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

Name: Name suppressed

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Partially Confidential

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Hello my name is and I am writing to you to share about the deeply broken nature of the public mental health system and especially the combination of no support and poor quality support in outpatient and community mental health services. If invited I would like to give evidence at a hearing however I would like my name changed if my submission is to be published.

I have been a mental health service user myself and both of my long-term partners also experience life-interrupting mental distress and or psycho-social disability. I also work in various parts of the system as a peer support worker and lived experience educator teaching current and future health professionals, especially around recovery orientated service delivery and supporting people in suicidal crisis.

I am making this submission in my personal capacity though I wanted to mention working in the system too as it gives me a 360% view of its tragic failings and the moral injury this does to health workers, especially lived experience workers and clinicians working in humanistic ways. I actually got into this line of work thinking that mental health organisations would be best placed to offer psychologically supportive workplaces which would benefit my personal recovery. I was wrong, however, as it turned out that the system was deeply broken, full of the vicarious trauma of being complicit in a system that routinely hurts and disappoints consumers, and indeed many mental health professionals have very low opinions of mental health services users, holding deeply paternalistic and pessimistic biomedical worldviews about us.

Care Planning only Ever Happens Without Us. In Finland the Open Dialogue model has demonstrated superior recovery outcomes having care planning meetings exclusively in the presence of service users and their chosen network of loved ones and support people. In our system the person is never ever in the meeting but rather are informed about the choices or treatment that it has been decided would be best for them. This approach is sanist, outdated, ineffective and steams from the hierarchy of knowledge known as episemic injustice in which the first person expertise of personal experience is seen as less than the third person expertise by educational that clinicians offer. Service users are deemed least credible, only slightly lower than their families and loved ones. Clinicians routinely discuss 'collecting collateral' which in practice means calling someone else in the person's life to substantiate the truth of what they have shared. But this hierarchy can also be seen among clinicians, with service users and carers at the bottom and psychiatrists on top, outranking the input of the OT's, social workers, mental health nurses and psychologists.

Handmaiden to Psychiatry. In nearly 6 years I have never seen a decision made about what support a service user will be offered that does not correspond with what the psychiatrist thinks is best. According to the models of care for various teams in both inpatient and community mental health services, decisions are supposed to be made by the multidisciplinary team, however in practice 'care review meetings' are just casual conversations that either agree with what the psychiatrist wants or where someone tries to convince the psychiatrist of another possible ways forward, but if

this is not supported by the psychiatrist that plan is not adopted. There is never a proposal made, never a vote, never a compromise, it's just total dominance of the biomedical worldview dressed up in friendly collegiality but with no transparency around decision making and governance. This means the team is not really multidisciplinary if everyone can only work within a 'beds and meds' paradigm.

Registrar Roulette. Many service users despair of having to tell their stories ('give their histories') over and over again and aren't aware that there is very limited opportunity for continuity of care when nothing can happen without a psychiatrist and the registrar placement schedule means that they all rotate every 6 months. This is out of line with the rhetoric of trauma informed care and these rotations would be less disruptive if care planning was done collectively rather than hierarchically.

Governance structures are absent. There is no industrial democracy in terms of decision making about how services run, but rather an ever expanding cohort of well-meaning but ineffective managers and executives who are like something out of an episode of Utopia or a chapter of the book 'Bullshit Jobs' by American anthropologist David Graeber where their role is to make more and more complicated systems of documentation and bureaucracy and compliance regimes, most often justified using the rhetoric of 'safety' for workers and consumers but not delivering on that either.

More work, less connection with service users. More and more onerous data entry and inefficiently facilitated meetings take time away from offering support and connection to people experiencing life-interrupting mental distress and lead to health workers moral injury. For community mental health clinicians workloads are excessive and 'caseloads' for 40 people or more mean it's impossible for clinicians to do a good job. Many more opportunities for connection and dialogue are needed. For a service user to be able to access one phone call and one face to face meeting for therapeutic dialogue a week an individual care coordinators 'case load' would need to be something like 10 people, not 40.

Peer/Lived Experience Workers Face Discrimination and Macroaggressions. An expansion of the peer workforce is often touted as the antidote to the issues discussed above however low wages, sanism and epistemic injustice and clinical hierarchies leads to low staff retention and stifles the expansion of the lived experience workforce. Currently approximately 300 people work in lived experience roles across NSW in a mix of inpatient and community teams. Starting wages are only slightly higher than minimum wage and the average length of a peer workers career is 2 years, indicating very poor retention. The 'Leading The Change Report' published 2020 by Melbourne Uni elaborates usefully on these issues.

The politics of 'safety' and 'risk'. The safety and risk paradigm that does the opposite of what it intends, as safety staff tracking apps, safety huddles, home visit safety checklists are all introduced to 'keep workers safe' but are not addressing the structural violence that service users experience, which is what leads to violence against staff. Service users don't just 'kick off out of nowhere' they are invariably survivors of violence and/or relational trauma who aren't being well supported by our system to heal from this. So called 'violent consumers' are people whose nervous

systems are functioning like war veterans but in our case there is no discussion of their 'shell shock' and how in the absence of trauma healing some situations will turn violent and that we have an essential part to play in changing that. Punishing people for their violent reactions to our violent system does nothing to reduce violence.

Assessment and Referral Merry-go-round. Due to the dominance of the biomedical model the things people are mostly offered are; mental state examination, clinical assessment (lots of deficit based questions about your problems, your childhood, your drug use etc), medication prescription and inpatient admission. From the user experience aka being on the receiving end I've found that having my distress documented, measured and categorised even by the most skilled and empathetic human actually does very little to decrease/ often increases my distress.

Treatment Resistant. People who have tried meds and not found them helpful will just be offered them over and over again. A person who has tried multiple psych meds without good effect will be labelled 'treatment resistant' when in fact meds are only one of a <u>multitude of treatment options</u>. If people have misgivings about trying them at all they are often told that no other help is available or are forced to take them with involuntary treatment via the mental health act.

No Such Thing as De-prescribing. The biomedical worldview often results in lifelong consumption of psychiatric medication, despite the well-known health effects that can see the use of long term anti-psychotic medication taking up to 25 years off the life span of the people taking it. Currently service users looking to reduce or withdraw from their medication safely have only online harm reduction guides with advice from critical psychiatry practitioners to rely upon. De-prescribing of SSRI's, benzo's and anti-psychotics is an area of mental health treatment that needs considerable development and this would be aided by setting up specialist teams and enabling physiatrists to specialise in this field.

Trauma abounds and therapy is nowhere to be found. The few psychologists employed in the public mental health system are often not able to offer therapy because their job is to 'care coordinate' if they work in a CORE team or to 'assess' if they work in a Crisis or Access team. A dedicated team of psychologists must be resourced to offer a variety of therapy and therapeutic dialogues that aid in personal recovery.

Learning how to have a big awesome life even with symptoms. Despite 20 years of the Recovery Movement public mental health services in NSW are still largely articulating 'treatment' in terms of clinical recovery, rather than personal recovery. 'Clinical recovery is an idea that has emerged from the expertise of mental health professionals, and involves getting rid of symptoms, restoring social functioning, in other words 'getting back to normal' [Whereas] Personal recovery is an idea that has emerged from the expertise of people with lived experience of mental illness.' (Mike Slade, 2009) As early as 1988 Pat Deegan articulated the alternative definition of recovery... "Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges; it is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again....The need is to

meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution." This fundamentally different worldview is hugely necessary for the approximately 2/3 of us who don't experience symptom reduction via medication and need support to make life more worth living in order to better balance the challenges of distressing

Psycho-social disability and reasonable adjustments. Because community mental health services are predominantly operating under a biomedical worldview, alternative conceptualisations, such as psycho-social disability are obscured. Much of the harm and suffering of having difficult symptoms of psychological distress is feeling like they are incompatible with essential parts of life and the shame and grief around what is lost and needs rebuilding after life-interrupting mental distress. There is an urgent need to offer support to people so that they can advocate for the reasonable adjustments necessary to avoid losing their jobs, housing and education and training courses. The CHIME conceptual framework for personal recovery by Leamy et al has been in existence since 2011 and is composed by five recovery processes: Connectedness, Hope and optimism about the future, Identity, Meaning in life, and Empowerment. Support for self-advocacy and counselling and coaching that enables a person to feel less shame and have more access to housing, education and employment clearly correspond with these key recovery processes. It took me 15 years to learn that my array of psychiatric diagnosis constituted a psycho-social disability and that with a note to this effect from my GP I could use the disability discrimination act to request adjustments to vary my hours and days of work, access additional unpaid leave and extend due dates for assessment at uni and TAFE. Shockingly few health professionals are in receipt of this information and thus shockingly few service users learn of it and are able to use the current legal protections they have to help them maximise their Connectedness, Hope and optimism about the future, Identity, Meaning in life, and Empowerment.

The interactions, services or supports that would be useful to fund.

- 1. Publically accessible free alternatives to suicide peer support groups
- 2. Publically accessible free hearing voices peer support groups (currently groups are run in some districts but only for someone who has a clinician as their 'care coordinator' and they are not accessible to the person once discharged)
- 3. Access to one to one peer support independent of clinical services
- 4. Unlimited free trauma therapy (not CBT! Internal Family Systems Therapy and somatic/ window of tolerance/ nervous system regulation/poly vagal theory approaches are far superior for trauma recovery and it took me years to discover there were alternatives to CBT!)
- 5. Free/massively subsidized DBT skills groups (that aren't dependent on a shaming BPD diagnosis to attend) with groups co-facilitated by peer support workers
- 6. Humanistic clinical care that is done with me rather than in my absence like open dialogue

7. eCPR training for community members as it teaches deep listening, attunement and being with big feelings, rather than mental health first aid which reinforces the bio-medical approach to 'treatment'

Recommendations for Reform

Changes to the mental health act to decrease forced hospitalization for people who don't find hospital helpful or healing,

Changes to the risk paradigm for clinicians so they aren't scared of losing their registration if someone they have offered support to dies ("the key to saving someone is to admit you are powerless to save anyone at all" - from chapter 9, 'Alternatives To Suicide: Beyond Risk and Towards a Life Worth Living', edited by Page and Stritzke),

Trauma and recovery centres setup to provide an alternative to the biomedical approach (psychiatry dominates the public mental health system thus an alternative system is needed).

Change of governance arrangements in the public mental health system and quotas for lived experience workers filling a certain proportion of team leader and senior executive roles.

Massive investment in the peer workforce with a much greater emphasis on reasonable adjustments due to psychosocial disability.

Massive investment in the provision of free long term mental health counselling (provided by all disciplines of health professionals including peer support workers)

Massive expansion of DBT skills groups that are co-facilitated by Peer Support Workers and accessible to people without a BPD diagnosis

An end to fear based risk adverse practices around suicide risk assessment - a clear message to clinical colleagues that if they practice in recovery orientated, trauma informed and strengths based ways, and someone unfortunately dies, that is not going to result in negative findings in coroners court or loss of professional registration or loss of employment. Coercive practices are the antithesis of trauma informed care and they will continue when clinicians fear these consequences.

Thank you for considering my submission.