Mental Health Submission to Productivity Commission



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About Justice Action

JA's preliminary submission on the Productivity Commission's inquiry into mental health can be found <u>here</u>. It includes statements by people with lived experience, evidence of endemic disregard for consumer rights, and responses by authorities to the Miriam Merten Reform negotiations. It documents the disrespect by health authorities to those held in hospitals even to their right to political involvement and their own community newspaper, <u>JUST US</u>.

Justice Action (JA) is a not-for-profit non-government organisation with a focus on procedural justice and human rights for those held forcibly or coercively in Australia's prisons, hospitals, 'care' homes and detention centres. JA links its past to groups concerned with prisoners' rights in the 1980's, wrongful convictions, deaths in custody and institutional corruption in the justice system, but has since expanded its focus to include the most oppressive segments of the mental health system.

Justice Action relies foremost on the commitment and voluntary work of its membership; which includes serving and former prisoners, victims of crime, those living with mental illness, carers, students, lawyers, jurists, academics and others. We are not reimbursed for our work; we do what we do because we believe in it. JA receives its only financial support from the independent social enterprise *Breakout Media Communications*, which was set up for that purpose.

Justice Action stands with the most marginalised people in the most difficult places. A brief summary of JA's history and achievements can be seen here.

JA fosters community based restoration and rehabilitation programs aimed at reintegrating the marginalised into society, with particular emphasis on programs informed and directed by people with lived experience of marginalisation and institutionalisation. JA prioritises the voices of the oppressed in delineating the nature of their oppression and finding responses to it.

Justice Action considers the right to choose or refuse medical treatment to be fundamental. Forced therapy is often unhelpful, sometimes harmful and always abusive; as is involuntary detention for 'medical' reasons.

Failed system: the medical model

"Insanity is doing the same thing over and over and expecting different results."

- Anonymous Al-Anon attendee

Our mental health system is failing.

Diagnosis and disability rates rise remorselessly even as ever more money is poured into providing care to a steadily growing patient population. A <u>2017 review</u> of mental healthcare in five English-speaking countries found that significant increases in expenditure and improvements in availability had not reduced the prevalence or seriousness of common mental disorders. After examining factors such as changes in population risk and diagnostic criteria, the authors concluded the most likely explanation is that "much of the treatment provided does not meet the minimal standards of clinical practice guidelines and is not targeted optimally to those in greatest need". The problem isn't a 'treatment gap', but a 'quality gap' and a 'prevention gap'.

"Australia has had increasing resources allocated to mental health care, with an increased mental health workforce, increased use of antidepressants and, more recently, increased provision of psychological therapies, including e-therapy. However, there is no evidence for any reduction in prevalence of disorders or reduction in symptoms. If anything, trends are in the opposite direction." - Jorm, et al (2017)

The current system: therapy or abuse?

The current mental health system is abusive rather than therapeutic.

The history of our responses to 'mental illness' is replete with human rights abuse. Sometimes the abuse has been deliberate and calculated, as with the invention of 'diseases' such as <u>drapetomania</u> and '<u>sluggish schizophrenia</u>' to justify political oppression. Other abuses reflect our discomfort with challenging and unconventional behaviour.

It has:

- Facilitated political oppression, as with in the pre-Civil War US South and in the Soviet Union.
- Served to pathologise and persecute deviance and difference, such as the endemic psychiatric abuse of LGBTQI+ people when homosexuality was stigmatised as mental illness.
- Killed and disabled uncounted people with fad treatments later condemned as unscientific and barbaric.

Improper police response to mental health crises: *curing the disease by killing the patient*

People with diagnoses of mental illness are *less* likely to commit violent offences than their demographic cohorts. While there are some symptoms, such as psychosis or mania, that can periodically increase the risk of violence, such acts are still rare; especially when you consider how often sufferers are *victims* of violence, including from carers and medical staff. If we were really locking people up in an attempt to prevent acts of violence we would be better off targeting higher risk groups – such as young men who binge drink and play contact sports. It's more politically palatable to preventatively detain alleged schizophrenics than premiership footballers though, so that's what we do.

Psychologically distressed people are more likely to cause disturbances and commit public order offences that can bring them into contact with law enforcement. Sometimes friends or family members call police in the hope they will help and protect someone in crisis. All too often the result is a violent confrontation, which is inevitably blamed on the sufferer, regardless of who initiated it. Sometimes it's lethal.

Justice Action has attended the aftermaths of many deaths in custody of those undergoing mental health crises; sometimes as a legal observer, sometimes assisting and supporting the families of the victims. Over that time a clear pattern has emerged.

Police and prison officers are never convicted of killings committed while on duty. Not murder, not manslaughter, not negligent homicide. Never in the history of Australia. Not once. This isn't set to change any time soon. Australian police and prison officers know they have complete legal impunity for killing on the job.

Inquest findings often strongly criticise officers for excessive or unnecessary use of force and for neglecting opportunities to de-escalate the situation. Changes are recommended. Officers receive training and counselling. Tactics and procedures are revised. 'Gaps' in processes are identified and closed. Sometimes less lethal weaponry is rolled out. Then it happens again. Similar criticisms are made and similar reforms promised as yet another family mourns.

Reforms are doubtless implemented with the best intentions. Police and prison officers may escape legal consequences for their actions but the emotional impact can be devastating and long lasting. They don't want to kill disturbed people. But it keeps happening, as do escalations into needless violence and charges. But whether it's training, culture or the nature of the job, the same mistakes are made over and over, year after year.

In 2012 Justice Action member Michael S was woken in the early hours to find his obese, middle aged neighbour lying in the middle of the darkened street chanting poetry. She was inert and unresponsive. In prior months she'd become dishevelled and repeatedly expressed

fears that police and Catholic clergy were coming after her.

After failing to persuade her to move from the road Michael called '000' for an ambulance, but the dispatcher formed the view she was having a psychotic episode requiring police intervention. He insisted Michael was in danger from his peaceful, unresponsive friend and should keep away from her until police arrived. Michael's assurances she wasn't dangerous and might respond badly to police were ignored.

Two police arrived well ahead of the ambulance with one aggressively questioning the woman about her substance use and ordering her to move from the road. When she made no response he threatened to 'tase' her, prompting an immediate challenge from Michael. The officer claimed he'd only been joking. The inquest into the death of Roberto Curti was then in the news so the 'joke' was in dubious taste.

The woman remained prone and unresponsive in the middle of the road until the ambulance arrived and she was lifted into a gurney. She was detained in hospital for several months and evicted from her home shortly after her release.

In 1989, after repeated reforms had failed to reduce deadly encounters between police and those in psychological crisis, Eugene, Oregon, implemented the <u>Crisis Assistance Helping Out On The Streets (CAHOOTS)</u> program in which mental health specialists instead of police are sent in response to mental health crisis calls to emergency numbers. This has led to fewer violent encounters and fewer arrests while saving the city money. Between 15% and 20% of 911 emergency calls are now dealt with by CAHOOTS teams at much lower cost than that of traditional first responders. Other US cities have begun implementing their own versions of CAHOOTS.

Indifference and coercion in the system:

Our mental health Gulag

Few in our society suffer the routine abuse and systemic denial of rights to compare with those considered to have a serious mental illness.

Among those who are legally adults, only the 'mentally ill' can have potentially dangerous medical treatment forced upon them against their will. Only the 'mentally ill' can be detained indefinitely not for something they've done, but for something a supposed expert says they *might* do. Only the 'mentally ill' are subject not just to physical confinement, but to long term psychological imprisonment in chemical restraints. Almost a third of Australia's mental health related hospital admissions are involuntary and those who voluntarily seek help often become involuntary patients if they object to the 'help' on offer.

It's little wonder those with 'serious mental illness' suffer so much death, disability and abuse at

the hands of those purporting to help and protect them.

Locked institutions, such as prisons and secure psychiatric wards, are where we like to hide those whose behaviour we find challenging or embarrassing. We don't like to look in such places so we don't see how toxic their cultures can become unless their harms become impossible to ignore; such as the stream of dead and crippled patients coming out of <u>Chelmsford Private Hospital</u> between 1964 and 1988. Some had been sent there by the courts for homosexual activity or substance abuse.

The carceral nature of the institution inevitably corrupts the delivery of healthcare and contaminates the culture of those who provide it. Prisoners have little choice of doctor or treatment. Providers often adopt the 'us and them' attitude of prison staff and come to see their function as protecting society (and the institution) from their patients. Progress is measured by how well patients adapt to the demands of a dysfunctional environment with none of the freedoms or responsibilities they will face when released. Because their release is often dependent on their therapeutic progress prisoners learn to game the measurements meant to inform their ongoing treatment. Medical decisions are too often influenced by the need to maintain authority and order among an unwilling population by inadequately trained and resourced staff. 'Patients' can be held for extended periods in solitary confinement, heavily sedated and strapped to their bed.

NSW prison wisdom: "If you don't want to be hit by the liquid cosh (forcibly sedated) you should keep demanding psych drugs so they'll think you want to abuse them. Telling them you don't want their medicine is a sure way to get it forced into you."

Forced mental healthcare not only abuses those subject to it and those who inflict it, it poisons the well for all potential service users. Those who believe themselves at risk of becoming involuntary patients will be reluctant to speak frankly about their struggles and may avoid contact with the mental health system. Because involuntary treatment is legislated and enforced at the State level there is a growing population of mental health 'refugees' who have moved interstate in an attempt to avoid it.

Kerry O'Malley is a friend of Justice Action with a long history of forced inpatient and CTO drugging with neuroleptic medications, beginning during a period of deep depression following the birth of her child. The drugging continued even after life-threatening bouts of neuroleptic malignant syndrome (NMS) until 2017, when genetic testing showed she had SNPs at CYP2C19 and CYP2D6 linked to impaired metabolising of neuroleptic drugs and increased risk of adverse reactions. Her CTO was finally lifted and Kerry was able to live independently in the community for over two years.

In 2019 <u>Kerry suffered a home invasion and sexual assault</u>. Her trauma was aggravated when police refused to take her complaint seriously due to her medical history. When Kerry sought psychological help she was again made an involuntary patient and forced to take

neuroleptic drugs. During her first appeal against the renewed CTO the NSW Mental Health Review Tribunal (MHRT) denied her permission to follow the management plan she codeveloped with her treating psychiatrist, because 'he is against the use of neuroleptic medication'.

Vital Issues with the current system demanding change:

representation, communication, and choice.

These are the vital issues supported by evidence in the JA <u>first Submission</u>. We showed how endemic is the disrespect, and how unsupported are consumers despite their enormous cost to the taxpayer. We proposed stable funding and democratic representation, also in the <u>Our Pick Report</u>.

- 1. Representation for consumers subject to involuntary treatment,
 - a. Examples of representation
- **2.** Communication: The right of all the community to expression computer and the internet
- **3.** Choice: control by consumers of their treatment options

1. Representation

A Model of Consumer Representation

We propose that the Productivity Commission adopts a model similar to that used by NSW for people in prison custody. The <u>Inmate Development Committees</u> (IDC) and the <u>Aboriginal Delegate system</u> have been used for decades as a credible representative expression for people who are excluded and living together.

Their stated role is to:

- identify and bring to the attention of correctional centre management any issues affecting the maintenance of, and services to, living areas
- identify and bring to the attention of correctional centre management issues affecting employment, education, recreation, family contact and inmate development programs
- provide feedback to inmates on all matters raised at committee meetings
- provide pertinent and relevant information on specific matters as might be requested from time to time by the governor
- direct individual inmate's concerns to the appropriate channels, such as to senior officers or other staff, governor, the Corrective Services Support Line (CSSL), Official Visitor, the Ombudsman or the Minister

For the IDC system in prisons they are elected but vetted by security. Monthly meetings with an agenda are prepared beforehand and are posted on noticeboards. Responses by the Governor are also posted and copies are distributed to the Commissioner and the official visitor to the Prison. IDC members cannot be treated differently because of their role. Although it is hard to monitor whether they receive benefits, accountability is deliberately secured.

Each pod or wing has its representative and they all meet together regularly with minutes taken.

The IDC system is well developed and was drawn on by Coroner Lee in the Dungay case in his sixth recommendation of dealing with a mentally ill person. It brings peer support and the role of the consumer into real situations.

We propose that any person under the control of the Health Department, either in a locked ward or under a CTO, should have such representation.

We propose that each ward should have their representative as they probably already do, but it must be more formalised to have hospital wide meetings once a month. Furthermore, minutes from the meetings should be shared state-wide across the hospitals and to existing state funded consumer representative organisations to assist them with their policies.

Training of peer workers and the recalling of representatives would also be issues for them to consider. Policies and their implications on consumers should also be discussed.

Current Consumer Representation Models

Consumer representation is already embedded in all health systems, but is discredited as the management chooses, not the consumers, and there is no independent funding or external support. They are currently selected similarly to the NSW Health "Consumer and Community Representative Selection Guidelines".

- Ways to select a suitable consumer representative are detailed: newspaper advertisements, contacting consumer organisations to appoint a representative, registers of interest (database of interested consumers are held by Area Health Services), contacting CCPU* to access databases of interested representatives (NSW Health Department Database and Health Participation Council), registers of interest held by the Premier's department
- To appoint a consumer representative they must meet a criteria issued or made by those requesting; this may include the consumer's past agendas, decisions, actions, fellow associates in their committee
- Guidelines also provide a background which include questions to consider and evaluate before and during appointment of representatives, as well as questions to evaluate the representative's experiences and changes that could or do occur due to the inclusion of the representative there needs to be emphasis on asking questions to change organisation's culture

*CCPU: Consumer and Community Participation Unit – a consumer organisation

- Have their own process of selecting representatives done via NSW Health Database of Consumer Representatives.
- Can request representatives from them and they will search database and <u>select based on your criteria</u>.
- Partners in Health Report: framework for community and consumer participation in NSW Health
- Equity Statement: encourages participation of communities to address health inequalities
- Appears common for consumer organisations to work at grass-roots level, have connections with carers

For further reading, the <u>NSW Current Consumer Representation in Mental Health Services</u> sets out the explicit selection criteria for consumer representatives.

The Problem with Current Consumer Representation Models

In the Forensic Hospital (NSW) and certainly in other hospitals too there is a representative system. At the VIMIAC biannual conference there was a discussion about the same in Victoria, however representatives for wards were selected by the administration. (See paper from conference). However, as seen in the testimony and reports from forensic hospital patients, this is not necessarily the case. One consumer Saeed Dezfouli informed us that there is a Consumer Forum Meeting each month, which is attended by the Director of Nursing Services and two clinical nursing consultants. The patients' delegates – unlike in the model we propose - are appointed by the Nursing Unit Manager, rather than selected by the consumers themselves. Furthermore, it is reported that the delegates filter significant issues, so that nothing controversial is raised and there is not enough of a consensus that issues need to be pressed on. Saeed said that he no longer tries to bring up these issues, as he feels it is "hopeless".

The Benefits of our Alternative Model of Consumer Representation

- A strengths-based approach to mental health treatment which is centred around consumer autonomy and consumer independence is more effective long-term if consumers are stripped of autonomy and treated is inherently different/lesser, there can be negative effects on self-esteem, quality of life, and psychosocial functioning.1
- Lack of self-esteem means that consumers are less likely to confront practitioners about behaviour or treatment decisions that they disagree with, thereby undermining their ability to advocate for their rights₂.
- Adopting a strengths-based approach to consumer rights in mental health and involuntary treatment provides a lens/paradigm within which to frame suggestions for reform, while moving away from a pathology-based model.
- Encouraging consumers to 'cultivate their interests, identify and build their own strengths and draw upon goals'3 external representation is inherently disempowering because it implies an inability on the part of consumers to advocate for their own rights and interests or to express their own strengths
- The external employment of consumer representatives is based on the assumption that the best-equipped/most qualified representatives are the ones applying whereas the reality with mental health is that many of the people most in need of representation and who have the most lived experience may not have the energy or may suffer from issues that prevent them from actively applying for such positions
- Moreover, should they apply, they may not fit the prescriptions of the selection criteria due to elements of their lived experiences
- The fundamental purpose of consumer representation is to provide a representative who is "uniquely qualified to comment on whether the services provided meet consumers' needs, as they have a developed understanding of mental health services from the consumer's viewpoint"⁴

Other examples

Consumer Participation Framework in Tasmania

- Emphasises need for monitoring framework

¹ Huiting Xie, 'Strengths-Based Approach for Mental Health Recovery' (2013) 7(2) *Iranian Journal of Psychiatry and Behavioral Sciences* 5.

² Johannes Hamann, Markus Buhner, Nicolas Rusch, 'Self-Stigma and Consumer Participation in Shared Decision Making in Mental Health Services' (2017) 68(8) *Psychiatric Services* 783.

³ Huiting Xie, 'Strengths-Based Approach for Mental Health Recovery' (2013) 7(2) *Iranian Journal of Psychiatry and Behavioral Sciences* 5.

⁴ Terence V McCann, John Baird, Eileen Clark, Sai Lu, "Beliefs about using consumer consultants in inpatient psychiatric units" (2006) 15(4) *International Journal of Mental Health Nursing* 258, 261.

- Describes a representation process
- Includes stories and perspectives of consumer representatives
- Details levels of participation

"Principles for selection of consumer and carer representatives

- Mental health organisations will select appropriately supported consumer and carer representatives
- Mental health organisations will select appropriately skilled consumer and carer representatives
- Mental health organisations will have transparent processes for the selection of consumer and carer representatives
- Mental health organisations will provide information to assist with the recruitment of consumer and carer representatives"

ACT Mental Health Consumer Network

"Consumers provide their expertise in a range of government and community settings
to improve services and programs throughout the ACT on a voluntary basis. Given this,
Consumer Representatives need to have their reasonable out-of-pocket expenses met.
This is achieved by negotiation between the requesting organisation and the Network
in accordance with internal and external consumer representative policy."

Consumer and Community Participation – South Western Sydney

- Framework for participation
- Involvement in decisions about individual healthcare
- Recently went under evaluation (July-Dec 2019)
- Mental Health Consumer Carer and Community Committee (MHCCCC)
 - "The MHCCCC brings together consumers, carers, community groups, other related service providers and senior representatives of the SWSLHD Mental Health Service to work to improve, promote and encourage continuity of care in SWS. The MHCCCC operates within the framework of the Fourth National Mental Health Plan, the National Standards for Mental Health Services, the NSW Mental Health Plan and the strategic and operational plans of the SWSLHD. The MHCCCC may concern itself with any issue of relevance to the mental health of the people of South Western Sydney. The MHCCCC extends to making recommendations within the SWSLHD to the SWSLHD Director of Mental Health, Board and Chief Executive."

National Register of Mental Health Consumer & Carer Representatives

Development of a Consumer Engagement Statement for the Commission (consultation report)

NMHCCF (National Mental Health Consumer and Carer Forum) Approach

ANALYSIS OF NMHCFF APPROACH - 20/01/20

- Consumer and carer representative selection guided by principles of appropriate support, appropriate skill, transparency and fair process, wide advertisement
- If no state peak mental health consumer organisation, selection panel established by state or territory government agency to include government representatives, consumer and carer representatives and NCMHCF representative
- Otherwise, state peak organisation to select consumer representative using their usual nomination process
- Effective support of consumer and carer representatives: clearly defined roles of representatives, remuneration, clear articulation of rights and responsibilities, adequate information flow and feedback, ongoing support e.g. mentoring, training and resourcing, conflict resolution processes

- Queensland Government Metro South Health (non-Government)
- Outlines process of getting involved prior to consumer engagement.
- Consumers are members of committees across various hospitals in Queensland
- Engagement activities like workshops are implemented which can include presentations by consumers

Comparison of Prison Mental Health Services Across Australia

Consumers of Mental Health WA

 NFP community based organisation for mental health reform consumer-led peak body for consumer representation

2. Communication

Each consumer should have a computer in their room just as has happened in the ACT prison system for eleven years. Controlled access to the internet, email services and whitelisted websites have been safely in place during that period. <u>Link to ACT report</u>. NSW Corrective Services is trialling a similar system at the moment in Dillwynia women's prison and John Moroney men's prison also at Windsor.

Videoconferencing and emailing comes with that. Currently 22,000 emails flow weekly through the ACT prison with 400 people.

In Queensland prisoners pay \$3.50 a week to rent their computer. In the ACT, nothing. The cost for each person in a locked hospital is around \$2500 a day.

3. Choice

The entitlement to choose treatment is essential.

We propose that Mental Health Review **Tribunals have a "consumer representative**" instead of a so called "community representative", who is almost always part of the mental health industry . That person should have limited tenure and is recallable.

Each consumer in a locked ward would have access to their personal trusted psychiatrist, psychologist or other support people using the online video counselling service that will be available via their computer. Consumers would have access to stable support in a culturally appropriate way. Consumers currently often have diagnoses in this way.

Reviews of professionals could be collated by the consumer organisations in the same way as GP's are currently done on Google. **Treatment options** could also be discussed with online blogs.

Education and legal support would also become available at little cost.

The **entitlement to refuse medication should be legislatively supported**. An advance directive should be lodged, and a trusted person or people be chosen to assist at times of crisis. The right to refuse medication would leave the person with the dignity and power of a choice, but could have the effect of a person being held in an area from which they can't leave, with the support of a peer worker.

Criticisms of Mental Health Productivity Commission Draft Report

Economic efficiency of mental health services

The primary emphasis of the inquiry is economic efficiency of mental health services (Mental Health <u>Productivity Commission Draft Report</u>, 2019, Vol 1, page 51-52). By privileging economic factors, it is at risk of deepening the many abuses that already exist. The inquiry should be informed primarily by a human rights approach.

School as hubs for medicalised mental health intervention

The inquiry sees schools as appropriate environments for the diagnosis of young people and for medicalised mental health interventions (page 12). However, using schools to diagnose students has led to the pathologisation of diversity. So, schools need to provide supportive environments for those students suffering with trauma.

Standards of care in prisons

The inquiry states "to improve mental health screening in correctional facilities" (page 33). However, prisons are dysfunctional environments that promote mental health problems. Assistance should be provided outside the prison system where possible.

Discharge into homelessness

The draft suggestion commits that "no-one be discharged from mental healthcare into homelessness" (page 30-32). Without a prior commitment to meeting the housing needs of the mentally ill, this is likely to result in a return to institutionalisation. Patients should be able to delay their release if they feel preparation has been inadequate.