Submission
No 136

INQUIRY INTO EQUITY, ACCESSIBILITY AND APPROPRIATE DELIVERY OF OUTPATIENT AND COMMUNITY MENTAL HEALTH CARE IN NEW SOUTH WALES

Organisation: BrainStorm Mid North Coast
Date Received: 13 September 2023

BrainStorm Mid North Coast – Regional Consumer Advocacy Group

SUBMISSION: Legislative Council Portfolio Committee 2: Health

Inquiry into the equity, accessibility, and appropriate delivery of mental health care in NSW

September 2023

BrainStorm Mid North Coast welcomes a review into improving the equity, accessibility, and appropriate delivery of mental health care in NSW.

We are a small non-profit community group in Coffs Harbour, established in 2016. Our members are people with a lived experience, carers, and family of people with a mental health condition. We provide emergency food and toiletry packs (attachment A) and information on services in our region to people on discharge from the mental health unit, Coffs Harbour Base Hospital. Prior to covid restrictions, we also hosted fortnightly morning teas and other activities within the Mental Health Unit, which have not yet recommenced. We also provide input from a consumer and carer perspective into reviews or consultations. BrainStorm Mid North Coast is committed to improving service delivery and mental health outcomes in the Mid North Coast Region.

While we welcome a review, we also note that this is one of many in a long series at the regional, state, and federal levels that have resulted in no discernible differences to service delivery in our region at all. Our submissions made to other inquiries therefore remain relevant, such as the Seclusion and Restraint Review, Productivity Commisssion Inquiry, and others, as there has been no noticeable change to service delivery at the community level. This is not only disheartening but also frustrating. Some of the previous material we have submitted to these inquiries is therefore included here, as it remains pertinent.

While the statistics on mental health get far worse, improvements in service delivery are not forthcoming. Why this may be the case is concerning, as much public money seems to have been directed to a multitude of reviews and inquiries with no substantive action subsequently undertaken. Hundreds of thousands of people continue to be let down badly by the mental health care system, and in many cases further traumatised by it.

In relation to the terms of reference:

(a) equity of access to outpatient mental health services

Access to outpatient services appears to only be possible in Coffs Harbour if you have been a very recent inpatient. You need to reach crisis point, be admitted to hospital, and then on discharge are given limited access to outpatient services in the form of temporary contact from a community services team and perhaps one follow-up appointment with a psychiatrist. It is unclear how it is determined who gets ongoing access to these community teams, and what range of services they encompass. This information is not always articulated or provided to consumers.

There is difficulty accessing psychiatric or psychological services directly via the outpatient clinic. For example - if a GP refers you to see a psychiatrist at the hospital outpatient service, the referral will be sent back to the GP asking the GP instead to “monitor” the patient. It is then incumbent upon the patient to continue to make GP appointments, when nothing can be achieved at these appointments as the GP cannot make medication changes or undertake medication reviews.

This situation leaves the consumer with the option of only being able to access very expensive private services if they wish to see a mental health care professional. However, waiting lists and medicare gap fees are sometimes insurmountable - meaning many (or even most low-income people) get no treatment at all. Many psychiatrists have closed their books to new patients, and the gap can be $250 even for a 15-minute consultation.

If you personally ring the outpatient clinic to request to see a psychiatrist, you will be either turned away or told it will first need to be discussed at a staff meeting to determine if your request is considered valid. For example, when one member rang the outpatient clinic directly in 2022, they were asked dismissively why they wanted to see a psychiatrist. When they informed them they wanted a medication review, they were told that the medication they were taking "was not relevant to them". Within a very short time frame after that call, the person was involuntarily admitted to the mental health unit. This was despite making all efforts to seek care.

There needs to be a "no questions asked" policy if someone rings or attends an outpatient clinic seeking to see a psychiatrist or other clinician. There is an urgent need for outpatient services to be expanded by eliminating restrictions on who can access them, reducing the timeframes and red-tape around assessment or triage processes, and by providing other public services as alternatives such as Community Hubs and Safe Havens/Spaces which are staffed by peers and clinicians. Greater and easier access to case management support via the outpatient service or Community Hubs is also recommended.

(b) navigation of outpatient and community mental health services from the perspectives of patients and carers

Navigating community mental health care services is difficult and time consuming. If you reach crisis point and are hospitalised, you are discharged with very little ongoing support within the community. There is a community mental health team who will contact you in the days or couple of weeks following discharge, but this offers very little practical support. For example, they may check you are taking your medication, but do not always link you to services if you are suffering from side effects or want to get counselling or see a psychologist. Many people do not need access to such services immediately upon discharge, but in the weeks or months following it.

There are two main paths to accessing services in the community that we are aware of. The first is to call the NSW Mental Health Access Line, which directs the enquiry to the Community Mental Health Services team at the Hospital. They then interview you to assess if you fit certain criteria, and a treatment plan is developed if you fit this criterion. However, a referral to a psychologist or a psychiatrist is not automatic via this service.

Therefore, this facility is restrictive and does not allow self-referrals to mental health professionals which is important. We would like to see the operation of this service modified to reduce or streamline the interview/triage process, and provide automatic referrals to psychiatrists, psychologists or counsellors if requested. The benefit of this service is that it removes the need to schedule a visit to a GP and can be done over the phone.

The other method to gain access to services in the community is via a mental health care plan from the GP. This may involve a waiting time and cost, as it may not be bulkbilled. However, GPs are generally more flexible with referring people to see psychologists and psychiatrists and offer care plans in collaboration with the person. The care plans are only for 10 sessions (although can be renewed yearly) and involve significant out of pocket expenses so are not suitable for everyone, especially those with chronic conditions and low incomes.

Mental health care plans are usually of insufficient duration to adequately treat many conditions, there are a limited range of clinicians available that can see patients in a timely manner, and the cost can be prohibitive. The necessity to continue sharing descriptions of your condition or history many times can also be emotionally draining. The main factor discouraging the greater use of mental health care plans is cost – the medicare gap can be considerable. People on healthcare cards need further subsidisation for therapy sessions under these plans.

Access to physical services appears to be usually triggered only in crisis situations, which is resource intensive as well as traumatising for the person. Preventing or obviating the need for tertiary level care by improving subsidised access to psychiatrists, psychologists, and counsellors as well as case management at the community level would improve navigation as well as provide the most appropriate form of care at the right time. Peer support workers are one valuable resource that can help navigate services that needs expansion and wider availability.

According to the Mid North Coast Local Health District website, people are referred to community services from the emergency department, general wards, and the mental health unit. However, whether or how this works in practise is questionable. For example, members of our group have never been referred to any community services (apart from the community team, with a limited role) on discharge, or even been given the phone number for the NSW Mental Health Line. It can be difficult to find information on services, or know how to access them, and it can be daunting for someone in recovery to try to follow this up independently.

On discharge from the public hospital, you are only usually told you need to go to a GP to get a prescription within the next week, which is difficult to do considering wait times. Then the GP tries to find a psychiatrist or psychologist that is available and within your budget to refer you to, if you would like follow-up treatment. Due to the difficulty, wait times and cost in accessing care at the community level, many consumers just stop trying. It’s simply seen as a futile exercise.

Navigation is therefore extremely challenging as there is a chasm at the community level of any affordable services in the private sphere, and restrictive “gatekeeping” of services in the public sphere. This is compounded by socio-economic factors that often affect people disadvantaged by poor mental health such as low income, lack of transport, homelessness or instability in housing, substance abuse and lack of support/isolation.

There is a lack of knowledge about the NSW Mental Health Access Line, the services it offers, and a perception that it can only be used in emergencies. Greater promotion and publicity of this phone line and awareness of the range of services it offers can help people more easily access local support. Information on this service should be given on discharge either verbally or via pamphlets that include other services available in the community including welfare services.

The gap or fragmentation on information on services could be partly addressed by an online regional portal which covers both public and private service providers and agencies (which is discussed under (g) benefits and risks of online and telehealth services), as well as peer support workers at community hubs. An online regional portal of information could benefit consumers as well as clinicians.

We would like to see the use of community teams expanded, the duration of treatment/contact under them lengthened if requested, automatic referrals to suitable community mental health services once the community team has completed its duties, and more frequent follow up if requested in the months after discharge, and not just in the couple of weeks afterwards.

There is also a lack of utilisation of peer support (both volunteer and paid), which can be invaluable in navigating the mental health care system. There is currently no support group for consumers in our region, despite us approaching several agencies to partnership with us to provide one. We have been unable to secure a venue or linkage with any agency within the community to provide a peer led support group.

Support groups are one very effective way to help consumers navigate the system in an informal and non-threatening way, as well as assist in minimising social isolation. We strongly advocate the assisted establishment of peer led support groups in communities where feasible. The quickest and most efficient way to learn about services and how to access them, and other matters relevant to mental health care consumers such as medications, is from peers who have experienced the same condition and the same issues. Peers also provide hope for recovery and give unique insight into services that allied health professionals lack.

(c) capacity of State and other community mental health services, including in rural, regional, and remote New South Wales

Capacity in Coffs Harbour and surrounding region of services is inadequate for the volume of need across the full spectrum of mental health conditions (mild/moderate/acute), as well as for the community demographics. For example, youth, elderly and culturally and linguistically diverse groups. There is great unmet demand for affordable and accessible psychosocial support services.

The scope of what is encompassed by "community mental health care services" needs to be expanded to include social inclusion as well as other factors that are crucial to mental health and wellbeing, such as access to education, employment, lifestyle or physical health activities, and housing. Social participation and inclusion programs for consumers are currently weak or non-existent in our region. This is more pronounced for consumers who cannot access the NDIS.

Mental health is not just dependent upon clinical healthcare services for treatment and support. There are a range of factors directly influencing mental health beyond these services, so linking and co-ordinating a variety of social, welfare, physical health and economic agencies that could help people with mental health conditions is important. Community Hubs could be used to improve social inclusion as well as provide peer support, access to other relevant services, and co-ordinate the provision of information across a range of domains.

We look forward with optimism to the establishment of a Community Hub in Coffs Harbour later this year, which we anticipate will greatly improve service delivery. We have been lobbying for a Community Hub for some time and are pleased that one will soon be operating, as this is vitally important for increasing provision of information as well enabling face-to-face contact with peers and clinicians in a safe and non-threatening environment.

We hope a Safe Haven also becomes operational within our community without undue delay, and that these are progressively expanded state-wide as a matter of priority. Community Hubs and Safe Havens are a cost effective and culturally appropriate way to improve capacity of services, increase their range and reach, and reduce pressure on acute care or emergency departments in regional areas. The Mental Health Co-Ordinating Council Report "Shifting the Balance" provides a comprehensive case for improving capacity by expanding community-based care, which we strongly support.

(d) integration between physical and mental health services, and between mental health services and providers

What “integration” means in practise is not clear. Is this referring to co-location of services, integration of health records, or referral paths between service providers and clinicians? Mental health often has co-morbidity with physical health conditions due to side effects of psychiatric medications, and physical health has direct impact on mental health. The links between mental and physical health are clear, but the division between physical and mental health care service delivery and providers can lead to omissions or oversights in care provided.

There needs to be sensitivity to consumer preferences as to record or information sharing between clinicians. Not all consumers want their mental health records or details freely shared with other clinicians or providers, who are treating physical health conditions. The perspective of the consumer is vital to this matter. While service providers or practitioners may see some benefit in the “integration” of these services via sharing records or information, some consumers may not.

Mental health raises specific concerns around privacy and confidentiality and some consumers may prefer these services remain distinct and operate independently. In particular, the integration of physical and mental e-health records should not be automatic, and consumers need to retain the right to either link or de-link these records.

The “integration” of services is a complex issue, which may be addressed in a variety of ways besides direct paths of information sharing between different service providers. For example, by lifestyle counsellors (or what the Productivity Commission called “low intensity therapy coaches”). This is by using a manpower category who informally co-ordinates aspects of both physical and mental healthcare, rather than by developing or enforcing more elaborate links between different service providers. Care co-ordination that encompasses both physical and mental health conditions is important and can be done with support workers operating from Community Hubs.

A support person (whether in the form of a case manager, peer worker, lifestyle counsellor, or low intensity therapy coach, recovery coach, mentor), who is familiar with the range of conditions the person has, as well as their unique situations and needs, may be able to link the person with services and providers more effectively and sensitively than developing additional levels of administration or bureaucracy, more intricate referral processes, or information sharing between clinicians. They could also provide diet, exercise and lifestyle advice as well as help a person access services in relation to these.

Community Hubs represent an effective way to integrate the delivery of these services, with a range of services for both physical and mental health offered in the same location. Given the complexities of treating mental health conditions, the links between mental health and physical health, and the limitations of current approaches “…it is now urgent that a more integrated patient-centred approach occur within the field of mental health, with a particular focus also on physical health. Both are intimately connected and influence each other, thus an approach which considers both body and mind as one interrelated nexus (is necessary)” (Ee et al., 2020:11).

Community Hubs can also reduce stigma as consumers are not identifying as someone with a “mental illness” by using the hub but are simply accessing a health service. In smaller communities, people may not want to access services that are specifically identified with mental health conditions, so hubs with a broader and holistic health focus would be beneficial. The expansion of “step-up stepdown" services could also enhance delivery and co-ordination of support across levels of care, and aid integration between services and providers.

Regular education and training for GPs around common side effects of different psychiatric medications is important as these are sometimes overlooked. A GP is usually the main clinician involved in treatment and first port of call for all health-related matters, so is typically aware of the mental health condition/s as well as physical conditions of their patients. However, GPs are general health care clinicians, not specialists, and the effects of psychiatric medications can be complex.

GPs need to have access to more regular training and information on mental health, to maintain up to date knowledge about conditions and their treatments. More training and support for GPs in recognising early symptoms of mental health conditions, identifying services available, helping the patient link to the most suitable one, and understanding medications/treatments can aid the integrative provision of healthcare. It would assist in more targeted referrals as well as more comprehensive care at the GP level.

Conversely, more emphasis and recognition by psychiatrists of physical health conditions generated by medications and prompt action to address them is also necessary. It should be mandatory to provide information verbally on physical side effects of any psychiatric medications when they are prescribed, either by the Psychiatrist or dispensing pharmacist. The sole reliance on information brochures within the medication packet is not adequate, as they can be confusing or not use plain English, and do not sufficiently meet the needs of groups such as CALD, or those with low literacy.

Providing more integrative and comprehensive or holistic care can thus be partly addressed by ensuring GPs have more education and training on psychological issues and monitor these more closely including making or offering follow up appointments with consumers (instead of assuming consumers will make these appointments independently if needed). Psychiatrists could also have more focus on physical health issues linked to the medications they are prescribing, and discuss these with the consumer, including addressing any methods they can use to lessen or mitigate the side effects.

The limited scope of GP services means that even in the case of obvious side effects from medications, little can be done except a referral to a psychiatrist for a medication review. This is not always feasible due to cost or access issues, so many physical side effects are not addressed, and this can cause a range of chronic health problems. Some of these are irreversible, increase mortality, or create memory or cognitive impairments and other serious conditions (Ee et al., 2020:2; Ritvo AD et al., 2023; Shi et al., 2022).

Additionally, many people do not receive the full therapeutic benefit from the use of drugs (Sarris & Lake, 2012:82). While there is evidence that drugs work for some people and some conditions, and can treat many of the symptoms of psychiatric disorders, there is less evidence that they can provide a "complete and sustained remission" alone (Ee et al., 2020:2). Access to other forms of treatment or therapy are imperative, including nutrition, exercise, and counselling for example. These may be more appropriate or beneficial than sole reliance on drugs, which is currently what many consumers only have.

Long term use of medications, which may not be necessary, presents a range of complications and it has been estimated that up to half of long term anti-depressant prescriptions have no evidence based indications (Van Leeuwen et al., 2021). People are prescribed with medications, repeat the prescriptions indefinitely or without review, and can take these medications for years, despite them being ineffective or producing harmful side effects. These side effects can significantly impair the quality of life or reduce lifespan. The availability of a fully subsidised medication review by a psychiatrist once every twelve months for anyone taking a psychiatric medication would be beneficial. This should also cover the main aspects of physical health status.

Integration between mental health care services and providers is mainly fragmented between the public and private sectors. While most of the infrastructure/services is public, many service providers are private. When you are discharged from a public hospital mental health unit, you are not always provided with information on private services available in the community. It's very easy to "fall between the gaps" and suffer in silence as you may not have the capacity emotionally or mentally to follow up treatment options yourself.

This is why case management, whether by a peer support worker or other similar professional (via the outpatient service or a Community Hub), can be very valuable and should be offered to more people with mental health conditions. These can be arranged on discharge from Mental Health Units or offered to those who have contact with community mental health care services. A case manager can also provide a stable link in continuity of care, which is often missing when the consumer has had to access many different clinicians for a variety of conditions.

Currently, it is incumbent upon the consumer to educate and inform themselves about their psychiatric condition/s, the physical side effects of any medication/s, alternative medication/s that can treat their condition, and which service providers are available in their region that may assist them. The consumer needs to become a strong and proactive advocate for themselves, and expert in their own condition as well as the medications they have been prescribed. This is not an easy task.

For enhanced integration we would like to see

- The co-location of physical and mental health care services within Community Hubs
- The use of lifestyle coaches/case mangers/ peer workers to co-ordinate care
- More training for GPs on mental health conditions and psychiatric medications
- More emphasis and information by Psychiatrists on physical side effects of medication
- Mandatory verbal information on the physical side effects of psychiatric medications
- Access to a fully subsidised medication review from a psychiatrist every 12 months that encompasses physical health status (such as weight, blood pressure, blood test).

(e) appropriate and efficient allocation of mental health care workers, including psychiatrists, nurses, psychologists, GPs, counsellors, social workers, allied health professionals and peer workers

The lack of psychologists, psychiatrists, counsellors, and bulk billing GPs in regional areas is well known and documented. The wait time and lack of bulk billing affects accessibility (current wait time in Coffs Harbour depending on clinic – 2-3 weeks), with many GPs now closing their books to new patients. Expanding the number of GPs in regional areas is crucially important, especially as many regional areas have experienced population growth combined with an aging population.

The lack of timely and affordable access to GPs and other allied health professional's results in more reliance on the emergency departments of hospitals for conditions which are better treated elsewhere. High numbers of presentations to emergency departments for mental health conditions, or to crisis services, is an indicator that the system is failing. Many people with mental health conditions need to reach crisis point before they can access care, which is then admission (voluntary or involuntary) to the mental health unit. This is far more resource intensive, as well as traumatic, than other types of care.

Trying to improve the allocation of these clinicians across the state without economic incentives or compulsory requirements to work in regional, rural, or remote areas as part of obtaining their qualification may be difficult. More fully subsidised training places for nurses, GP's and allied health professionals in TAFE or University campuses located in those regions may assist this goal in the medium to longer term.

There may be potential to expand the scope or allocation of visas for certain occupations under the schemes operating, as well as streamlining these processes and reducing costs associated with it. Subsidising more international students who wish to undertake certain courses and then reside in Australia to work is also a feasible option. The shortage is critical so measures to increase the workforce, both physically and via online services, needs to be addressed in innovative ways.

The expansion of peer support workers is a very positive option, as they offer unique insight into self-management as well as navigation of the myriad of services available. They provide guidance with compassion, dignity, and hope, and give faith in future wellbeing – which is vital for recovery. The ability and capacity of peer workers to play a role in mental health management and care is currently underestimated and underutilised. There needs to be more fully subsidised places for peer workers, and more diversity in the peer support workforce. Identifying as having a mental health condition (being a "peer") may be one factor preventing some people from following this occupation choice. A more neutral term such as recovery coach may encourage more people to take up this profession.

(f) the use of Community Treatment Orders under the Mental Health Act 2007

According to Justice Action, NSW has one of the highest rates of imposing CTOs worldwide, with nearly 7000 issued in 2022. The use of CTOs are not always effective as therapeutic tools. The application of punitive measures undermines establishing a therapeutic relationship needed for any benefits to be obtained. Alternatives to CTOs need to be developed, as the way they are currently administered can be seen as demeaning and intrusive.

For example, not giving sufficient notice of breaches of the CTO (as required), directing people to attend the emergency department for an assessment within a very short time frame (rather than making an appointment at the Mental Health outpatient service), directing the person to attend more appointments than is necessary under the order, and not providing copies of the order as required when a breach has been determined.

We advocate the elimination, reduction, or revision of CTOs as these are not always beneficial, can be very invasive, and involve the threat of police force if they are breached. If they cannot be eliminated, they need to be revised or reworded to be less onerous and restrictive, particularly around the use of police presence or use of police force to take a person who has not complied with the requirements to the hospital. Instead, community treatment teams could visit the person at home for example. A more collaborative approach to developing and enforcing the requirements of a CTO should be encouraged, such as determining preferred methods of contact, more options and flexibility around dates and times of appointments, and frequency of contact from the case manager.

Entering a CTO can be voluntary and can be seen as one way to access services and support such as a psychiatrist or a case manager but should not be *necessary* as the only way to access these services.

The intent of the CTO is to enforce access to services, but it's currently framed and operated with the assumption that the patient is not compliant and is resistant to treatment which is not always (or even often) the case.

People may have relapsed for many reasons, such as lack of access to medication reviews, and not always because they refuse to take medication. The current tone and manner that CTOs are framed and applied does not give dignity and respect to the patient and perpetuates stereotypes and myths about people with chronic mental health conditions - such as they are unwilling to take responsibility for their condition or lack insight into it. We strongly advocate and encourage the revision of the CTO framework and education and training for staff about their responsibilities and obligations under it.

An example of the recent application of a CTO from one of our members highlights some of these issues:

The consumer was discharged in late June or early July 2023 from the Mental Health Unit at Coffs Harbour Base Hospital with a 6-month CTO which required two reviews by a psychiatrist 3 monthly intervals and fortnightly contact by a case manager. This CTO was voluntarily agreed to by the consumer, who felt it was the only way to get access to a psychiatrist which they had not been able to obtain in the previously except during hospital admissions.

The person attended their first appointment for review with a psychiatrist as required on 13th July. However, at that appointment the psychiatrist deemed that the consumer had not answered the questions in the way the psychiatrist "preferred" (they did not like their "attitude") so they were considered "technically" in breach of the CTO. This is despite meeting their only legal obligation under the CTO, which was to attend a review in person. Due to this, another appointment was then made for a further review one month later, 10th August.

The consumer forgot to attend the additional psychiatrist appointment on the 10th August, due to having another medical appointment booked the same morning. They had also lost the pathology report for the compulsory blood tests required under the CTO. After missing that appointment, they were contacted on Tuesday 15th August and told that the psychiatrist appointment would be rescheduled. They were offered the dates of 11th and 25th of September, neither of which were suitable.

They were then given an ultimatum by the case manager that one of those dates must be chosen or they would be in breach of the CTO. Every text message sent regarding appointments came with a threatening and intimidating "warning of breach" if there was non-compliance, which the consumer found extremely offensive and stereotyping/stigmatising as well as unnecessarily coercive.

The consumer expressed this frustration and anger at the manner the texts were being sent in and was then told on the same day – prior to either accepting or rejecting the appointments offered on 11th or 25th September – that they were now in breach of the CTO and would be given written notice of that. Also, that they must attend a psychiatrist review on Friday 18th August (in 3 days), by presenting at the emergency department. It appeared the appointments offered on 11th or 25th of September had now been withdrawn without notice, and the consumer was considered already in breach for either missing the appointment on 10th August or not having the blood test.

No written notice of this breach was received as indicated. The following day, on Wednesday 16th August, the consumer was then told written notice of a breach would instead be received if they did not present to the emergency department on Friday 18th August. The consumer had a pre-existing arrangement on 18th August so did not present to the Emergency Department on that date.

On Tuesday 22nd August a notice of breach was placed in the letterbox telling the consumer they had been given sufficient notice of a breach under the Act, that they must now attend the Emergency Department immediately or the Police would be attending their home, and that the conditions of the CTO were attached. No paperwork was attached to this letter, and there was no pathology request form for a blood test. This situation was only resolved when the consumer contacted bureaucrats within the MNC LHD and complained about the process and timeframes used and asked how to apply to have this CTO revoked.

This example shows that CTOs can:

- be applied without due process
- use the resources of Emergency Departments and the Police unnecessarily
- can escalate to Police intervention quickly and without cause, and
- can generate extreme pressure, stress, and anxiety for consumers during periods of time when the focus should be on recovery and healing.

We agree and endorse the position of the Justice Action organisation on the use of CTOs. Their discussion/research paper on this is very comprehensive and presents the case clearly from a consumer perspective including many case studies. It's linked from https://justiceaction.org.au/community-treatment-orders/

(g) benefits and risks of online and telehealth services

The main benefits of online and telehealth services are convenience, ease of access, ability to be anonymous for some services, and usually reduced waiting times for access. People may be more willing to access some services in the privacy of their own home than attend clinics where they could be identified or seen. Some people may feel more comfortable raising issues related to their mental health in an online capacity where they are not necessarily visible and may not have to identify themselves.

Health workforce shortages in regional, rural, and remote areas may be partly addressed by telehealth initiatives, however access to technology needs to be considered as a potential barrier to uptake. Low-income earners may not have sufficient hardware, internet access or data capacity to benefit. While most or nearly all homes now have access to the internet, some may have limited capacity with data allowances.

Private rooms with the free use of the internet to use these services within community hubs or safe havens could be one method to enable easier access to online services. There is a risk that some of the most vulnerable consumers with highest need have financial, technical and literacy barriers to using online services. Therefore, telephone services should always operate in tandem with online services and be co-ordinated to address service gaps.

Telehealth services are not a substitute for face-to-face services with a health care professional. Telehealth services may offer an adjunct to physical services but not a replacement. Some people are not comfortable with the use of online services for various reasons, and the provision of online services should not be viewed as a suitable or sole alternative in all cases. Online services, telephone services and face-to-face services should all be offered, and be co-ordinated to maximise service delivery outcomes.

Face-to-face services can be considered crucial for some people due to the nature of their mental health condition. Being in the physical presence of a clinician or therapist can impart a sense of comfort or support which is lacking in the online delivery of services. Online services may increase the sense of alienation and isolation. Online services may be suitable as a temporary solution for some, whereas others may find them suitable longer term for their needs. If all options are available (online/telephony/in person), then consumers can choose the service delivery method most suitable to their needs. People should not be forced to use telehealth services due to lack of other options.

The re-establishment of bulk billed tele-psychiatry services is promising however it is unclear yet if this has made any difference at the service delivery level in this region. GPs may require more information about this service, as well as others that are available for mental health at regional, state, and federal levels, as GPs are often not fully aware of what is available or where to direct people if they cannot refer them to a local psychiatrist or psychologist. The quickly changing and evolving landscape in the digital mental health field may be one factor for this.

Awareness campaigns of online services that are already available and the Head to Health portal are important, as recognition by consumers of the different online services available is variable, and online service delivery appears fragmented. We support the development of a regional online navigation platform for mental health services, based on the HealthPathways portal currently used by most PHNs, which incorporates the ability to book consultations with service providers.

We would like to see the range of services contained within these regional portals to be expanded to include for example – emergency accommodation services, subsidised food outlets (food banks), welfare services, public transport routes, education and training/employment agencies, locations of pharmacies and bulk billing medical clinics, support groups, and rebates available from state and national governments for utilities and services.

There is therefore scope for regional portals on mental health services to provide information to mental health consumers beyond clinical services, and to link consumers with a range of social services that can support and enhance their mental health by reducing financial stress, and making it navigate clear and easy across the range of clinical, allied health, psychosocial and welfare services available at a regional level.

Forums or chat rooms moderated by peers could also be attached to some online services, as there is great support and reassurance offered by other consumers, which can reduce social isolation as well as provide information informed by lived experience. Online support groups represent a positive alternative to other forms of support and need to be considered as a viable alternative to face-to-face groups.

The main risks we see with the use of online and telehealth services is privacy, data retention (or storage and retrieval of recordings or records made), data breaches and issues around third-party access. How these services and the information provided in them are stored, who can access them, and issues around record retention are the main concerns. Consumers should always retain the right of consent around recording of calls or sessions (recording should not be compulsory to use telehealth or online services). Regulation around record retention and consent for this needs to be clear and encompass both private and public spheres.

The use of electronic health records for mental illness in particular poses many concerns and we do not believe e-health records should be compulsory or phased in as a necessary part of the stepped care model. The use of e-health records needs to be matter of individual choice, and not implemented without consent by the service provider. Wide consumer consultation and information around this needs to be undertaken prior to implementation. In summary, we see the benefits and risks as:

Benefits

- convenience
- privacy
- reduced waiting times
- may be available out of normal business hours
- useful for people without transportation or with physical disabilities
- cost – may be free or cheaper than face-to-face services

Risks

- May be seen as a substitute for rather than an alternative to other services
- Retention of records and third-party access
- Consumers not being aware of or informed of implications of the terms of service
- High or unregulated fees or costs for some services
- May not enhance continuity of care
- May not meet needs of vulnerable or socially or physically isolated groups – eg. CALD, those with literacy issues, limited technical skills or restricted access to hardware/wifi
- The range of services and their scope can be overwhelming and confusing to navigate
- Inadequate evaluations or lack of reviews to determine effectiveness and efficiency
- Poor links to physical services or lack of follow up

(h) accessibility and cultural safety of mental health services for First Nations people, culturally and linguistically diverse (CALD), LGBTQIA+ people, young people, and people with disability

First nations: Indigenous communities can access a variety of agencies for health care needs including mental health care in this region, however we are unable to comment on access issues. Indigenous healers may be one asset as mental health care workers. The use of indigenous healers was canvassed by the Productivity Commission and represents a method to expand the range and reach of services in a cost effective and more culturally appropriate way. The World Health Organisation recognises traditional medicine and traditional healers as a valuable and vital resource at the primary health care level, and they may have particular significance in the mental health care sphere where culturally sensitive support could aid recovery.

CALD: Coffs Harbour and the surrounding region has an ethnically diverse population, including refugee groups, which the services do not appear to recognise. Language and cultural differences are not accommodated in information brochures or in signage (for example, there is a large Indian population, as well as Afghani and Sudanese refugees). We would like to see services that more closely accommodate the differences within the community and are tailored to meet the needs of these groups. Trauma experienced by displaced communities for example, could be addressed. There are refugee settlement agencies which offer various services, but the links between these services and other services available in the community are not clear.

LGBTQIA+: We are not aware of any access and safety issues for this community in our region. A diverse range of peer support workers in Community Hubs can provide sensitive access to a variety of services for many minorities, including indigenous, CALD, and LGBTQIA+ communities.

<u>Young people</u>: The Mental Health Care Unit has no beds for youth, which means young people (under 18) need to be transferred to Lismore Base Hospital for treatment. This causes great hardship and stress. One example is a sole parent family, whose 14-year-old daughter needed to be treated as an inpatient. Due to no allocated beds for youth at Coffs Harbour Base Hospital, she was transferred by ambulance to Lismore. The mother then had to spend 4 weeks in Lismore to be close by, so needed to send some of her other children to Sydney for care. An elderly relative also had to come to Coffs Harbour to care for another.

The absence of allocated beds for adolescents in Coffs Harbour has been raised many times over many years but no action on this has been taken. This is an unacceptable situation for a regional centre the size of Coffs Harbour (population 78 000) and causes immense stress and anxiety for families during an already very difficult time. Beds located within the Mental Health Unit specifically for young people needs to be a matter of priority. Mental health wards for adolescents like the one in Lismore (population 44 000) need to be expanded to all main regional centres at a minimum - currently there is only one in Lismore and one in Newcastle.

There is a lack of services dedicated to youth in Coffs Harbour. While it may appear that there are many service providers, most of these are booked out many months (even up to one year) in advance with others not taking new clients. This means that parents can sometimes only access services for their children via the NSW Mental Health Line. Depending upon the assessment, the child may be offered unlimited access to a psychologist as well as a psychiatrist as needed. Alternatively, access to a psychologist may be provided but is short term. Continuity of care is therefore an issue.

Given that many adolescent mental health issues relate to self-harm or eating disorders, there is a need for access to early detection and intervention programs specifically for these conditions. This may require education and training for teachers, as well as expanding the availability of counsellors at schools, and incorporating more detailed information on mental health into school curriculums.

<u>People with a disability</u>: People with a physical disability as well as a psychosocial disability may be able to access the NDIS with greater ease, and therefore have greater support and access to services via case workers, peer workers or social workers. We are not aware of any specific significant issues related to access for this group.

<u>The elderly</u>: Our region has a large proportion of retired and elderly people. Many of the elderly are vulnerable to social exclusion and isolation, as well as lacking the skills to access online or telehealth services.

(i) alternatives to police for emergency responses to people experiencing acute mental distress, psychosis, delirium, dementia or intoxication in the community, including but not limited to Police, Ambulance, Clinical, Early, Response (PACER)

The Police should not be used for most acute mental health cases, and instead specially trained paramedics are preferred. The exception to this may be life threatening or public safety situations. If the Police are automatically called for emergency mental health cases, further training in mental health and dealing with people who have mental health conditions is urgently required. It should form a core component of training. Discrimination and bias still exist, based on poor understanding of these conditions.

The automatic use of the Police is based on stereotypes that all people with mental health conditions in crisis situations are potentially violent or dangerous, and we would like to see this myth addressed based on the facts and reality around mental health admissions and conditions. **People with mental health conditions are far more likely to be the victims of violence, than perpetrators of it**. The fear around people living with mental health conditions who may be experiencing a psychotic episode or crisis is unfounded, exaggerated, and based on inaccurate assumptions that need to be dispelled.

It is extremely traumatic for people with mental health conditions to have contact with the Police Force in emergency situations and more sensitivity and compassion is needed. There is scope for vast improvement in this area, which needs to address a cultural issue within the Police Force itself. The Police are not equipped to deal with these matters, and do not appear receptive to improving their ability or capacity to respond to them.

As part of a general stigma reduction approach, we support more education and training about mental illness for Police. People with lived experience can be used in training, so that the barriers between the Police and people with mental health conditions are reduced. This is important given that people with a mental illness are overrepresented in every part of the justice system.

On-going education and training should be regularly undertaken, and not just once as part of initial training. The appropriate use of force, methods to de-escalate situations, and effective communication with people suffering from mental health conditions should be aspects covered.

We advocate the elimination of pepper spray and tasers when dealing with unarmed or non-violent people suffering a psychotic episode or other mental illness. The use of pepper spray and tasers, as well as excessive force, is not only totally unnecessary but generates extreme pain and trauma. The frequency that these are used when police attend a mental health call-out should be officially recorded, monitored, and used as a performance indicator. Alternative methods to approach, restrain or sedate people with mental health conditions needs to be urgently addressed in training.

While PACER teams or similar are the preferred option and should be widely used, but in some locations may not be feasible. If uniformed police are deemed essential or clinicians are unavailable, then every shift should have at least one specially trained officer with expertise in mental health conditions and interaction/communication with people with mental illness who attends, directs the team and co-ordinates with ambulance or hospital staff. If combined police/clinician teams are used, the clinician should be the main point of contact with the person with a mental health condition, with the police remaining unobtrusive and only participating when necessary.

Police uniforms can be confronting and frightening for people suffering from a mental health episode. It may be better differentiated or demarcated from the view of the patient/consumer if a vest over the uniform is worn, like a high-visibility vest but that looks more clinical (like being white in colour, or another colour). This may clearly signal to the person that while the police are in attendance, they are there in a different capacity to normal. This could help reduce stigma and fear.

Communication is the most important way to de-escalate the situation and deal humanely and compassionately with the person involved. Very simple and easy techniques like using the person’s name, speaking respectfully, and explaining clearly what is happening can make a big difference to the experience from the consumers perspective. No mental health patient should be transported to the hospital in a police van, which happens on numerous occasions.

All people with a mental health condition should be treated with dignity and respect, which is often not the case when excessive force is used, or the police respond in the same manner as when they are dealing with a criminal matter. People with mental health disorders are suffering from symptoms of a **health condition** and are not **criminals or inherently dangerous**. It’s vital this distinction is kept upper most in the minds of responding/treating teams. The unfounded <u>fear of potential violence</u> from a consumer should not result in the <u>actual use of violence</u> and excessive force by Police in the form of weapons like tasers and pepper spray, or extreme and painful physical restraint.

(j) any other related matter.

<u>Sole parent families</u>: The Productivity Commission Inquiry reported that the household characteristics of people with a mental illness shows that one parent families with children are the largest group represented (over 30%), and single parents are more likely to suffer from social exclusion and poor mental health. Both single parents and their children are at greater risk for developing mental health conditions.

There is a clear link between sole parent's mental health and children's mental health. Children raised in sole parent households are significantly more likely to be exposed to all the risk factors associated with developing mental health conditions. This includes socio-economic disadvantage (which can be directly linked to poor physical health), personal trauma (including the breaking up of the family unit, disjointed care arrangements with primary caregivers, potential exposure to domestic violence, substance abuse or mental illness within the family unit), instability in housing, and being in the child protection system (PC Vol 2:661).

Children within sole parent families are therefore more vulnerable to poor outcomes in physical, social, and emotional health and face multiple risk factors (PC Vol 2:662). Both parents and children within sole parent family units therefore need to be considered a significant group who merit special measures when developing mental health prevention and support programs, or addressing access, equity, and appropriateness of service delivery issues.

We would like to see greater support for sole parents with mental health conditions, as well as sole parents more generally as well as their children. This would lead to less incidences of formal intervention/removal of children from the family unit. This can have a devastating impact on both parent and child and could be prevented with greater support at the community level and access to respite. Respite services could be like that currently offered to carers.

Developing specific measures targeted at these family units is therefore strongly supported, and we believe one parent family units need to be recognised and identified as a priority for practical support and assistance in treating and preventing mental ill health at the community level. We would like sole parent families to be included alongside other segments of the community that are targeted for specific measures such as indigenous, LGBTQIA+, CALD and young people as they have very specific needs and are the largest group represented in mental health statistics which is currently not recognised in any access and equity measures.

<u>Natural disasters:</u> The impact of natural disasters like fires and floods on communities can be extensive and long lasting. We would like to see the development of innovative and flexible programs such as rapid response teams, that deal specifically with mental health issues, that can be deployed quickly in times of these crises. Access to free psychological support at the earliest possible time is important in communities that have faced traumatic natural disasters. Early intervention may avoid the need for more extensive support and care later.

While communities are resilient and can develop local strategies, the early and additional provision of professional or specially trained manpower could be crucial to improved recovery. This could be low cost, if formed by volunteers with a particular skill or qualification in this area (like the State

Emergency Service). Southern Cross University (Dr Eric Brymer) is currently undertaking research into this area which could also inform the development of options to address this.

Stigma and discrimination: Unfortunately, there is still widespread discrimination and stigma. This can deter people from accessing services, or from seeking support. Methods to achieve this need to be actively explored and further expanded such as talks in schools, and at hosted events within the community. For example, we are not aware of any stigma and discrimination reduction programs operating within our community.

Prevention: There are few or no proactive or preventative strategies to address known physical side effects of psychiatric medications, or to prevent mental health conditions developing. Prevention strategies to reduce the development of disorders have been successful for other health conditions, like cancer and cardiovascular disease, but similar programs for common mental health conditions are lacking (Jacka et al., 2013). Preventing conditions developing is easier and more cost effective than treating them once they have emerged. More emphasis on prevention, and more focus on primary health care, is a more suitable focus than the continued expansion of, or reliance on, tertiary level or acute services.

Complaints mechanisms: The Official Visitor Program, Health Care Complaints Commission, NSW Ombudsman and Law Enforcement Conduct Commission are not effective or appropriate for consumers to lodge complaints about care with. For example, complaints lodged with the Official Visitor in 2022 have still received no response. A single independent complaint body specifically for mental health consumers that can deal with a range of complaints or concerns across both the public and private spheres would be preferred.

Conclusion

Thank you for the opportunity to participate in this Inquiry. We look forward to the outcome and to changes that may eventuate from it. In summary, our lived experience in relation to the inquiry is that there are too few public community level services and service providers, waiting lists are too long and costs too high for private services, and medicare gaps for services are too large for mental health care plans to be of benefit to low-income earners (ie. those on healthcare cards). Community Hubs, Safe Havens and the peer worker workforce require far more investment and expansion.

We are optimistic that this inquiry will lead to investing in fixing the mental health care system as a matter of urgency before more people die, and more people suffer unnecessarily. This is an issue of quality of life, as well as human rights. The fact that the system is broken is obvious – someone now needs to have the courage to take responsibility to fix it.

This problem is not unique to NSW, and is experienced worldwide – up to 50% of people in high income countries and 85% of people in low to middle income countries do not receive required mental health treatment (Ee et al., 2020:2). The World Health Organisation estimates that fewer than half those affected by depression, and in some countries less than 10%, receive treatment (Bodeker, 2018:99). Cost and access issues are crippling, and many people are left without any form of support or therapy at all.

Those with mental health conditions suffer in silence and are mostly a voiceless and powerless segment of the community. It is unconscionable that today in NSW, many people still cannot access treatment for mental health conditions, and still cannot afford it. It's a complicated issue that needs to be proactively addressed now not only for the benefit of current consumers, but for future generations. Collaboration and innovation are the ways forward. Rather than focussing on the problems of the past, we can focus on moving forward with hope into the future. Let's take this opportunity to make genuine and lasting change.

ATTACHMENT A:

Contents of the packs provided on discharge, with an information brochure on local services:

CARE PACK

CONTENTS

FOOD PACK

1 1Lt **UHT milk**

1 750g **muesli**

1 500g **pasta**

1 500g **pasta sauce**

1 420g **baked beans**

1 185g **tuna in spring water**

1 100g **rice crackers**

2 125g **diced fruit in juice**

2 30g **soup in a cup**

2 40g **oat bars**

5 85g **instant noodles**

HYGIENE PACK

1 **toothpaste**

1 **toothbrush**

1 **roll on deodorant**

1 **pocket tissues**

2 15ml **body wash**

2 15ml **body lotion**

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