side effects. There's no social support, there's no allied health support, even when we asked for it."* Carer, 2023

Furthermore, carers told us that the administration of medication to consumers under CTOs in their areas can be dangerous, and sighted instance of negligent healthcare.

> *"(the consumer) was on two consecutive CTOs even before I'd stepped in. What had happened in each case was that, um, they were administered a really high dose of antipsychotic every single month, so it was … a subcutaneous injection to the buttock once a month, every single month… and then at the end of the CTO there was no tapering off, (the consumer) was just dumped. So (the consumer) went through a really high withdrawal and that led to, when I stepped in, that was like the direct cause of (the consumer) losing (their) job and then eventually reoffending because (the consumer) wasn't getting help."* Carer, 2023

The forced provision of slow-release medication in this way raises further issues for consumers who are released from a CTO after receiving a slow-release anti-psychotic injection; in these cases, consumers have been administered medication that will remain in their system beyond the life of the treatment order. This systemic issue represents legal and medical negligence wherein the administering of medication that cannot be stopped at the end of a legal injunction. Selecting an alternative to this method of medication must be the first responsibility of the committee to uphold the legal rights of the nearly 8000 people in NSW affected by CTOs.

Patient rights under Community Treatment Orders

While the Mental Health Review Tribunal (MHRT), a specialist quasi-judicial civil tribunal[xiii], overseas the provision of CTOs, the Mental Health Act empowers local staff in community health services with broad-sweeping powers over how CTOs are delivered, with seemingly little transparency over how decisions are made at the local level. For example:

- Carers frequently report that they are not notified of upcoming hearings or notified with insufficient time to attend hearings.
- Following a hearing, the MHRT provides details of the treatment plan to the treating team, but consumers and carers are routinely not given copies of this information. As a result, consumers, carers, and general practitioners have no way to know if the treating team is complying with the treatment plan.

- Consumers and carers may also not have a sufficient understanding about 'breach orders', what actions could instigate a breach and what happens to a consumer following a breach.
- Finally, consumers and carers are often unaware how to seek review of a CTO and seek an end to compulsory treatment.

> *"Our experiences with CTOs are not good. And even when we asked 'How do we get rid of this? How do we negotiate our own terms?' and nobody would tell us. I even rang the Mental Health Review Tribunal, and they wouldn't tell us anything … they refused to engage with either by phone or by email. So, it's a very opaque system." Carer, 2023*

This lack of transparency affects not only the consumers and carers understanding of and information about their CTOs, but also about how their rights are upheld throughout process. Additionally, this lack of transparency means consumers and carers have little to no recourse to respond when a patient's rights are being violated.

At the systemic level, little is known about the provision of CTOs across NSW and the upholding of patient's rights in this process. Very little information is made available about how decisions are made by local community health teams and the MHRT, limiting opportunities for consumers and carers to gain a greater understanding of these legal processes. To be sufficiently transparent, the MHRT and the Ministry of Health would have to publish:

- greater demographic information
- individual or joint reasonings for the decisions made by the court
- qualitative data reflecting the reasons for doctors referring consumers for a CTO
- the number of 'breach orders' issues by each local community mental health teams
- and the outcome of 'breach orders' in each local community mental health team.

Carers have also found that legal representatives allocated by the Mental Health Advocacy Service are largely ineffective in their roles.

> *"With any of these orders that do restrict patient's rights, I don't believe the only advocate for them in that room should be a lawyer, I should also be another doctor and probably a doctor of the patients choice … because another doctor can challenge the psychiatrist. The lawyers do not have the information background to challenge psychiatrists, they only have a legal background. … It was really inappropriate having legal representation, they really couldn't do anything, they were required to be there, but they could not do anything."* Carer, 2023

Legal representation is provided at tribunal hearings for the assumed purpose of ensuring that a consumer's rights, liberty, and dignity are not being restricted or interfered with any more than is absolutely necessary[xiv], in line with the principals of the tribunal. However, carers have told MHCN that legal representation is not helpful or effective due to: consumers and carers lacking sufficient access to solicitors in preparation for hearings; and solicitors lacking sufficient information about and understanding of the medical practise and evolving discourse of patient's rights to act in their roles.

The overuse of medication under CTO's, especially without any other therapeutic supports, must be urgently reviewed within a human rights and recovery context as both a vital and necessary measure to protect consumers from negligent healthcare. Ultimately, eliminating the use of coercive CTOs should be the long-term aspiration of this committee.

While some carers do support the use of CTOs as the least restrictive practise to keeps consumers from facing lengthy inpatient stays, there is an ethical imperative for alternatives to all restrictive

practises to be explored and developed wherever possible, including alternative too, and alternative kinds of medication in individual cases. Currently, as only the clinical evidence of the treating team will be available to the Mental health Review tribunal, consumers and carers have difficulty in challenging the team's evidence. Second opinions should be provided when sought in mental health as in other cases when treatment is being queried before a Tribunal hearing and made available to the Tribunal to consider when assessing the treating teams Treatment Plans. MHCN also believes that a cross- government approach to investing in mentally health communities should be the long-term goal of the NSW government to reduce the need for restrictive practises in the community; strong individual mental health starts with strong communities.

At present a consumer can be 'breached' for failing to meet their obligations under a CTO, however, there are no consequences for when community mental health service fails to meet its obligations. Amendments should be made to the Act to require the Mental Health Review Tribunal to include a detailed Treatment Plan in all CTOs including;

- details on the obligations of declared community mental health services,
- a requirement that that the community mental health service prepare a Care Plan that outlines how the service will meet its obligations under the CTO,
- and provide provisions to ensure that penalties apply to declared community mental health services which fail to meet their obligations under the CTO.

recommendations

9. The Mental Health Act should be amended to strengthen the protection of the rights of consumers and carers and to ensure adequate supervision and review of clinical decision making in accordance with the law and human rights principles when imposing involuntary treatment including under CTOs. This includes (and is not limited too) the following changes:
    a. Ensuring involuntary treatment in the community under CTOs:
        i. is justified and the treatment delivered is effective,
        ii. medication is discontinued or changed if it is not effective,
        iii. is proportionate relative to harms prevented and side effects experienced,
        iv. genuinely represents the least restrictive care
        v. is supported by counselling and other non-pharmacological supports.
    b. Ensuring second opinions are available on demand to challenge (or uphold) clinical evidence provided to the Mental Health Review Tribunal by the treating team about the matters in 'a.' above
    c. All CTOs to include details on the obligations of declared community mental health services, a requirement that that the community mental health service prepare a Care Plan that outlines how the service will meet its obligations under the CTO
    d. Requiring that when a consumer is admitted to a mental health facility following a breach of a CTO they should be subject to the same provision of the Mental Health Act (2007) as any new admission – that is, two authorised medical practitioners must examine the person to determine that they should continue to be detained and they should be bought before the Mental Health Review Tribunal to confirm the lawfulness of the detention as soon as possible.

e. Ensuring consumers, carers, and any treating doctors involved in a person's care are given copies of the treatment plan, as well as information about healthcare professionals and patient's and carer's rights and responsibilities.
f. imposing an obligation that all CTO 'breach' events must be recorded as an incident in the Health incident reporting system and reviewed by senior management, triggering an automatic requirement for a second opinion to be provided to review the treatment regime imposed.
g. Stipulating that data must be collected by the Ministry of Health about the number of breach orders issued by all community mental health services and published annually.
h. Mandating that the carer of a person is notified of an upcoming hearing and notified in sufficient time to attend the hearing.

5 The use of emergency services to respond to crisis

MHCN implore this committee to focus keenly on preventing crisis in the community by fully resourcing community mental healthcare services. Crisis requiring emergency response can often be avoided when other services are accessible earlier in the escalation towards a crisis point. As mentioned above [see 1 access to mental health services] several spaces for crisis services exist, however the lack of general awareness in the community and the conflicting information about which crisis services is appropriate for different crisis situations probits access. As a result, carers are often forced to contact emergency services to respond to a crisis.

Fear of Police violence limits crisis interventions

The use of NSW police officers to respond in crisis is extremely inappropriate and dangerous for all parties involved. From 2017 to 2023, "almost half of the people involved in critical police incidents … were experiencing a mental health crisis"[xv]. This alarming news, and a raft of other negative interactions between police officers and carers/consumers has created a pervasive sense of fear among our community. Carers in NSW avoid contacting emergency services in times of crisis for fear of police involvement.

> *"I don't believe the police should be involved, full stop. … When my (consumer) needed to be taken in, I, um, I was really, really frighted that the police would become involved, so I told a lie, and, um, I acted like one of the, um, the silly members of the public that they talk about… Once (the ambulance officers) were in, I locked the door and told them he was psychotic. This was my way of keeping the police out. They, they took (the consumer) in that time, but I guess I won't get away with that again."* Carer, 2023

Carers have told MHCN that there is no consistent or clear model for how decisions are made regarding the wellbeing of consumers and carers who come into contact with the police and other emergency services. An unclear imbalance of power exists across the state wherein Ambulance officer and Police officers in different parts of NSW hold decision making authority over the outcome of an emergency response operation.

> *"I was shocked to find out that an ambulance officer could overrule the police…. the police officers, they're saying 'Yes, (the consumer) does, (the consumer) needs to go to the clinic.' … the ambulance officer said 'No, and were not going to take (them).'"* Carer, 2023

When emergency respondents choose not to administer further crisis intervention, such as admitting a consumer to hospital, then the task of ensuring the carers and consumers safety in a crisis falls to the unpaid, generally untrained, carers.

The Police, Ambulance, Clinical, Early Response (PACER) has been introduced across several LHD's in NSW since 2019 including some regional locations. Initial reports of the Central Coast PACER program shows some positive outcomes including significant reductions in the number of people in the area being transferred to hospital by police[xvi]. While all initial reports indicate positive outcomes, a full evaluation of the PACER programs across NSW is required to ensure the programs efficacy, and, more importantly, to learn what aspects of the program has led to it's success to begin replicating those outcomes using the least restrictive practises possible. In addition, variations to this model should be explored for smaller populations where a full time PACER team is not warranted so that regional and rural communities can benefit from this innovation.

Fear of restrictive practises in hospitals limits crisis intervention

The carers consulted by MHCN also conferred that in situations where a consumer may be admitted to a hospital, they can be left in Emergency Departments (EDs) for significant lengths of time due to lack of available spaces in a mental health specific inpatient facility. This places pressure on hospital EDs which are ill-equip to handle mental health crisis alongside other presenting emergencies. In these circumstances the consumers and carers may be subject to inappropriate conditions, such as seclusion rooms, or may suffer trauma from witnessing distressing events, such as human disfigurement and resuscitation, in a general medical facility.

> *"I took my (consumer) a few years ago to the GP because (the consumer) was in crisis, and they said no help, no appointments were available. So we wandered around the shopping centre instead of going to the emergency room because that would have made it much worse."* Carer, 2023

Similarly, carers fear the harmful practises known to take place in mental health in-patient wards and the impact of harmful practises, like physical and mechanical restrain, chemical restraint, and seclusion rooms. Hospitals are often avoided where possible due to these harms and carers will avoid utilizing emergency services for this reason. With a lack of safe alternatives carers will, again, take on the unpaid, sometimes dangerous, work of responding the crisis without service support.

When a person is experiencing serious distress, but is unable or unwilling to seek assistance, carers are advised to contact police and ambulance to determine of a person should be taken for a mental health assessment against their will, instead of being able to have their loved one assessed at the scene by a competent mental health professional. This can place carers in a terrible dilemma because a high proportion of the number of the deaths of people involving Police are people requiring mental health service support.

Non-restrictive crisis and emergency care must be a reform priority in order to improve trust in the lived and loved experience communities. Programs such as the PACER program have been successfully trialled and should receive a substantial boost in funding. Further, all Police should receive a lot more mental health training (especially in no-violent de-escalation techniques and use of minimum force in physical restraint) as well as a lot more support for their own mental wellbeing, as emergency response workers are evidenced to be a very high-risk group for traumatic experiences.

recommendations

10. To minimise the number of Police responses to mental health crisis in favour of mental health crisis response team and to improve those responses when they do occur:
    a. More effective and proportionate non-lethal means of de-escalation must be developed and potentially lethal responses only implemented if there is an immediate and proportionate risk of serious injury or death.
    b. The number of injuries and deaths of mental health consumers must be tracked and reported as a Key Performance Indicator of NSW Police.
    c. The Police, Ambulance, Clinical, Early Response (PACER) program trail should be fully developed and funded across all NSW LHDs, especially in regional areas.
    d. All Police should receive a lot more mental health training (especially in no-violent de-escalation techniques and use of minimum force in physical restraint as well as a lot more support for their own mental wellbeing.

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[iv] The Mental Health Line, Mental Health Branch, NSW Ministry of Health, May 2023
[v] GP Mental Health Shared Care Program, Central and Eastern Sydney Primary Health Network
[vi] Service Model for Head to Health Adult Mental Health Centres and Satellites, Australian Department of Health, June 2021, p.16
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[xii] Guidance on community mental health services, World Health Organisation, 2021, p.6-8
[xiii] The Tribunal, The Mental Health Review Tribunal, Dec 2022
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[xvi] 'Pacer' shows strong results in first six months, NSW Health, NSW Government, Dec 2020