

**Submission
No 36**

INQUIRY INTO THE MANAGEMENT OF HEALTH CARE DELIVERY IN NSW

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**Submission to the Legislative Assembly Public
Accounts Committee Inquiry into The
Management and Delivery of Health Care in
NSW**



Justice Action

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Executive Summary

In 2014, Miriam Merten, a mother of two from Lismore, passed away the following day after her time spent in seclusion at Lismore Base Hospital. Appalling CCTV footage released to the media depicted Ms Merten falling to the floor numerous times, exposing the preventable nature of her subsequent death. Ms Merten had a history of admissions to Lismore Base Hospital and had been put into seclusion over 100 times. The nurse on duty used this history as a justification for not following baseline protocols. Miriam's death and the events leading up to it were exposed by the media, particularly due to the horrific and degrading treatment she was subjected by NSW health staff at Lismore.

Miriam's Merten's death has exposed major problems in delivery of mental health care in New South Wales, practices designed to ensure the welfare, rights and human dignity of mental health patients were not followed particularly those related to the proper use of seclusion and restraint.

This submission argues that the Miriam Merten case highlights the need for systemic change to provide greater oversight and accountability and ensure that the use of outdated and harmful practices are abandoned in favour of treatment that takes a patient-centred and evidence-based approach.

Recommendations

1. Currently, there are no official State, Territory or Federal procedures to record consumers preference for regular or irregular medication. Justice Action believes this inevitably results in biased records that do not reflect patient wishes as well as an overall lack of transparency regarding practitioner's treatment of vulnerable members of the community.

Measures should be implemented to formally record whether mental health consumers want their medication in the medical registers, used to guide treatment. The Justice Action proposal aims to gather data detailing consumer preference in order to create transparency regarding the scope of forced medication. Accurate data would allow for a comprehensive review of the treatment of mental health consumers, provide the consumers with a greater sense of agency and as such, mental health systems can become more effective, transparent and accountable.

2. Justice Action supports empowering mental health patients to direct their own care and calls for involuntarily detained persons with a mental illness to be assumed competent unless proved otherwise. They should be given the right to refuse or consent to treatment. Just as the legal system assumes innocent unless proven guilty, so too should the burden of proof favour the presumption that involuntary patients are competent unless proven otherwise. In order to review a patient's capacity in the specific context in which it occurs, a medical practitioner independent of the treating team should be required to assess the patient and provide an opinion of patients capability of being involved in decisions that affect them.

3. Justice Action calls for a total abolition of the use of out-dated and harmful use of seclusion and restraint in favour of more effective and compassionate patient-centred approaches. Furthermore Justice Action believes that involuntary treatment is only ever justified in preventing immediate and tangible harm to others or the self. Thus, while we support the use of medical practitioner discretion to apply involuntary medication to calm and treat patients who are presenting a clear danger to themselves or other individuals, this is to be considered a short-term and last-resort measure.

4. Staffing levels must be increased and maintained at a level that is adequate to deliver appropriate and Individualised care to all patients.

5. As noted by BEING NSW the peak organisation for people with a lived experience of mental illness there is an urgent need for greater transparency regarding the performance of mental health services and facilities.¹ Very little data that is collected is published in a way that renders it accessible to consumers. This impairs the ability for consumers to exercise informed choice and increases distrust of the system and reluctance to engage with mental health systems with potentially devastating impacts on patient recovery.

1. Facts of case

- Miriam Merton died at Lismore Base Hospital at around 10.30am on the 3rd of June 2014. The cause of death was found to be 'traumatic and Hypoxic brain injury caused by numerous falls and the self-beating of her head on various surfaces the latter not done with the intention of taking her own life'²
- Miriam Merten was well known at the hospital and had been admitted a number of times over a period spanning many years.
- Ms Merton was placed in seclusion at 11.50pm on 1 June 2014 and this seclusion ended on 5.10am on the 2nd of June 2014.
- The Coronial Inquest into Ms Merten's death found that the treatment of Ms Merten did not comply with the relevant standards in numerous respects.
- Miriam Merten was heavily sedated and contained for more than five hours in a room that was empty of all but a mattress on the floor.
- While in seclusion, Miriam was monitored by nurses via a video monitor and received no contact with the nurses on shift.
- Miriam was not provided with food, water, or toilet facilities while in seclusion.
- Footage of the incident revealed Ms Merten with no clothing and covered in excrement.
- CCTV footage records Ms Merton as suffering at least 25 falls between 11.50pm on 1 June 2014 and 6.49am on the 2nd of June 2014. These falls were not recorded on clinical records or observation charts.

¹ Being, "Submission For The Inquiry Into The Management Of Health Care Delivery In NSW To The Public Accounts Committee" (Being, 2017) <<http://being.org.au/whatwedo/publications/submissions/>>.

² "Findings In The Inquest In The Death Of Miriam Merten" (Coroner's Court of NSW, 2016). <<http://www.coroners.justice.nsw.gov.au/Documents/Findings%20-%20Miriam%20Merten.pdf>>

- Inadequate staffing levels and a lack of support from hospital management have been cited among the factors leading to Ms Merten’s death.³

2. Use of Seclusion and Restraint

Ms Merten’s case highlights the problematic use of coercive intervention as a short-term management solution in the treatment of mental illness. Mental health patients possess the same human rights as every other individual in the world. According to both international and national law, they should be treated as citizens entitled to community support. Mental health facilities have a duty to care for patients in a humane, respectful manner. Justice Action has continuously called attention to the inappropriate and excessive use of these practices within Australia’s Mental Health systems with our report *Mad in Australia* praised by the National Mental Health Commission for including the voices and experiences of mental health treatment of individuals within the justice system. This report has been included with this submission as Appendix C.

Whilst the NSW Government’s Ministry of Health Policy Directive states that *“it is the position of NSW Health that clinical and non-clinical staff working in mental health facilities in NSW will... reduce the use of restrictive practices such as seclusion and restraint.”*⁴, the Merten incident shows that this policy is not always reflected in reality. Miriam Merten’s death exposes a healthcare system critically disengaged from proper care and treatment practices for patients suffering from mental illness.

Placement of vulnerable patients in an environment of seclusion often induces traumatic distress and harm. Restricted, cell-like surroundings inevitably carry connotations of punishment, offering little to no benefit in terms of treatment and rehabilitation. Instead, isolation serves as a ‘social solution’ to the administration of the mentally ill in a system, which is definitively lacking in established frameworks for the treatment of mental health issues.

Seclusion encourages the development of a dehumanising and apathetic attitude towards patients, which is why Justice Action calls for its total abolition. The replacement of these harmful practices with more humane and effective forms of treatment has been acknowledged as an achievable goal by NSW Health who state that *“While seclusion and restraint are used in some mental health facilities to manage disturbed behaviour, others have found that these strategies can be safely avoided.”*⁵

2.1 Seclusion in NSW

³ Ibid p.9

⁴ Mental Health and Drug and Alcohol Office, ‘Aggression, Seclusion & Restraint in Mental Health Facilities in NSW’, *Ministry of Health*, http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2012_035.pdf, June 2016.

⁵ Ibid.

Recent government policy has identified the reduction, and preferably elimination, of seclusion practices as a national safety priority to be pursued as soon as possible.⁶ In 2005 Australian health ministers agreed on National Safety Priorities for Mental Health, of which one of the major focuses was on reducing the use of both restraint and seclusion, and where possible, abolishing the practice all together. Additionally, Health Ministers Brad Hazard and Tanya Davies agreed in 2005 that seclusion and restraint constituted an inappropriate infringement of rights and caused psychological and physical trauma.⁷

The NSW Health Statistics published in 2016, show a decline in the rate of seclusion since 2011 from 10% to a rate of 8.7% in 2016. Following the treatment and subsequent death of Ms Merten, NSW should be looking to further decrease and discourage the use of seclusion and restraints as a form of treatment. Yet patients in NSW continue to experience seclusion at a rate of 8.7 times for every 1000 days spent in a health facility as reported between 2015-16.⁸ Notably, the reporting requirements which inform these statistics lack transparency and rigour leading to question if they reflect the true extent of the problem. This is not acceptable under national standards, nor is it adequate at an international level, with many countries entirely reducing seclusion rates to zero.⁹

2.2 Need for Legislative Change

In 2013, Juan E. Méndez, the United Nations rapporteur on torture, called for:

*"An absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities ... in all places of deprivation of liberty, including in psychiatric and social care institutions."*¹⁰

Whilst Australia may not be legally required to change their current practices regarding the treatment of mentally ill patients, it is clear that the use of these out-dated practices are no longer acceptable in any nation with a commitment to the protection of human rights.

⁶ Chris Lloyd, Robert King & Tawanda Machingura, 'An investigation into the effectiveness of sensory modulation in reducing seclusion within an acute mental health unit' (2014) 12(2) *Advances in Mental Health* 93, 93-100.

⁷ Kate Aubusson, 'Naked, drugged and secluded: 'Horrorific' footage of patient's death at Lismore Base Hospital sparks statewide investigation', *Sydney Morning Herald* (online), May 12 2017 <<http://www.smh.com.au/national/health/naked-drugged-and-secluded-horrific-footage-of-patients-death-at-lismore-base-hospital-20170512-gw3bec.html>>.

⁸ Mental Health Services in Australia, *Use of restrictive practices during admitted patient care* (2016) Australian Government <<https://mhsa.aihw.gov.au/services/admitted-patient/restrictive-practices/>>.

⁹ ABC News, 'NSW Government announces parliamentary inquiry into death of Lismore mum Miriam Merten', *ABC News* (online), 12 May 2017 <<http://www.abc.net.au/news/2017-05-12/nsw-government-inquiry-lismore-mum-miriam-merten-death/8521198>>.

¹⁰ United Nations, "Report Of The Special Rapporteur On Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment" (United Nations, 2013).

According to Mental Health Procedure¹¹ when clinicians recognise that a consumer is becoming distressed or aggressive, or when consumers report feeling this way, ward staff must support them to employ a range of therapeutic interventions including:

- Encouraging self reflection.
- Encouraging the consumer to let staff know when they are feeling distressed or agitated.
- Intervening early when a person displays signs of agitation or notifies staff they are feeling agitated.
- Spending one on one time with the consumer and actively engaging with them.
- Employing active listening skills to hear what the consumer is trying to convey.
- Using short, clear sentences in a lower tone of voice.
- Promoting opportunities for contact with a friend or family member (as long as this is agreeable to the consumer and safe for all concerned).
- Activating the Safety Plan and using strategies negotiated with the consumer and/or family that help them manage stress or curb unacceptable behaviour.
- Engaging the consumer in a physical activity.
- Using sensory modulation equipment.
- Providing feedback about the consumer's behaviour and how it impacts on other people.
- Offering an opportunity for time out in an unlocked area where the consumer can be on their own to calm down (e.g. bedroom, quiet room).

Furthermore, there are few express provisions safeguarding mental health patients' rights in Australian States and Territories, and little emphasis on ensuring that treatment is carried out in the least restrictive environment. In fact, significant areas are simply not covered by legislation in many jurisdictions.

This applies particularly to complaints handling, monitoring mechanisms and review procedures. Ms Merten's case has attracted a considerable amount of publicity largely due to media outlets obtaining, and choosing to distribute, CCTV footage of her final hours. However, the lack of transparency and adequate oversight of patient care raises questions about how many similar cases of neglect and systemic failure remain unknown.

3. Forced Medication

3.1 Miriam Merten Case

The Miriam Merten case exemplifies a severe consequence of the impact of forced medication on mental health patients in Australia. Miriam Merten was a woman in distress who was well-known to staff at the medical facility. Miriam Merten had been sedated with psychotropic drugs before being confined to a seclusion room for five hours, creating the circumstances that led to her death.

¹¹ NSW Health, "Aggression, Seclusion & Restraint In Mental Health Facilities In NSW" (NSW Health Mental Health and Drug and Alcohol Office, 2012).
<http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2012_035.pdf>

Miriam Merten's history of treatment included numerous occasions in which was denied the dignity to control her own treatment and instead placed in isolation on forced medication. Forced medication reduces a person's quality of life as it takes away their capability to make decisions and can contribute to mental health staff and the wider community failing to recognise and respect the dignity and humanity of mental health patients.

3.2 Justice Action's position and Previous Campaigns

Forced medication is a significant breach of personal autonomy and violates a patient's human rights and also the required Principles of Care outlined in the NSW Mental Health Act 2007.

The UN Convention on the Rights of Persons with Disabilities (CRPD) places emphasis on viewing persons with disabilities as 'subjects with rights' who are capable of claiming those rights and making decisions for their lives based on their free and informed consent and fundamental freedoms.

We believe that forced medication must be described in a way that reflects its operational effect: a coercive method of involuntary treatment. Using terms such as "risk aversion" and "emergency medication" merely distracts its actual meaning while normalising a clear power imbalance between the consumer and workers. Justice Action concedes the value of forced medication in limited short-term situations, however the regular breach of patient integrity with forced medication routinely usurps patients' rights regarding personal autonomy. Furthermore, alternatives to forced medication must be developed and utilised to ensure efficient and ethical treatment of mental health consumers. Justice Action strongly supports alternatives such as the use of consumer workers i.e. fully rehabilitated ex-consumers as caregivers.

JA was an active participant at the 10th National Seclusion and Restraint Reduction Forum in 2015, where the National Mental Health Commission (NMHC) launched its position paper that supported the reduction in the use of involuntary practices. The paper avoided the issue of "forced medication" despite referring to "involuntary treatment orders" as a form of restrictive practice. JA distributed flyers to focus the discussion on the issue of forced medication¹². The panel at the conference argued that mental health consumers were yet to raise concerns regarding forced medications, and that it was Justice Action's job to "get those voices out."

Appendix B '*Mental Health Accountability and Chemical Restraint: Research and Recommendations*' documents research Justice Action have undertaken into mental health consumer preferences regarding medication, and the willingness of authorities to consider collecting this data. This was followed by the report '*Mad in Australia*' (included as appendix C) which exposes the history of abuse of mental health patients in

¹² "Justice Action Leaflet Prepared for The 10th National Seclusion And Restraint Reduction Forum May 28-29th, 2015, Melbourne, Australia"
<<http://justiceaction.org.au/images/stories/CmpgnPDFs/SeclRestPpr020615.pdf>>.

historical and cultural context. It identifies how the culture of doctors forcing medication on mental health patients began, in breach of their ethical obligations, and despite the lack evidence regarding its effectiveness.

Since Justice Action's publication of '*Mad in Australia*', reports of forced medication suggests little has changed, and the use of chemical restraint actually have have increased inadequate staffing levels make it difficult for mental health staff to properly monitor and care for patients placed in seclusion or restraint. The impact of inadequate staffing, along with institutional reluctance to correct this problem, was noted in the Coronial Inquest into Ms Merten's death.

3.3 Alternatives to Medication

Despite government recognition that practices such as forced medication, seclusion and restraint infringe patients rights and may cause considerable psychological trauma, there is a continued reliance on these practices within the NSW mental health system. The death of Miriam Merten highlights the need for those responsible for mental health care to prioritise the use of safer alternative treatments.

According to the *Mental Health Act 2007* (NSW), people diagnosed with a mental illness or mental disorder have the right to be provided with sufficient information regarding treatment alternatives and to elect the means of their own recovery.¹³ Involuntary detention and treatment should only be administered when there are no other safe options available and where certain criteria are satisfied.¹⁴ Holistic patient-centred alternatives, some of which are listed below, can prove significantly more effective in the long term.

a) Social Support

Social support for mental health patients refers to the ability of individuals to develop and access relationships with other individuals, groups or the larger community. This network of friends, family or community is crucial in sustaining social and financial support, and plays a critical role in improving and managing an individual's psychological condition.¹⁵

Separating patients from their support network while holding them in seclusion induces feelings of helplessness and can exacerbate pre-existing mental health issues. Social support has been evidenced to be a crucial factor in enhancing resilience to stress and trauma induced disorders and thus is vital to the long-term care of mentally ill patients.

b) Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) is a form of psychotherapy aimed at re-routing thought patterns, behaviours and beliefs. The therapy involves identification of an

¹³ *Mental Health Act 2007* (NSW) s 68(e).

¹⁴ *Mental Health Act 2007* (NSW) Chapter 3 Involuntary admission and treatment in and outside facilities.

¹⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2921311/>

individual's 'root issues' and development of strategies to overcome them while abstaining from use of medication.¹⁶

Commonly used in treatment of anxiety disorders, depression, and substance abuse, CBT places emphasis on changing an individual's mindset, breaking the habit of negative thinking, and encouraging a more positive outlook.¹⁷ An illustrative technique used is goal setting whereby the individual is encouraged to work towards a certain objective such as management of anger.¹⁸ By facilitating lifestyle changes, durable advancements and individual growth can be achieved.

c) Acceptance and Commitment Therapy

A fundamental principle of Acceptance and Commitment Therapy (ACT) is to teach acceptance and understanding about aspects of your life beyond your personal control. The theory of mindfulness highlights the importance of enhancing one's emotional wellbeing, and letting go of negative thoughts that hamper your ability to function effectively at work and/or in social situations. Mindfulness is widely considered a traditional approach that seeks to stabilise your values, intrinsic moral compass, and assists patients in clarifying what is truly important and meaningful in their lives.

Acceptance and Commitment Therapy is accepted as a useful treatment method for individuals suffering from stress-related problems, anxiety, and depression.

d) Biofeedback Therapy

Biofeedback is a non-drug treatment that helps patients control involuntary bodily processes, such as heart rate, and blood pressure through a series of relaxation strategies. Biofeedback has been found to promote relaxation and reduce a number of conditions associated with chronic stress. For instance, if a person suffers from severe headaches, using relaxation techniques may help to obstruct brainwaves that activate specific neurotransmitters causing headaches. The therapy acts as a natural painkiller to unconscious bodily processes such as intense sympathetic arousals. These relaxation exercises include taking deep breaths, alternately tightening and relaxing different muscle groups, focusing on guided images, and mindfulness meditation.¹⁹

Researchers have found that biofeedback therapy is effective in alleviating symptoms of anxiety, autism, depression and even schizophrenia.²⁰

e) Acupuncture

Acupuncture is another alternative form of natural treatment that can provide relief to inmates facing mental health issues. This is a traditional Chinese remedy that focuses on

¹⁶ Better Health Channel, *Cognitive Behaviour Therapy* (2016)

<<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/cognitive-behaviour-therapy>>.

¹⁷ Ibid.

¹⁸ Ibid.

¹⁹ <http://www.webmd.com/a-to-z-guides/biofeedback-therapy-uses-benefits#1>

²⁰ <https://draxe.com/biofeedback-therapy/>

balancing the body's energy system.²¹ Fine sterile needles are inserted into specific sites along the body's meridians to clear energy blockages and encourage the normal flow of qi through the patient.²² According to traditional Chinese beliefs, acupuncture has been known to treat depression by understanding the bodily functions that cause this illness.²³

f) Exercise

Exercise provides another tool to assist patients in relieving stress and aiding physical relaxation. Not only is exercising physically beneficial, it is able to boost an individual's mood by deflecting negative thoughts, giving a better sense of self-control and offering social contact.²⁴ The release of hormones such as endorphins and serotonin elicits positive feelings in the brain.

Mindfulness-based exercises such as yoga and pilates additionally lower stress and anxiety which helps with bi-polar and depression.²⁵ A healthy lifestyle that incorporates exercise and a balanced diet would greatly promote physical and emotional wellbeing.

g) Hobbies and Interests

Encouraging patients to develop and engage in interests and hobbies can assist in the development and maintenance of optimal wellbeing. This can include participating in arts and crafts, listening to music, reading books, and creating social clubs. Taking part in these activities can bring contentment and happiness while activities such as gardening and bush walking allow patients to enjoy nature and feel refreshed and rejuvenated. Therapies that encourage patients to explore new interests and hobbies such as Wilderness Therapy also assist with the development of interpersonal relationships and social networks.²⁶

h) Community engagement

Helping people with mental disorders engage with the community is also beneficial to their recovery. Community centres, such as 'Hearing Voice Groups' and 'Living Skills Groups' allow better social integration and support. Volunteering activities give patients a sense of self-worth and accomplishment. Laughter clubs and Toastmasters clubs provide patients with a place to express themselves and be better heard.

²¹ The Health Lodge, Acupuncture as a Treatment for Stress, Anxiety and Depression (Nov 2015)
<<http://thehealthlodge.com.au/blog/acupuncture-as-a-treatment-for-stress-anxiety-and-depression>>.

²² Australian Acupuncture and Chinese Medicine Association Ltd, *Acupuncture*
<<http://www.acupuncture.org.au/AcupunctureandChinesemedicine/Acupuncture.aspx>>.

²³ Ibid.

²⁴ Physical Activity Australia, *Exercise and mental health*, (September 2015)
<<http://www.physicalactivityaustralia.org.au/exercise-and-mental-health/>>.

²⁵ Harvard Health Publications, *Yoga for anxiety and depression* (April 2009)
<<http://www.health.harvard.edu/mind-and-mood/yoga-for-anxiety-and-depression>>.

²⁶ Newcomer, *8 Alternative Mental Health Therapies Explained* (Dec, 2012)

Additionally, communication with family and friends is vital to recovery. Given a central aim of mental health treatments is reintegration into society, community engagement should be greatly emphasized and promoted.

4. Lack of Accountability and Openness

4.1 HEALTH STAFF VIOLATING PRACTICE

The extensive failure of medical staff to adhere to the monitoring protocols surrounding seclusion lead to the avoidable death of Miriam Merten by traumatic and Hypoxic brain injury. It was unjustifiable for the staff to disregard observation policies contained in the Ministry of Health Procedure²⁷ during Merten's seclusion period.

While the procedure stresses the safety and wellbeing of the individual as vital and maintains that the individual be closely monitored to ensure prompt response to deterioration in their physical condition, these principles underlying the use of seclusion were not adhered to in the treatment of Merten. Staff are required to provide the patient with information entering seclusion (point 4.9), conduct observations in accordance with stipulated requirements (point 4.10) and adhere to clothing and wellbeing requirements (point 4.11).

Within 60 minutes of seclusion a M.O is required to conduct a physical and psychiatric review of the patient (point 4.8.2), however Merten did not have her physical health assessed following reports of head banging and high doses of psychotropic medication. One to one observation is also required during the first hour (point 4.10), however, the senior nurse decided against this. The policies also dictate that observations must involve verbal communication if the patient is awake (point 4.10), that the patient should be afforded the opportunity to use the bathroom at reasonable times and that they should be offered water. However, none of these policies in point 4.9 were adhered to.

While point 4.11 stresses that the consumer should not be placed naked in seclusion unless this compromises their safety or the safety of others and that efforts should be made to offer them alternative clothing if they remove their clothing, Merten was unclothed for a significant period of seclusion. These clothing policies are aimed at maintaining the dignity of the consumer and this purpose was clearly disregarded in the case of Merten.

Physical and psychiatric reviews needed to have been conducted every 4 hours or urgently if there are concerns for the individual's safety (point 4.8.3). Any physical injury or emotional trauma resulting from the intervention must also be appropriately treated and recorded (point 4.8.3 & point 4.9). Despite having these policies in place, the nursing staff did not request an urgent review or treat Merten following the 25 falls she had. These falls were not recorded in observation or clinical records either.

²⁷ Mental Health Services in Australia, *Use of restrictive practices during admitted patient care* (2016) Australian Government <<https://mhsa.aihw.gov.au/services/admitted-patient/restrictive-practices/>>.

This is a blatant disregard of the policies in place to ensure the safety of patients under seclusion. The Coroner's report stressed that "it is inconceivable that the nature and number of falls were not observed."²⁸ Merten should have been removed from the environment in which she was at risk of repeatedly falling and head banging, she should have been assessed for injuries, should have had neuro observations and such incidents should have been appropriately reported.

In summary, the nursing staff failed to adhere to an array of procedures designed to ensure the proper care, safety and dignity of Miriam Merten. This prevented the provision of health care to Merten and exemplifies the failures of health care delivery in NSW despite the policies and procedures put in place. Having these policies in place is insufficient if staff are going to disregard them. An increased understanding is needed regarding these policies, more extensive training is required and greater accountability for non-compliance to avoid the reoccurrence of this appalling treatment.

4.2 Reporting System and Clinical Governance

The appalling treatment of Merten only came to light due to her death. The 25 times that she fell were not recorded on the Health care record or the Register and only became apparent after investigation of CCTV footage in response to her death. Furthermore, Merten's treatment was only brought to the public's attention through the extensive media coverage of the incident. The policies²⁹ dictate that observations must be recorded as well as "any adverse events relating to the incident" (point 5.2). This was not adhered to in Merten's case and it is not clear how many other individuals have been subjected to similar treatment.

As the Human Rights Watch asks, "how many other Miriam Mertens are suffering in silence?"³⁰

The reporting system and clinical governance is clearly inadequate as the procedures are not properly adhered to and reports are not independently verified in the absence of clear physical harm. The failure to properly observe and accurately report incidents during seclusion enables abuse to remain undetected. This considerable issue poses the question: How is the safety, wellbeing and dignity of other individuals in seclusion being maintained and monitored? Furthermore, how are staff appropriately held accountable for failures to observe reporting requirements and failures to accurately describe incidents? If the injuries individuals sustain are not visible will reports be independently verified to ensure their proper and humane treatment?

Merten's treatment has brought these questions and a range of others to the forefront of

²⁸ "Findings In The Inquest In The Death Of Miriam Merten" (Coroner's Court of NSW, 2016). <<http://www.coroners.justice.nsw.gov.au/Documents/Findings%20-%20Miriam%20Merten.pdf>>.

²⁹ Mental Health Services in Australia, *Use of restrictive practices during admitted patient care* (2016) Australian Government <<https://mhsa.aihw.gov.au/services/admitted-patient/restrictive-practices/>>.

³⁰ Kriti Sharma, 'Australia's Cells of Horror Neglect and Abuse in Mental Health System Caught on Camera' *Human Rights Watch* (online) 16 May 2017 < <https://www.hrw.org/news/2017/05/17/australias-cells-horror>>.

community concern. Her treatment was inconsistent with community expectations regarding the delivery of health services in NSW and failed to reach the national standards encapsulated in relevant law and policies. The mental health sector is trusted to care for one of the most vulnerable sectors of our society. Stories of abuse, like that of Merton's, invoke justified community outrage and distrust of the mental health system.

The reporting system requires urgent amendment to strengthen the accountability of staff who fail to record instances appropriately and to ensure the proper protection and treatment of vulnerable members of our society. It is not sufficient for these issues to come to light after the fact and as a result of a particularly horrific incident. Reports need to be accurate at the time and medical professionals need to be advised at the time of the incident in order to respond to the needs of the individual. Reports also need to be independently verified and recording incidents during use of seclusion should be closely monitored.

Given that the senior nurse in Merten's case had a recorded history of abusing patients³¹, it is clear that reforms need to be made to clinical governance. The clinical governance processes expounded in point 6.1.3 of the Ministry of Health Procedure include monitoring seclusion usage on a monthly basis and providing after-the-fact advice to clinical staff regarding the use of seclusion at the Mental Health Clinical Governance meeting. There is clearly room here for more frequent independent monitoring of mental health facilities to increase accountability and protect consumers.

5. Legal Guidelines and Obligations

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Numerous international recommendations and the *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)*³² condemn forcible medication, yet it continues to be allowed under Australian law. Out of the 79 countries that have ratified the *UNCRPD*, Australia is the only one to reserve its right to forcibly medicate the disabled. According to Justice Action's media release,³³ Australia was criticised for its forcible detainment and medication of people with mental illness by the United Nations Committee on the Rights of Persons with Disabilities (the body of human rights experts tasked with monitoring the implementation of the *UNCRPD*). It is clear that Australia is falling below international standards of care.

³¹ Anthony De Ceglie, Annabel Hennessy, 'Miriam Merten death: Nurse on duty the night she died had history of abusing patients' *The Daily Telegraph* (online) 17 May 2017 <<http://www.dailytelegraph.com.au/news/nsw/miriam-merten-death-nurse-on-duty-the-night-she-died-had-history-of-abusing-patients/news-story/f1750cfaafe50a48f5225b47df5c4ec5>>.

³² *Convention on the Rights of Persons with Disabilities (UNCRPD)*, opened for signature on 30 March 2007, A/RES/61/106 (entered into force 3 May 2008)

³³ Justice Action, *United Nations Urges Mental Law Changes* <http://www.justiceaction.org.au/index.php?option=com_content&view=article&id=225:united-nations-urges-mental-law-changes&catid=45&Itemid=1010>

The case of Miriam Merten demonstrates a clear violation of the rights codified by the *UNCRPD*. Article 15³⁴ provides for freedom from torture or cruel, inhuman or degrading treatment or punishment. Miriam Merten suffered grossly degrading treatment before her death, due to the health staff's abject failure to ameliorate her state of undress, provide adequate access to washroom facilities or continuously ensure her safety through attentive observation. The indifferent and careless treatment of Miriam Merten reveals that Australia's treatment of persons with disabilities still falls tragically short of international standards. There is still more to be done to improve the standards and mechanisms available to people with disabilities in Australia.

Optional Protocol to the UN Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT)

It must be noted that Australia is a signatory to the *Optional Protocol to the UN Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT)*.³⁵ The federal government is moving towards its ratification and has announced it will be passed into domestic law by December 2017³⁶. *OPCAT* codifies a number of fundamental human rights and aims to regulate and improve conditions in detention.

The case of Miriam Merten exposes significant breaches of basic human rights that are systemic across Australian mental health facilities. The actions of the health staff in Miriam Merten's case clearly fall short of this international benchmark. Although Australia became a signatory to *OPCAT* in May 2009, the eight-year delay before announcement of its ratification in February 2017³⁷ exposes the reluctance of the federal government to take serious action against violations of fundamental human rights of people in detention. The federal government must hold to its promise to pass this convention into domestic law in a timely fashion to effectively protect the rights enshrined within it and prevent similar tragedies from occurring again in the future.

Mental Health Act 2007 (NSW) s68(f)

Miriam Merten's case also reveals breaches of state law intended to protect the basic rights of patients with mental illnesses. All mental health units in NSW are required to act in accordance with the principles of care outlined in the *Mental Health Act 2007 (NSW)*.³⁸ S68(f) of the Act states:

³⁴ *Convention on the Rights of Persons with Disabilities (UNCRPD)* Article 15

³⁵ *Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT)*, opened for signature on 4 February 2003, A/RES/57/199 (entered into force 22 June 2006)

³⁶ Australian Human Rights Commission, *Optional Protocol to the Convention against Torture (OPCAT)*, May 2017, <<http://www.humanrights.gov.au/our-work/rights-and-freedoms/projects/optional-protocol-convention-against-torture-opcat>>

³⁷ Ibid

³⁸ *Mental Health Act 2007 (NSW)*

(f) Any restriction on the liberty of patients and other people with a mental illness or mental disorder and any interference with their rights, dignity and self-respect is to be kept to the minimum necessary in the circumstances.³⁹

The restriction of Miriam Merten's liberty was thus a clear violation of s68(f). There is no evidence that the health staff trialled alternative measures to seclusion, nor any to show that seclusion was absolutely necessary or used as a last resort. Furthermore, the senior nurse had an obligation to adequately observe and assess the patient's behaviour with the view of ending the intervention as soon as possible. Her actions, however, demonstrated that the senior nurse had no intention of ceasing the interference with the patient's liberty during her shift. Even if the seclusion had been the only possible measure, which is uncertain in the circumstances, the constraint on Merten's liberty grossly exceeded the minimum necessary.

Furthermore, CCTV footage of the incident revealed that she was naked and covered in excrement during her seclusion.⁴⁰ In accordance with this subsection, such an interference with her dignity should have been kept to a minimum by the health staff. However, no proper efforts were made to attire the patient. Although Miriam Merten became incontinent of faeces at 0440 hours, she was only granted access to toilet facilities at 0515 hours.⁴¹ The health staff's inaction created an unnecessary and severe interference with the patient's dignity and self-respect, and marks a clear breach of the subsection.

Employment Health Assessment: Policy and Guidelines

Miriam Merten's case also calls into question the policies regarding employment of health staff, particularly due to allegations that the senior nurse on duty during the incident had a history of abusing patients. The document *Employment Health Assessment: Policy and Guidelines*, an April 2000 publication by the NSW Premier's Department, states the need for health assessments of staff.⁴² However, the language of the document and the use of the terms "employer" and "employee" suggests that the need for regular health assessments may only become apparent after a candidate is successfully admitted into a position:

An employer may require employees to undertake regular health assessment where:

- there is a residual risk to health even after the best possible control measures have been implemented and relevant tests are available to detect any adverse health outcomes that may arise; and

³⁹ *Mental Health Act 2007 (NSW) s68(f)*.

⁴⁰ "Findings In The Inquest In The Death Of Miriam Merten" (Coroner's Court of NSW, 2016).
<<http://www.coroners.justice.nsw.gov.au/Documents/Findings%20-%20Miriam%20Merten.pdf>>

⁴¹ *Ibid*, p. 3.

⁴² New South Wales Premier's Department, *Employment Health Assessment: Policy and Guidelines* (2009)

- current and accurate health/medical information is needed for the purpose of determining the ongoing fitness of an employee to carry out the inherent job requirements and job demands of the position.⁴³

However, members of the health service work in close contact with a diverse range of individuals with varying capacities and backgrounds. Therefore in terms of work capacity, the values and attitudes of a job applicant are just as significant as their physical and mental wellbeing. Pre-screening assessments for potential employees to ensure a high ethical standard of values would assist in admitting only employees who are fully capable of handling the pressures of working with a diverse range of patients.

6. Conclusion

The Tragic and avoidable death of Miriam Merten has exposed the extent to which the NSW Mental Health system is failing to protect the welfare, rights and dignity of mental health service consumers.

Justice Action calls on the NSW Government to ensure that all consumers of mental health services are treated with the respect that they deserve. Mental health service consumers must be supported with the information and practical support that they need in order to manage their recovery in an informed and empowered way.

Mirian Merten's death occurred due to the failure of a system in which the needs of the mentally ill are regarded as an imposition, which can be overlooked if necessary. The recommendations outlined above aim to restore power to individuals and ensure that the right of mental health patients to respectful and patient-centred treatment is treated as the highest priority at all times.

⁴³ Ibid, p. 5.

Appendix A: Terms of Reference

LEGISLATIVE ASSEMBLY PUBLIC ACCOUNTS COMMITTEE

Inquiry into the Management of Health Care Delivery in NSW Terms of Reference

That the Committee inquire into and report on the management of health care delivery in NSW, with particular reference to:

1. a) The current performance reporting framework for monitoring the effectiveness and efficiency of health care service delivery in NSW;
2. b) The extent to which efficiency and effectiveness is sustained through rigorous data collection, monitoring and reporting;
3. c) The adequacy of the provision of timely, accurate and transparent performance information to patients, clients, health providers and health system managers;
4. d) The extent to which the current framework drives improvements in the health care delivery system and achieves broader health system objectives;
5. e) Any other related matters.

Appendix B: Mental Health Accountability and Chemical Restraint. Research Report and Recommendations.

Mental Health Accountability and Chemical Restraint Research Report and Recommendations March 2015

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Mental Health Accountability and Chemical Restraint: Research Report and Recommendations is a Justice Action study into mental health consumer preferences regarding medication and the willingness of authorities to consider collecting this data.

*"You win the battle but lose the war, if the goal is to help the person get better. There are many ways to heal."*⁴⁴ (Aaron Levin)

Executive Summary

Data collection on the use of seclusion in mental health management has resulted in increased awareness of its harmful effects and a dramatic lessening of its use. As a result, however, it has been postulated that the use of medication to sedate consumers against their preference may have increased.

In an attempt to establish data collection for consumer (patient) preferences, thirty-five mental health authorities from both Australia and New Zealand were contacted. They were asked to consider altering the required procedural forms to include a question on whether the consumer actually wants the medication that is given to them. Of the thirty-five participants contacted not one person in authority was prepared to discuss the proposed question.

Justice Action, recognising the lack of responses by these individuals, has redirected its research away from this initial 'top down' approach to instead work directly with consumers themselves. Research was conducted recording the consumer's preference to medication of over 100 consumers from Australia and New Zealand across five mental health wards.

Consumers responded to their own suggested question, 'Do you find your medication beneficial to you?' The overwhelming response to this question was negative, with 81% of respondents believing that their medication was not beneficial to their treatment. The remaining 19% agreed that the medication was beneficial, but many suggested that their compliance was motivated by a desire to establish goodwill with their psychiatrists and treatment teams to encourage favourable treatment and an early release.

From the evidence compiled, the 81% of patients surveyed who do not consider their medication to be beneficial indicated that the majority of consumers would prefer not to receive their medication. It is very concerning that consumer preferences towards their own medication is not acknowledged nor seen as important. The absence of official instruments to record the preference of consumers represents a complete absence of consumer agency in the treatment of mental health conditions.

Moreover, the results of eight months of logged contact and discussion with mental health authorities has unearthed significant issues surrounding the transparency and accountability of the treatment of vulnerable individuals.

Background

'Mental Health Accountability and Chemical Restraint, Research Report and Recommendations' is the culmination of eight months of logged contact and discussions

⁴⁴ Aaron Levin, "Covert Drug Administration: 'Win Battle, But Lose War'." *Psychiatric News*, 40(10) 10.4

with mental health authorities, initiated after the 9th National Seclusion and Restraint Forum. The report is a response to the concern that forced medication could replace the now significantly reduced use of seclusion for mental health consumers.

The Forum revealed a reluctance to discuss the reality of this important issue. Justice Action's subsequent proposal to include consumer preferences on the National Inpatient Medical Chart (NIMC) exposed the total unwillingness of mental health authorities to commence data collection on consumer preferences to medication. Justice Action contacted thirty-five health professionals and authorities (the participants). These individuals included attendees of the 9th National Seclusion and Restraint Reduction Forum and the Chief Psychiatrists from Australia and New Zealand. The thirty-five participants were emailed a proposal for amendments to medical treatment forms with a section to log consumer preference to receiving their medication. Each of these participants was emailed the proposal and received an average of four follow-up phone calls.

Justice Action received only five responses and of them, four accepted the need for better accountability and measurement of forced medication. However, of all the thirty-five participants contacted, none were prepared to enter into a discussion about the inclusion of a question regarding consumers' preferences. In the face of this poor response, Justice Action conducted research into the extent and level of acceptance of medical treatment in a survey of consumers.

The 2013 report entitled '*Mad in Australia*'⁴⁵, published by Justice Action, highlighted the legal and personal implications of forced treatment for mental health patients. This publication emphasised the abuse of forced medication and proposed other responses to mental illness. Justice Action outlined their concerns in this report that 'the therapeutic benefits of involuntary medication can mask, rather than relieve the symptoms of medical illness(es) often with sedative effects, which are used as chemical restraints'⁴⁶. This can result in the use of chemical restraint by psychiatrists as a subsequent by-product of medical administrative practices.

Since the publication of '*Mad in Australia*', reports of forced treatment and sedation investigated by Justice Action suggest nothing has changed and that the use of chemical restraint may even have increased as an alternative to the more thoroughly monitored physical forms/practices of seclusion and restraint (e.g. isolation in rooms for long periods of time, being physically restrained by bindings, etc.). Disturbed by this suspected increase, Justice Action created a proposal for procedural change in the administration of treatment for mental health consumers, identifying the use of forced medication as a possible abuse of trust and authority by professionals. In its email to the thirty-five participants, Justice Action proposed including a "Yes/No" question on existing medical paperwork regarding the consumer's preference to the medication being administered. This simple question, "Does the medication being administered to you suit your preference?" would allow accurate

⁴⁵ Justice Action, '*Mad in Australia: The State's Assault on the Mentally Ill*' (2007).

⁴⁶ Penelope June Weller, 'Developing Law and Ethics: The Convention on the Rights of Persons with Disabilities' (2010), Cited in '*Mad in Australia*', Justice Action (2013) 23.

data to be collected and recorded, as to whether consumer consent is given, in order to assist future mental health policy (Appendix A). Such a step also encourages dialogue, cooperation and compromise between medical professionals and consumers, thus potentially contributing to a break down the 'us' and 'them' mentality.

Data Collection Proposal

Currently, there are no official State, Territory or Federal procedures to record consumer's preference for regular or irregular medication. No official quantitative or qualitative records for consumer preference to treatment exist. Justice Action believes this inevitably results in biased records that do not reflect patient wishes as well as an overall lack of transparency regarding practitioner's treatment of vulnerable members of the community. Measures should be implemented to formally record whether mental health consumers want their medication in the medical registers, used to guide treatment.

Justice Action proposed that the *Medication Handling in NSW Public Facilities* document⁴⁷ be amended to include the question 'Do you want the medication that is given to you?' to ensure that consumer preference to medication, reflecting the wishes of the consumer, is recorded on every individual medical chart in a checkbox format. It was alternatively proposed that this question be asked at the point of prescription, in addition to the form in the *Guide to Poisons and Therapeutic Goods Legislation for Medical, Nurse and Midwife Practitioners and Dentists*.⁴⁸

The Justice Action proposal aimed to gather data detailing consumer preference in order to create transparency regarding the scope of forced medication. Accurate data would allow for a comprehensive review of the treatment of mental health consumers, provide the consumers with a greater sense of agency and as such, mental health systems can become more effective, transparent and accountable. Of the thirty-five participants contacted across nine jurisdictions by Justice Action, only four individuals from NSW, ACT, SA and NZ responded positively, advocating their support for the procedural change proposals to ensure their jurisdiction did not partake in harmful practices. One particular response from a participant demonstrated the disdain with which the proposal was treated, evidenced by the suggestion that the proposal was 'dramatic... over the top... [and] to be disregarded'.

The lack of transparency and accountability of the leading mental health figures and government officials in both Australia and New Zealand gives rise to many concerns including the human rights implications of such procedures. It would appear that the practice of administering involuntary medication is considered to be above reproach or immune from review or discussion.

⁴⁷ NSW Government Department of Health, '*Medication Handling in NSW Public Health Facilities*' (2013) <<http://tiny.cc/iecomx>>.

⁴⁸ *Nurse, and Midwife Practitioners and Dentists*' (2007) 3 <<http://tiny.cc/uacomx>>.

The lack of discourse on chemical restraint can be considered to be a direct result of the lack of data being collected on coercion of the consumer by the state. The absence of such data was noticeable at the 9th National Seclusion and Restraint Forum, despite multiple presenters alluding to their concern for consumer health and safety⁴⁹. The Forum neglected, and was seemingly reluctant to discuss, the realistic possibility that medication is increasingly being utilised as a form of chemical restraint. The persistent use of coercive medicine nullifies the ultimate goals of the Forum - to increase patients' involvement and improve the mental health system.⁵⁰

Consumer Directed Research

The independent research Justice Action has undertaken has exposed the dynamic of the relationship between the physician and consumer, which cultivates unequal bargaining power and the opportunity for physicians to exploit the vulnerability of the consumer. By disagreeing with medical professionals and opposing their treatment, consumers run the risk of being clinically judged by psychiatrists as possessing a lack of insight. This can then be used to justify further involuntary treatment and even refused release. Given this, it is likely that the anonymous nature of Justice Action's survey allowed it to record responses that may not have been given in a more public, official setting for fear of being perceived as opposing treatment and the potential consequences of this.

Methodology

Following the poor response from authorities to proposed changes, Justice Action went directly to the consumers, using a survey, to collect quantitative data (with opportunity for additional optional qualitative response if desired) on the issue of forced medication.

This research was founded on a consumer proposal, and asked whether consumers felt that their medication was beneficial.

Consumers from Australia and New Zealand across five mental health wards were posed the question, 'Do you find your medication beneficial to you?' (N=100). Respondents recorded their answer as 'Yes' or 'No' and were given the opportunity to expand on the reasons for their response.

Results

Of the 100 consumer participants to the question 'Do you find your medication beneficial to you?':

- 81% of the respondents answered 'No'
- 19% of the respondents answered 'Yes'

⁴⁹ Justice Action, *National Forum of Seclusion and Restraint* (2013) <<http://tiny.cc/6w4nmX>>.

⁵⁰ Ibid

Our findings suggest that a significant number of consumers not only objected to their current treatment plan, but also would not actively partake in their medication regime if they did not have to.

It is important to note however, that of those who found medication beneficial and would comply with medication of their own volition, most cited reasons not directly related to their mental well being in justifying their response. Instead, justifications included that medication would help them sleep or because they believed compliance would help them get out of the system and return home sooner.

Previous Research into Consumer Preference

As stated earlier, that no research has been conducted in Australia regarding consumer preferences in medication. However, some research has however been conducted overseas and is outlined below.

In Sweden, Greenberg et al. (1996) interviewed 30 forcibly medicated acute-care inpatients after discharge about their attitudes and experiences of forced medication. Fifty per cent expressed fear of side effects; seventeen per cent feared addiction and objected to others controlling them; forty per cent felt angry; thirteen per cent embarrassed; one third helpless, and one quarter fearful.⁵¹

Von Essen & Sjoden (1993) found that a trusting relationship between staff and patients was considered a key element of care for psychiatric patients.⁵²

Findings by Olofsson et al. (2000) indicated that closeness with and attention from nurses and physicians might reduce patient feelings of discomfort and increase feelings of security when subjected to coercion.⁵³ The Swedish study by Haglund et al. conducted in five locked wards at department of psychiatry for inpatient care in Sweden found that forcibly medicating a patient was connected with “a violation of patient integrity” and “psychological discomfort”, experiencing anger, panic and sadness.⁵⁴

In a study published in the United Kingdom, sixty-nine patients who were diagnosed with schizophrenia were questioned regarding their satisfaction with and subjective experiences of treatment with anti-psychotic medication.⁵⁵ Two-thirds indicated that they found the medication to be beneficial, however sixty-four per cent reported that they were experiencing side effects and only fifty-eight per cent said that their healthcare professionals dealt with their side effects effectively.⁵⁶

⁵¹ Forced Medication in Psychiatric Care: Patient Experiences and Nurse Perceptions, K. Haglund. L. Von Knorring

& L. Von Essen, *Journal of Psychiatric and Mental Health Nursing*, 2003, p. 66

⁵² Ibid.

⁵³ Ibid.

⁵⁴ Ibid

⁵⁵ Gray, R., Rofail, D., Allen, J., Newey, T., ‘A survey of patient satisfaction with and subjective experiences of treatment with anti psychotic medication’ in *Issues and Innovations in Nursing Practice*, 2005, 52:1, pp. 31-37.

⁵⁶ Ibid, 34-35.

McEvoy and Colleagues (1981) found that forty-seven per cent of a sample of mentally ill patients felt their medication was unnecessary.⁵⁷ Allen and Barton (1976) sampled a group of inpatients who were dissatisfied with staff interactions. These patients perceived psychiatric residents and nursing staff as “authoritarian” and said there was not enough informal communication between staff and patients.⁵⁸ This indicates that the patients valued “sincere relationships with all levels of treatment personnel.”⁵⁹

More generally, patients were unhappy with the lack of information shared about medication effects. (Distefano et al., 1980; Glenn, 1978) The majority of patients expressed displeasure with the use of seclusion techniques to control violent and no.-compliant patients. (Binder et al., 1983) As seen in a study by Soliday (1985) consumers said that these methods of seclusion is too frequently used as a punishment and tends to humiliate people.⁶⁰

Noble and Douglas (2004) found that the single most common request from patients was a desire to make decisions for themselves.⁶¹ Furthermore, there were indications of a relationship between patient’s requests and outcomes of care as better outcomes were associated with services meeting patients’ requests or acknowledging requests that could not be met.⁶²

Gibson, Cartwright and Read (2014) found that patients had predominantly negative views of anti-depressants because they have limited information about the medication or about other treatment options. In the study, patients expressed a preference to psychotherapy rather than medication and generally believed that they had been given insufficient information about medication effects, with 40% saying that they had not been informed about side effects.⁶³ Some evidence also suggested that physicians had not discussed alternative treatments to anti-depressants.

Discussion

Given these results, it is clear that the current system in Australia and New Zealand, as well as internationally, is not consumer focused. Consumers are either not involved in the decision-making for their treatment or their agreement is frequently coerced or ignored. Consumer preference or objection is regarded as irrelevant and has no official or de facto role in treatment decision-making processes.

This indicates a significant ethical issue not yet addressed within current codes of

⁵⁷ Corrigan, P. ‘Consumer satisfaction with institutional and community care’ in *Mental Health Journal*, 1990, 26:2

⁵⁸ Ibid

⁵⁹ Ibid, 157

⁶⁰ Ibid

⁶¹ Lorraine Mary Noble and Brian Christopher Douglas ‘What users and relatives want from mental health services’, (2004) 17(4), *Current Opinion in Psychiatry*, <http://journals.lww.com/copsychiatry/Abstract/2004/07000/What_users_and_relatives_want_from_mental_health.11.aspx>.

⁶² Ibid.

⁶³ Kerry Gibson, Claire Cartwright and John Read, ‘Patient-centred Perspectives on Antidepressant Use’ (2014) 43(1) *International Journal of Mental Health* 81-99.

practice that govern mental health authorities, despite the Australian Commission on Safety and Quality in Health Care (ACSQHC) emphasising the need for a consumer-centric approach.⁶⁴

Changes should be made to medication recording systems to include a recorded acknowledgement of consumer preference, ensuring that consumer autonomy remains protected and that exploitation does not occur. This could be achieved by incorporating the question proposed by Justice Action to the thirty-five participants, namely 'Do you want the medication that is given to you?'

The medication process will be consistent with the obligation to uphold the rights of consumers as outlined in the Australian Government's National Standards for Mental Health Services (NSMHS).⁶⁵ In particular, the inclusion of a clear Yes/No question will meet NSMHS guidelines by ensuring that 'all care delivered is subject to the informed consent of the voluntary consumer'⁶⁶ as well as adhering to 'the right of the consumer to be involved in all aspects of their treatment, care and recovery planning'.⁶⁷

The collection of answers to the proposed question by consumers will also help fill what the National Mental Health Consumer and Carer Forum (NMHCCF) said was a gap in 'clear, regular and reliable public reporting' with regard to seclusion and restraint.⁶⁸ The NMHCCF also said that 'chemical restraint is unacceptable as a form of involuntary restraint in any circumstances and is 'exceptionally dangerous... for people with mental illness'⁶⁹ reinforcing the need for change as asserted by Justice Action.

The NSW Health Policy Directive states that chemical restraints can only be used in 'extreme circumstances when other forms of management of a less restrictive nature have been proven unsuccessful'⁷⁰. However, as indicated in '*Mad in Australia*', under the *Mental Health Act 2007* (NSW) the safeguards for patients against non-compliance with this directive are not yet secure enough to ensure patient protection. More generally, the NMHCCF has said it is their position that involuntary seclusion and restraint 'should be eradicated from use in Australia's mental health services'.⁷¹

Bradley Foxlewin of the NSW Mental Health Commission has advocated against seclusion and restraint, saying that the practice is 're-traumatising' patients.⁷²

⁶⁴ Electronic Medication Management Systems- A guide to Same Implementation (EMM) 17(Figure 5.2).

⁶⁵ Australian Government, *National Standards for Mental Health Services (NSMHS)*, (November 2014) <<http://tiny.cc/pocomx>>.

⁶⁶ Ibid, 1.3.

⁶⁷ Ibid, 1.10.

⁶⁸ Ian Hickle, 'Ending Seclusion and Restraint in Australian Mental Health Services' (paper presented at the National Mental Health Consumer & Carer Forum, 2009) 8 <<http://tiny.cc/34comx>>.

⁶⁹ Ibid, 6.

⁷⁰ NSW Government Department of Health, '*Policy Directive: Seclusion Practices in Psychiatric Facilities*' (2007), cited in Justice Action '*MAD in Australia*' (research discussion paper, 2013) 16.

⁷¹ Hickle, above n 25, 7.

⁷² NSW Mental Health Commission, 'Our People Deputy Commissioner Bradley Foxlewin' <<http://tiny.cc/b5domx>>

Emphasizing the need for transparent and open discourse, this paper mirrors the views of the Executive Director of the Brain & Mind Research Institute, Professor Ian Hickie, who stated that ‘the frequent requirement to seclude and restrain people with an acute mental illness highlights the ongoing failure of the mental health system to provide high quality care.’⁷³ The serious disenfranchisement within the current mental health system needs to be addressed through fair and open discussion in order to improve the recognition of patient’s (consumer’s) fundamental human rights. The present study is limited in scope. However, the findings provide powerful evidence that warrants further investigation into mental health consumer’s wishes and perception of medication compliance from a larger national sample. The findings also provide a clear example of legitimate concerns towards the failings of current medical practice and procedure that needs to be addressed.

Recommendations

The overwhelming desire to reject forced medication, as indicated in the data presented, raises concern that the chemical restraint of mental health consumers may be widespread. Furthermore, those who indicated that they consider their medication to be beneficial only as a method of perceived compliance cannot be said to have given free and voluntary consent. Moreover, in this case medication becomes beneficial only as a means to an end. These results allow for the possibility that the provision of involuntary medication may result in chemical restraints currently being employed on a large scale across Australia and New Zealand. As stated by the NMHCCF, ‘chemical restraint is unacceptable as a form of involuntary restraint in any circumstance’.⁷⁴

It is recommended that:

Consumers should be given the opportunity to have their preference to particular medication and treatment recorded.

This should be recorded in the ‘Medication Handling in the NSW Public Facilities’ document, posing the question ‘*Do you find your medication beneficial?*’.

Alternatively, the question could be posed at the point of prescription, adding it to the provisions in the *Guide to Poisons and Therapeutic Goods Legislation for Medical, Nurse and Midwife Practitioners and Dentists*.⁷⁵

Consumer led research into the issue of consumer preferences for the use of medication should be supported.

Justice Action encourages the implementation of these procedures and advocates for open and honest discourse surrounding seclusion and restraint in order to achieve the best care for at-risk and vulnerable individuals.

⁷³ Hickie, above n 25, 4.

⁷⁴ Ibid, 6.

⁷⁵ NSW Government Department of Health, above n 5, 3.

Glossary of terms

Consumer: A person who has or has had direct experience of mental illness and has used or is currently using mental health services.⁷⁶

Restraint: When somebody's movements are restricted by the use of straps or belts (physical restraint) or sedation (chemical restraint).⁷⁷

Seclusion: When someone is confined in a specific room from which they cannot freely leave.⁷⁸

Appendix A

Combination of two emails sent for survey 12 August 2014

Dear...

Please see Justice Action's linked Report on the 9th National Seclusion and Restraint Reduction Forum. We have continued our research and ask for your response on the proposal underneath.

Earlier, we proposed the inclusion of a section in local Seclusion and Restraint Registers that would indicate whether an individual consumer wants the medication(s) administered prior, during or immediately after following restraint and/or seclusion. However, it is clear that the greater the focuses on the reduction of Seclusion and Restraint around an incident, the more likely that forced medications cloaked are regular 'treatment' will occur. The culture of the mental health industry has permitted this false division between treatment and sedations. This is a serious fault, primarily in the sense of coercion of consumers, and it being anti-therapeutic.

We would like to direct your attention to a serious issue. As the Report expresses, the Forum raised significant issues involving the reduction and elimination of seclusion and restraint practices in mental health facilities. However, there was an avoidance of the topic of medication, where the Forum failed to present corresponding data from any States on the rates of chemical restraint use. The absence of data and significant reduction in national rates of seclusions encourages the possibility that chemical restraint is being used as an alternative remedy to seclusion.

The administration of medications to mental health consumers against their wishes is equivalent to the overpowering of them by physical force. For too many consumers, it is much worse, with significant side effects; the issue of chemical restraint, however justified, was carefully avoided.

The strident voice of Justice Action and our distribution of 'Mad in Australia', ensured exposure of the issue. It is clear that involuntary medication is as critical an issue as

⁷⁶ Victorian Government Department of Health, *Strengthening Consumer Participation in Victoria's Public Mental Health Services* (2009) 2.

⁷⁷ Australian Government National Mental Health Commission '*Glossary; definition of 'restraint'*' (2014) <<http://tiny.cc/aoeomx>>.

⁷⁸ Ibid, '*definition of 'seclusion'*'.

physical restraint, but much more insidious. If the consumer is being overpowered, motivation is irrelevant. The question as to whether the patient wants the medication or not should be recorded; it is dishonest to say that only the psychiatrist's motivation is relevant, if so called treatment is prescribed.

Without data on restraint, there cannot be an accurate reflection of the current state of seclusion and restraint practices, which impedes efforts to improve the mental health system. Further, there are no records of the consumer's preference on the use of regular medication, which in turn gives no regard to the feelings of outrage in the use of restraint and sedation, threats of restraint or sedation, or other inducements to the same effect. It would be unreasonable to reject the premise that a consumer's wish be recorded, especially when viewed in context with the coercive forces of the treating parties, as the 'Mad in Australia' (linked above) report has demonstrated.

To resolve the gap in the data collection of coercion against the consumer, we have found the following opportunities for the question "Do you want the medication that is being provided to you?" to be posed to consumers and recorded.

We have focused on the NSW Health System; however, other states have similar processes and forms. Section 4.8.1 of the Medication Handling in NSW Public Facilities document (PD2013_043) Outlines a list of items to be specified in a medication chart order.

We propose that the question of whether a consumer "wants the medication given to them" be included in these requirements. This will be recorded on the attached National Inpatient Medical Chart (NIMC), in addition to all other required items necessary for all admitted patients. We propose a row to be included after 'Prescriber Signature', which would read "Consumer wants medication" followed by a checkbox for 'Yes', in a similar format to the 'VTE Risk Assessed' checkboxes.

A further option is for the question to be asked at the point where a decision is made to prescribe medication. Currently, there is no documentation for the consumers' response to the doctor about prescription. The question and response should be recorded in the prescription, as an addition to the particulars listed on the Guide to Poisons and Therapeutic Goods Legislation for Medical, Nurse and Midwife Practitioners and Dentists (TG12/25, pg. 3), as well as the doctors clinical notes, as referenced on page 18 of the Electronic Medication Management Systems – A Guide to Safe Implementation (EMM). These responses would form part of the patient medical records, and the question may then be asked whether the consumer wants the treatment at the point the decision is made to treat, indicated in the third step of the 'Inpatient Medication Management in Hospitals' chart in the EMM document (linked above, pg. 19, Figure 5.3).

We have found that while the Australian Commission on Safety and Quality in Health Care (ACSQHC) emphasises a patient-centered approach in the issuing of medication, it is clear that this is not always the case. The EMM guide (as above) suggests an approach that involves the consumers in all aspects of medication management with the exception of a key component: the decision on treatment. This is evident in Figure 5.2 on page 17 of the EMM guide, in which the consumer forms

the center of the diagram, linking to all principles, except the decision on appropriate treatment.

In incorporating this question into these key points, the medication process will be consistent with the obligation to uphold the rights of consumers, as outlined in the Australian Government's National Standards for Mental Health Services. In particular, it will address the criteria that "all care delivered is subject to the informed consent of the involuntary consumer" (1.3) and for "the right of the consumer to be involved in all aspects of their treatment, care and recovery planning" (1.10). It will also be consistent with ACSQHC's National Safety and Quality Health Service Standards, which outlines the need for an agreed medication management plan (4.14).

We understand the variety of forms used, and the inertia involved. However, any data collection focusing on coercive care, such as seclusion and restraint, that does not include the use of forced medication is deliberately misleading and not useful in demonstrating the issues at hand. To not record consumers' views on receipt of medication is disrespectful to not only the consumers themselves, but to a wider society who are concerned with mental health and the meaning of 'recovery'.

As part of our proposal, we are seeking responses from various State agencies regarding the elimination of unnecessary involuntary medication.

As part of your response, we would appreciate it if our views are presented in any committees or hearings through which you have input, or are able to provide us with an avenue through which may present such views.

Kind Regards

Olivia Richards Hill and the Justice Action Team

Appendix B

Media Release: Friday 28th August

Mental health accountability research

"Research showing the total unwillingness of Australian mental health authorities to be held accountable was launched at the Mental Health Services([TheMHS](#)) conference held in Perth. How can we discuss positive forces for change at the conference when there is such structural concealment, disempowerment and hypocrisy from those being allowed to guide the industry?" said Justice Action Coordinator Brett Collins.

"Following the 9th National Seclusion and Restraint Reduction [Forum](#) in Canberra last year, Justice Action contacted all participants and every Chief Psychiatrist in Australia and NZ with a proposal to collect data on the use of involuntary medication for mental illness. Data collection for seclusion has now started, resulting in dramatic lessening of its use, but we postulated that chemical restraint may have replaced seclusion as a result. We asked those people in authority to discuss the possibility of including in the required paperwork, a question to those receiving medication about whether they wanted it" said Mr Collins.

"Over eight months beginning December 18th we logged emails, phone calls and visits to those thirty five representatives across all jurisdictions. Most participants were contacted five times. Thirty of the thirty five acknowledged receipt of the proposal but would not engage on the issue. One person said it was out of step with reality. Only four consumer representatives indicated their support. Not one person in authority was prepared to discuss the question" said Mr Collins.

"While the psychiatrists were trying to ignore the question, patients themselves initiated the same research in one major hospital. The question raised was: Do you find the medication beneficial to you? Over 81% answered: 'no'. The medical profession is clearly in breach of their ethical obligations and they know it" said Mr Collins.

The Justice Action publication, "[Mad in Australia](#)" outlines the history of abuse of people with mental health issues breaching international [expectations](#).

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Appendix C: Mad in Australia Report

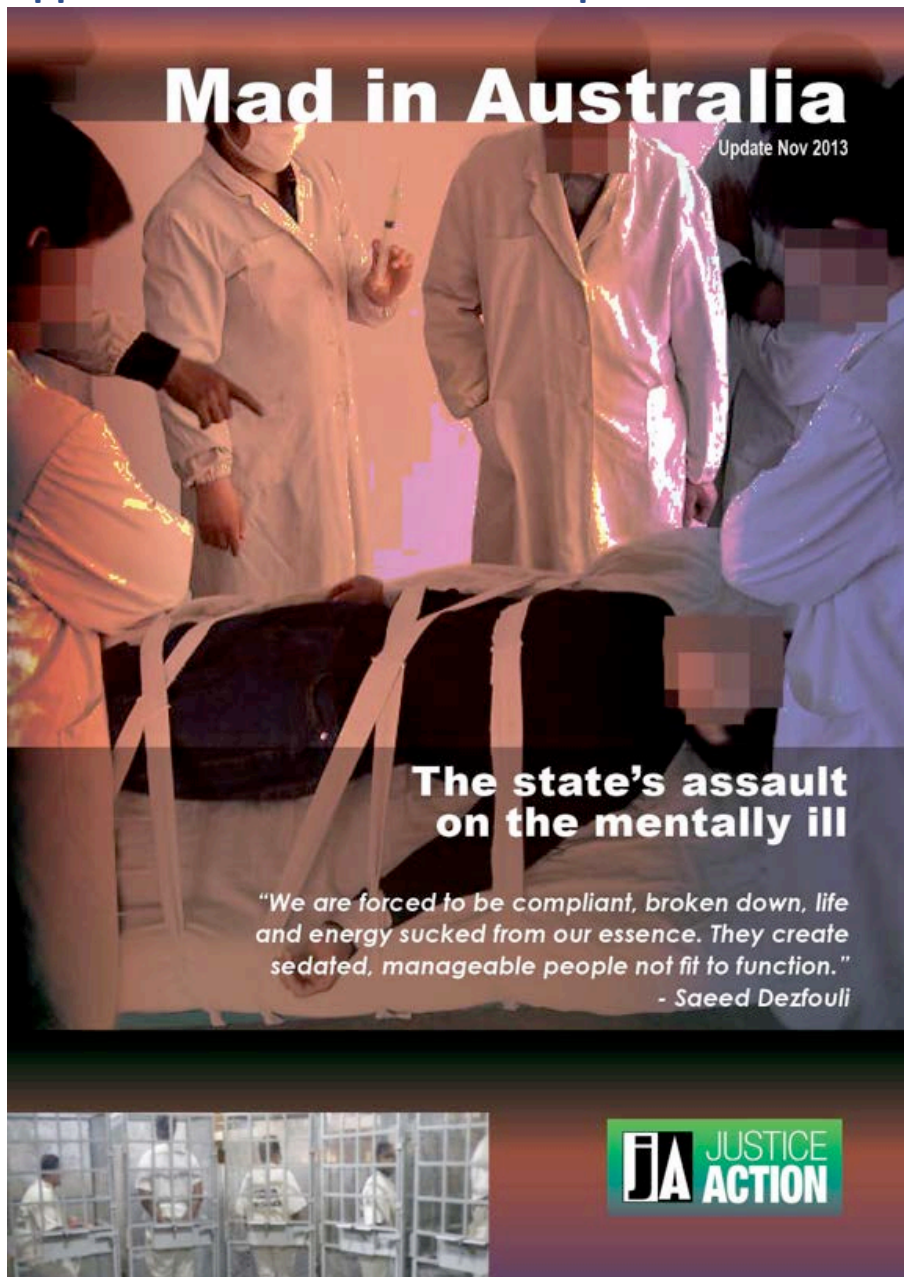


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Foreword

I first met Saeed Dezfouli in 2002 while working as the Executive Officer of the NSW Consumer Advisory Group [1]. He requested support for a range of problems he and other consumers were experiencing at Long Bay Jail.

Over the next few years, I started to explore how we could shine a light on the treatment of forensic patients in NSW. I learnt that this was not an area where the bureaucracy in NSW wanted any support from consumers to change even after they helped develop the Charter for Mental Health Care in NSW in 1998 [2] with Professor Beverley Raphael. Forensicare in Victoria has been much more progressive in how it has partnered with consumers and carers to bring its forensic services into the 21st century. To find the support I needed in NSW I had to look outside the mental health area and found Justice Action [3] in 2003, which took on Saeed's case to bring his concerns to a wider public.

The same frustration that I was feeling was expressed in the Obsessive Hope Disorder Report [4] which noted that mental health urgently requires vigorous advocacy and broad based community

leadership. This report criticised the Government's response to the 1993 National Inquiry into the Human Rights of People with Mental Illness [5] as inadequate and under-resourced.

My hope with the start-up of the National Mental Health Commission is that NSW will no longer be able to ignore the issues identified by MAD in Australia. One of the challenges for John Feneley, the NSW Mental Health Commissioner, is to avoid service-focused thinking and instead embody a people-centred approach to mental health reform.

I believe he is well on his way to bringing these issues to the NSW Government's attention.

Douglas Holmes

Consumer Researcher and Activist

November 2013

1. Introduction

Mad in Australia documents the history of abuse towards mental health patients in Australia, with reference to international practices. It describes the historical and cultural context of the abuse of mental health patients, and identifies the beginnings of a culture of doctors forcing medication on mental health patients.

Mad in Australia also draws specific attention to a significant element of this subject – the ethical dilemmas and corruption underlying the relationship between the pharmaceutical industry and medicine.

The history of mental illness treatments [1] is stark. During the worst times treatment amounted to 'killing patients' by drowning them and then reviving them in the hope of cleansing them of their 'unhappy condition'. The most barbaric 'therapies' were justified by the belief that the mentally ill were subhuman and should be disposed of.

The twentieth century ushered in a new era of psychiatric treatment with the development of psychiatric drugs by pharmaceutical companies. Such developments supposedly introduced more humane and scientifically correct methods of treatment. However, the political and economic power of the pharmaceutical industry has brought their products and agendas into the limelight for public scrutiny. Bracken & Thomas (2009, p. 245) argued that the credibility of the psychiatric profession has

been brought into disrepute 'through the corruption of our research and training agendas by the interests of major drug companies in alliance with senior individuals from our profession' [2].

Our report draws on the World Health Organisation's (WHO) eight-year study which compared the effectiveness of treatments in Western and developing countries. In follow-ups conducted after five years, 64% of mental health patients were asymptomatic in developing countries as opposed to a mere 18% in developed countries [3]. The results indicate that social support nurtures higher rates of recovery while medical intervention is harmful. The project 'Soteria' produced similar findings, with 68% of patients who received neuroleptic (antipsychotic drug) treatment relapsing within the two-year follow-up period compared to a 31% relapse rate for those who had undergone the community inclusion program and continued to avoid medication after the project [4].

Mad in Australia concludes that the significantly lower recovery rate of mental health patients in developed countries may be imputed to the 'scientific' drugs and chemicals lacking in developed countries. These findings confront the presumption that neuroleptics effectively treat symptoms of mental illness.

Given such statistics, the practice of forced medication (with neuroleptics) must be regarded as a serious violation and infringement of basic human rights with no empirical justification. The power and control of the pharmaceutical industry remains undiminished despite the studies that expose the failures of the psychiatric drugs it vigorously promotes. Investigations have shown that such psychiatric drugs are sometimes ineffective, dangerous, or both [5].

In fact, a recent study concluded that newer classes of anti-depressants (which are the most prescribed psychiatric drug) are merely a placebo for most patients [6].

Mad in Australia explores the legal and personal implications of forced treatment of mental health patients with reference to domestic and international principles and practices. It raises the moral questions about involuntary treatment and shows that disregarding patients' rights to control their medication is unethical, unreasonable and counterproductive. It argues that the right of individuals to make choices about how their body is treated is inherent in one's civil recognition as a person.

Moreover, this report claims that personal control of health services is a fundamental human right and should be overruled only when critically necessary. This analysis presents a reality that is functionally different to the legal and ethical framework implemented by the state. It focuses on the lack of human rights protection in Australia, particularly for involuntary patients, and the corruptible framework built by powerful pharmaceutical companies that heavily influence the mental health profession.

In the widely circulated report, *Not for Service* (2005), by the Mental Health Council of Australia and the Human Rights and Equal Opportunity Commission, evidence of the injustices experienced by mental health care patients in Australia was documented, and recommendations were proposed. However, these recommendations have been ignored by the government, and the voice of the consumer has therefore been stifled [7].

Mad in Australia examines international standards (particularly those presented by the Mental Disability Advocacy Centre, and supported by the Council of Europe), which recognise the rights of mentally ill patients. It considers the many jurisdictions that no longer allow forced treatment to be an automatic consequence of involuntary confinement. This situation is contrasted with the Australian position, which disregards the fundamental human rights of involuntary patients to be active participants in decisions regarding their treatment, especially when it comes to practices of sedation.

Mad in Australia also assesses the normative value of involuntary medication, arguing that it is untenable within a principled framework of the relationship between state and citizen. It shows that involuntary treatment fails to achieve its intended effects. Research demonstrates that it disturbs rather than helps patients, causing very significant side effects that they fear and detest. In fact, it could be argued that, in circumventing patients' rights to consent to and decide which chemicals, if any, are used in their treatment, mental health care professionals are instead poisoning their patients.

While this paper concedes the value of forced medication in very limited short-term situations, it also exposes the reality of the regular breach of patients' integrity when, instead of discussing options with patients and letting them make the decision, patients' rights are routinely usurped, superseded by the beliefs of their doctors in a routine that has proven to be both unjustified and, often, even harmful. This paper highlights the discriminatory nature of forced injections, which infringe on the rights of disabled people to be treated with respect for their physical and mental integrity on an equal basis with others.[8]

The latter half of this paper proposes alternative approaches to forced treatment. These include patient-centred psychological treatment that is effective for patients in psychosis, as well as other measures proposed by patients themselves that are not currently considered but are consistent with domestic and international law. These methods require effort, patience and respect.[9] This paper concludes with the proposition that consensual treatment is the only acceptable form of 'care'.

2. History – The Abuse of Mental Health Patients

At the start of the 18th century, the 'insane' were typically viewed as wild animals who had lost their reason.[10] They were subject to scorn and ridicule by the public, sometimes kept in madhouses in appalling conditions, often in chains, and neglected for years or subject to numerous tortuous

'treatments' including whipping, beating, bloodletting, shocking, starvation, irritant chemicals, and isolation.[11] Hateful rhetoric like 'poisonous slime' and 'malignant biological growths' further vindicated the liberal use of force in shockingly inventive ways like choking patients by wrapping a wet towel around their necks and twisting it until they fell unconscious or slugging them to the same effect with a hard bar of soap in the toe of a sock.[12]

Moral treatment was an approach to mental disorder that emerged in the 18th century. The ex-patient Jean-Baptiste Pussin (1746–1811) and his wife Marguerite, and the physician Philippe Pinel (1745–1826) are recognised as the first instigators of more humane conditions in asylums. William Tuke (1732 – 1822) also played a fundamental role in developing more humane approaches that came to be known as moral treatment.[13]

In 1797, Pussin first freed patients of their chains and banned physical punishment, although straitjackets could be used instead.[14] Patients were allowed to move freely about the hospital grounds, and eventually dark dungeons were replaced with sunny, well-ventilated rooms.

Pinel used the term 'treatment moral' for the new approach. At that time, the word 'moral', in French and internationally, denoted either psychological/emotional (as a mental state) or moral (as an ethical principle). Pinel distanced himself from the more religious approach that was emerging in Britain, and considered that excessive religiosity could be harmful to the patient.[15]

With 'moral treatment,' patients were cared for with the utmost diligence and humanity. Patients were housed in facilities to match that of a modest hotel, and staff were selected according to specific job requirements such as 'pleasantness of expression' and 'softness of tone'.

Those in asylums were treated as humans, given lectures, responsibilities, and a quasi-family to interact with in an attempt to ease their reintegration with the wider society upon release.[16] These requirements made staff harder to hire and asylums more expensive to maintain.

The 'moral treatment' movement was initially opposed by many madhouse keepers and medics, the latter opposing it partly because it cast doubt on their own approach. By the mid-19th century, however, many medics had changed their strategy. They became advocates of moral treatment, but argued that since the mentally ill often had separate physical/organic problems, medical approaches were also necessary.

Making this argument stick has been described as an important step in the profession's eventual success at securing a monopoly on the treatment of 'lunacy'. [17]

The increased institutionalisation and bureaucratisation of the mental health sector led to disregard of 'moral treatment' and the rise of the modern formula of patient oppression in an attempt to regulate their stay at asylums and ease the financial burden on the mental care industry.

There have been many different theories[18] about the cause[19] of mental disease in patients. Theories including bad spirits, unregulated blood flow, madness-causing bacteria, diseased brain cells, overstimulation of nerves and too many or too sensitive dopamine receptors, were all treated 'scientifically' at varying points in history.

These theories were sometimes used to justify various treatments such as leeching, drowning, opiates, lobotomy, electroshock (now actually increasing in usage in WA) and neuroleptics, which all had the common side effect of oppressing the patient and transforming them into submissive bodies.

This reduced activity in patients is regarded as an improvement in their condition, and thus a reflection of the supposed effectiveness of these treatments.

The practice of mental health treatment has changed over the decades, resulting in the replacement of that which was already bad by that which is even worse.

Although treatments may appear to have improved, the main focus of today's 'scientific' and widely accepted treatment of the mentally disabled is in fact a system of complete control, and not the rehabilitation of patients with such conditions.

In Australia, many involuntary patients are sedated (and medicated) against their will, exemplifying the desire of mental health institutes not to nurture but to oppress.

The use of neuroleptics has been relied on as a basis for the theory of mental disease, an illogical conclusion as medical treatment should be grounded by sound scientific evidence, not the other way around. Such placement of the cart before the horse is alarming.

The treatment patients received at the notorious Chelmsford Hospital epitomise the mental health paradigm in Australia. Chelmsford Hospital's infamous 'Deep Sleep Therapy' left patients either more damaged or dead, and yet almost half a century later, victims have yet to receive a formal apology.[20]

Released every few years under a different name, new neuroleptic medication promises improvements over the old, the main difference being a reduced probability of extrapyramidal

symptoms (movement disorders). However, neuroleptics are still widely used to calm and settle patients, despite their controversial and debatable effectiveness in curing the disease in question. The treatment rates of the current psychotic medication (Clozapine, Paliperidone) are the same as the old antipsychotic neuroleptic medication (Chlorpromazine, Haloperidol).

There are non-medicinal treatments that offer alternatives to neuroleptics, but the monopoly of psychiatrists (and behind them the pharmaceutical industry) has blocked challenges to the efficacy of neuroleptics. Mosher[21], Rappaport[22], Crane[23] and Breggin[24], all fell out with the National Institute of Mental Health (NIMH) in the USA over alternatives to neuroleptics.

Even more staggering is the power of the pharmaceutical industry to suppress potentially helpful medications. During the 1950s, pharmaceutical companies denied research on the benefits of lithium for bipolar research. This is in large part due to the lithium's status as intellectual property: as a naturally occurring element, it is not possible to take out a patent on it. Despite the potential benefits of lithium as a medication for a myriad of illnesses, both medical and psychological, there is no funding for research as costs are too high and there is no profit involved.[25]

Loren Mosher started a moral treatment project named 'Soteria', which delivered unprecedented results: '... subjects in both groups (who participated in the project) improved significantly and comparably, despite Soteria subjects not having received neuroleptic drugs'.[26] This project was aimed at both curing and preventing the relapse of schizophrenia.

His work was replicated in Sweden, but was refuted in the USA by the National Institute of Mental Health (NIMH), which doubted that ordinary people working in Soteria could treat mental illnesses more successfully than highly educated psychiatrists.

'The importance of social inclusion to good mental health and an effective and responsive community-based approach'[27] further supports the notion that drugs are not necessary in treating the mentally ill, as demonstrated by the Soteria project.

Perhaps one of the strongest indicators of the inadequacies of modern Western treatments for mental illness is the WHO's eight-year study into three poor countries; India, Nigeria and Colombia (1969), which in the two- and five-year follow-ups revealed that patients in these Third World countries were performing significantly better than those in the USA and four other First World countries.

After five years, 64% of those in the developing countries were asymptomatic compared to 18% in developed countries.

These results support the argument that Third World countries have more effective treatment in relation to mental health. As Whitaker stated, 'Africans and Asians were better off because they lacked the very drugs on which we rely.'[28]

Up to now, the most widely accepted theory states that neuroleptics are able to treat the symptoms of mental illness (such as schizophrenia) by blocking dopamine signals but not the mental illness itself. Any blockage of dopamine results in impaired concentration, reduced motivation, increased perception of pain, and in some cases renders the person incapable of experiencing pleasure.

Additionally, neuroleptic medication has been proven to increase a patient's sensitivity to dopamine, as the restriction of dopamine due to neuroleptics forces the brain to produce more dopamine receptors.

In addition to this, Magnetic Resonance Imaging (MRIs) of patients taking neuroleptics showed that frontal lobe size and white matter reduced as the medication was continued, exacerbating symptoms of reduced cognitive abilities.

3. The Power of the Pharmaceutical Industry

One of the medical community's major responsibilities is to protect us from the commercial excesses of the pharmaceutical industry, but what we find is the exact opposite. They are in bed with them. [29]

The pharmaceutical industry is a superpower in the Australian and global economy. The vast amounts of money underpinning the industry give it the ability to dictate and demand many self-serving interests. Figures released by the Department of Industry, Innovation, Climate Change, Science, Research and Tertiary Education show that the Australian pharmaceutical industry turned over about \$22 billion in 2009-10.[30] The industry spent \$1.02 billion on research and development in 2008-09 and exported \$4.12 billion in the 2009-10 financial year.[31] Furthermore, although it was ranked 55th on population in the world in 2009, Australia was the 12th largest pharmaceuticals market by sales.[32] According to a leading health economist, Australia spends up to \$3 billion a year more than it requires in comparison with similar countries.[33] The expenditure on the Pharmaceuticals Benefit Scheme by the government has more than doubled over the last decade, from \$3.2 billion in 1999-2000 to \$8.3 billion in 2009-10.[34]

The power and influence of the industry in the US is also staggering. In the US, pharmaceutical industry lobbyists outnumber Congress members. In 1999 and 2000, lobbyists for the pharmaceutical industry had a \$197 million budget, which was \$50 million more than the insurance and telecommunications industries.[35] In 2000, the industry invested \$15.7 billion in marketing. Dr

Joanna Montcrieff, a Senior Professor at the Department of Mental Health Sciences at University College in London, stated that drug manufacturers spend billions yearly on marketing and advertising, far beyond expenditure on actual research.[36]

As Loren R. Mosher says, 'What should be the most humanistic medical specialty has become mechanistic, reductionist, tunnel-visioned and dehumanizing. Modern psychiatry has forgotten the Hippocratic principle: Above all, do no harm.[37]

The pharmaceutical industry has adopted an agenda of robustly heightening public hype around a specific psychiatric illness depending on which drug it wishes to market. When the industry produced Xanax in the 1980s it generated a surge of interest in panic disorder. This was the first time a pharmaceutical company invested huge amounts of money to market its product and link that product to a new and specific diagnostic category. Although there were other psychiatric disorders during the 1980s, they paled in importance. It became clear that only disorders that the pharmaceutical industry could derive a profit from received much attention.

This culture of discriminatory treatment and selective sponsorship continues to affect psychiatric treatment today. As one critic states, 'it may often be far more effective to sell the clinical indication of the existence of a disorder than to focus on selling the treatment for it'.[38]

The power of the pharmaceutical industry heavily influences the mental health profession, which provides a productive field for industry profits. Medical and psychiatric professionals are now so dependent on pharmaceutical companies that they are reluctant to reveal conflicting interests and to criticise the overuse and misuse of psychotropic drugs. Pharmaceutical companies have effectively assumed authority over those professions that have been entrusted to care for patients in mental health facilities.

This situation exposes a crucial element in understanding the treatment of patients, namely those doctors, nurses and psychiatrists are medicating vulnerable patients. The Australian Medical Association president Steve Hambleton stated that doctors must be cynical about the influence of the pharmaceutical industry. He refused to use professionals recruited and trained by pharmaceutical companies, 'for the express purpose that their ultimate aim in life is to get the dose of whatever is prescribed (increased). That is a conflict of interest'.[39]

As Ray Williams noted, 'in 2001, US pharmaceutical company profits averaged 18.5% of revenue compared with 2.2% for the rest of the Fortune 500 companies (*Fortune* magazine, April, 2002). Imagine what the figures are today'.[40]

An Age investigation found that thousands of GPs have attended federal government-approved mental health training programs that are fully sponsored by Pfizer.[41] Pfizer continually tries to reassure GPs that Pfizer training will enable GPs to better diagnose psychiatric illness.[42] The inevitable result is that Pfizer will prescribe more psychiatric drugs. A 2003 analysis by Monash University found that most people tested were being diagnosed with a mental disorder they did not even have.[43] Pharmaceutical representatives regularly host promotional events for mental health professionals, giving information on specific drugs or general mental health issues and even promotional 'gifts'.[44] Reports show that drug companies spend \$30 million a year on hospitality for health professionals to attend 'educational events'.[45] The Australian Medical Association has described such 'educational events' as 'marketing exercises' for drug companies. Pharmaceutical companies also often employed and trained nurses who would then work for free or for subsidised wages at GP clinics.[46]

Medicines Australia reported that from 2011 to 2012, it spent \$29.4 million on hospitality for 385,871 health professionals.[47] Sanofi-Aventis spent \$54,348 on a weekend training session for 80 neurologists at the Rendezvous Hotel in Melbourne, including \$24,683 on flights, \$15,480 on hotel rooms and \$13,184 on meals. Pfizer spent \$192,924 hosting 104 GPs for a weekend meeting at the five-star Sofitel Hotel on the Gold Coast. Pfizer also spent \$612,962 on a one-day meeting of 221 GPs at the Sheraton on the Park in Sydney. These are only a few of the many 'hospitality' benefits afforded to medical and health professionals courtesy of large pharmaceutical companies.

The above paragraphs exemplify how the overbearing power and influence of the pharmaceutical industry has seriously undermined the credibility and ethics of the medical and health professions.

4. International Treatment of the Mentally Ill

There are multiple international examples where states have appropriately balanced the needs of the state with the rights of the individual, serving as a valuable point of comparison with the Australia legal framework. In particular, note the distinction between involuntary confinement and the restriction of the right to refuse certain medical treatments. In Europe, the legal right of individuals to make decisions in relation to medical treatment can be found in the right to privacy in Article 3 of the European Convention on Human Rights (ECHR), stating the right to be free from inhuman treatment.[48]²⁴

Further the Mental Disability Advocacy Centre (MDAC), supported by the Council of Europe, states that 'the right to decide is not contingent on the convenience of economic efficiency to the state of the person being treated, nor whether the decision to refuse treatment by the patient is not the correct thing to do. It is simply a right that we enjoy'.[49]

The MDAC argues that the relationship between compulsory detention and treatment does not necessarily follow.[50] Theoretically there is nothing inconsistent with involuntary detention and allowing the individual the authority to make treatment decisions.[51]

Although it has been argued that justification of confinement was for medical benefit, this is not the way human rights law, and the ECHR in particular, have viewed confinement.[52] According to the MDAC, the Strasbourg Court has never suggested that there must be an effective treatment plan for the justification of confinement.[53] Confinement has been determined on dangerousness and severity, rather than treatability. Thus, even if a patient is confined on grounds of being dangerous, there should not be an automatic removal of a patient's rights to treatment decisions.

There is an increasing international view that if patients are able to understand relevant information in relation to treatment decisions, they ought to be able to decide on their treatment, regardless of their place of residence. The Committee for the Prevention of Torture outlines this view:

Patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of a person to a psychiatric establishment on an involuntary basis should not be construed as authorising treatment without his consent. It follows that every competent patient, whether voluntary or involuntary, should be given the opportunity to refuse treatment or other medical intervention.[54]

The MDAC advocates that the right to make treatment decisions should depend on capacity, rather than confinement.[55] What constitutes 'capacity' itself is a debated issue. The individual should have the intellectual capacity to understand the diagnosis and basic information. In New South Wales, for example, according to section 153(1) of the *Mental Health Act 2007*, the test for determining whether a person is mentally ill or mentally disordered is on the balance of probabilities (i.e. a member of the Mental Health Tribunal must be satisfied on the balance of probabilities that the person is a mentally ill or a mentally disordered person). It is the responsibility of the doctor to explain the treatment information in basic language. The United Nation reinforces this responsibility with Principle 11 of the 'Principles for the Protection of Persons with Mental Illness':

Informed consent is consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and easy to understand information in a form and language understood by the patient on:

- a) The diagnostic assessment;
- b) The purpose, method, likely duration and expected benefit of the proposed treatment;

- c) Alternative modes of treatment, including those less intrusive; and
- d) Possible pain or discomfort, risks and side effects of the proposed treatment.

An invasion of a person's body is an interference with their private life under Article 8 of the ECHR. However, Article 8(2) allows for medical treatment 'for the protection of health'. The courts have, however, emphasised the need for vigilance when assessing whether someone 'needs' medical treatment. *Bensaid v United Kingdom*[56] reinforced that 'mental health must be regarded as a crucial part of private life associated with the aspect of moral integrity'.

The Council of Europe has established that treatment without consent should be based on law and 'only relate to strictly defined exceptional circumstances'.[57]

Treatment without consent must therefore be based on clear grounds related to the health and safety of the patient or for the protection of others.

Article 8 is clearly applicable to complaints that concern a matter of 'private life', a concept that covers the physical and psychological integrity of a person. [58] It reiterates that a person's body concerns the most intimate aspect of private life. Thus a compulsory medical intervention, even if it is of minor importance, constitutes an interference with this right. [59]

In some Canadian jurisdictions, patients with the capacity to make treatment decisions are able to exercise the right to make those decisions. The medical profession initially received this approach with great concern, but contrary to their fears, implementation raised few practical problems and with time the medical profession is broadly content with this approach, which has been in operation for almost twenty years.[60] The recognition of the patient's right to make treatment decisions has resulted in closer consultation and relationships between the treating doctor and patient.[61]

In *Flemmings v Reid*, [62] a Canadian court found that an involuntary psychiatric patient expressed, while he was competent, that he did not wish to be medicated. The Court found that setting aside his competent wishes was contrary to his right to life, liberty and security under section 7 of Canadian Charter. American courts rejected the argument that involuntary hospitalisation equates to a patient's incompetence to make treatment decisions. In *Lessard v Schmidt*, [63] it was established that only a finding of 'dangerous to self or others' is necessary in order to deprive a person of their individual freedoms. Furthermore it was found that lengthy hospitalisation might increase symptoms of mental illness and make transition into society more difficult. [64]

In *Rodgers v Okin*, [65] the court held that hospitals could not forcibly medicate voluntary or involuntary patients with a mental illness except in cases of an emergency in which failure to do so would cause harm to the patient or others. The court also highlighted that:

1. Involuntary hospitalisation did not equate to incompetence;
2. Detained patients with a mental illness had a qualified right to refuse psychotropic and antipsychotic drugs;
3. Some kind of procedural mechanism taking into account the issue of side effects and other factors was necessary to ensure that the patients' rights were respected.[66]

In *Rennie v Klein* [67], the District Court took a similar approach and decided that, in the absence of an emergency, the right to refuse treatment is grounded on the emerging constitutional right to privacy. The court noted four conditions when this can be overridden:

1. Whether or not the patient can be confined without endangering other patients or staff;
2. If the medication refused would have curbed the dangerous tendencies;
3. Whether the patient is competent to make the decision; and
4. Whether or not there is a less restrictive alternative available.

Since *Rennie* and *Rodgers*, all states except Utah have recognised the right to refuse treatment as separate from the involuntary hospitalisation treatment decision. [68]

Likewise, Scottish law does not allow compulsory treatment simply based on involuntary admission. It requires a separate compulsory treatment order. [69]

4.1 The Issue of Human Rights

Literature on the right of mental health patients to refuse treatment is grounded in the United Nations human rights ideals and international principles on the rights of the individual. This includes, but is not limited to, Principles of Persons with Mental Illness and Improvement of Mental Health adopted by General Assembly Resolution in 1991, the United Nations Convention on the Rights of Persons with Disabilities, 2007, and the United Nations Standard Rules for the Equalization of Opportunities for Persons with disabilities, 1993.

These protections of international law are insufficient for two key reasons. Firstly, despite Australia being a signatory to many international conventions promoting the protection of human rights, the power to enforce these treaties lies within the Federal government in passing those treaties into domestic law.[70] Secondly, even when the international agreements are enacted into domestic law (thus becoming enforceable and binding on every Australian citizen), they are usually written in such a way that facilities (such as Long Bay Forensic Hospital) can still abuse the rights of the patients without suffering any real consequences.

Countries such as the United States and Canada have a Constitutional Bill of Rights, and the United Kingdom has a Statutory Human Rights Act, thus providing a legal basis by which action can be taken for violation of an individual's rights. Unfortunately, human rights in Australia are much less entrenched than in similar liberal democracies, relying on a few implied rights in the Constitution and Common Law protections, with the exception of the ACT,[71] and Victoria,[72] both of which have a Bill of Rights. These are evidently not strong enough to protect individuals from a paternalistic health department and interventionist state authority.

The lack of explicit and enforceable human rights protections for mental health patients creates a farcical situation where the needs of individual people, which have been recognised time and time again in aspirational human rights statements, are ignored in the face of bureaucratic inertia and systemic abuse.

5. Australian Legislation

In some Australian jurisdictions, as in the United States and Canada, clinical standards alone are no longer considered a sufficient justification for the restriction and loss of liberty of mentally ill patients. [73] The statutory tests for compulsory treatment, although differing with jurisdictions, generally consist of a number of objective criteria superimposing a 'dangerousness' or harm prerequisite over a 'need for treatment'. [74] The *Mental Health Act 2007* (NSW), for example, is more representative of the 'dangerousness' standard in its requirement that 'care, treatment or control of the person' must be necessary in order to prevent 'serious harm' likely to themselves and others from their mental illness. [75] The need for treatment, and the benefits from such treatment, is the approach taken in the Victorian and ACT provisions. [76] The Victorian Act requires that the person's illness must require immediate treatment (in line with the standard preferred by the court in *Lessard v Schmidt*). [77]

International legal frameworks may be contrasted to those in NSW, Victoria and the ACT, under which a person subject to an order authorising compulsory treatment may generally be provided with medication regardless of whether or not they object. [78] This stems from the understanding that

involuntary patients are incompetent to make treatment decisions while in confinement. [79] However, this justification is far from compelling, given that there is no express requirement that a patient be incompetent in order to be subjected to compulsory treatment. [80]

Regardless of the validation that is given in the legislation, in a practical sense, the NSW legislation in particular simply creates a blanket authority that an involuntary patient does not have any right to refuse treatment that the treating doctor 'thinks fit'. There is no need or requirement for external application to give a doctor this power; rather, legislation assumes incompetence on the part of the patient regardless of the specific circumstances of the individual.

Australian mental health statutes, specifically the *Mental Health Act 2007* (NSW), in addition to listing a set of objectives regarding the provision of care and treatment, also contain an attempt to give direction to decision-makers to implement those objectives with little or no input from the patient. This decision is left to the discretion of the treating doctor. [81]

For example the objectives of the *Mental Health Act 2007* (NSW) are:

- a) To provide for the care, treatment and control of persons who are mentally ill or mentally disordered, and
- b) To facilitate the care, treatment and control of those persons through community care facilities, and
- c) To facilitate the provision of hospital care for those persons on a voluntary basis where appropriate and, in a limited number of situations, on an involuntary basis, and
- d) While protecting the civil rights of those persons, to give an opportunity for those persons to have access to appropriate care, and
- e) To facilitate the involvement of those persons, and persons caring for them, in decisions involving appropriate care, treatment and control.[82]

However, section 84, which governs the treatment of patients, states that:

An authorised medical officer of a mental health facility may, subject to this Act and the Mental Health (Forensic) Act 1990, give, or authorise the giving of, any treatment (including any

medication) the officer thinks fit to an involuntary patient or assessable person detained in the facility in accordance with this Act or that Act.[83]

This broad authorisation allows involuntary patients to be treated against their will in NSW. There is little safeguard of the patients' rights and no need for any other independent application to get authorisation to override lack of consent. The NSW position is not in line with any of the international standards and trends.

As international law develops to recognise the right to refuse treatment, even for patients who are involuntarily hospitalised, NSW has stood still in the protection of civil and human rights.

The *Mental Health Act 1996* (TAS) provides a more desirable approach to the treatment of involuntary patients than other jurisdictions in Australia. Under the Act, a patient in the Tasmanian jurisdiction cannot be forcibly treated merely when the treating doctor 'thinks fit'. Rather, an application has to be made under the *Guardianship and Administration Act 1995* and the Board determines whether to grant the application. [84]

Tasmanian legislation appears to have favoured the rights of the patient and has created a rebuttable presumption that involuntary patients are competent, unless decided otherwise by the Board. The approach taken in Tasmania demonstrates that while patients can be involuntarily detained, they are still able to maintain some level of recognition of their rights. [85]⁶²

Ultimately, despite the good intentions in the objectives of the *Mental Health Act 2007* (NSW), which value the rights of the patient, in reality, the legislation has granted exceptional discretion and power to mental health professionals. If a patient refuses medication, a nurse or doctor in the facility has the power to force it via injection or orally – all in the 'best interests' of the patient. [86]⁶ There is currently no independent body that authorises the use of forced medication, providing a necessary element of accountability over a process that could easily be abused.

6.The Reality of Forced Treatment in Australia

In theory, and according to the law, forensic mental health facilities (such as Long Bay Forensic Hospital) provide for the care, treatment and control of persons who are classified as mentally ill or mentally disordered within the prison system. These facilities are intended to provide treatment to patients, while also protecting their civil rights and allowing them to have access to appropriate care.

There is, however, a fundamental discrepancy between the way the system should operate, and the way it functions in practice. Traditionally, patients rely on beneficial care and advice provided by

health practitioners, but this is constantly being subverted in a system where treatment decisions are not made by informed and consenting patients but by the whims of the state.

Unlike people in prisons, patients in forensic mental health facilities can be forced into involuntary treatment programs indefinitely. Human dignity is inherent in all people, and this dignity does not diminish when it resides in those who are mentally ill and disabled. [87]

However, mental health patients are often condemned to a world where their fundamental rights as human beings are forfeited, and they live at the mercy of the state's discretion [88] as sometimes asserted through the Mental Health Review Tribunals.

It is evident that patients are often dehumanised in the course of their treatment: visitors are discouraged and sometimes refused entry, and social support is often seen as an unwanted disturbance rather than a constructive community right.

Forced medication is a regular form of 'treatment' for many such patients who are prejudicially assumed to be incapable of making any rational decisions. Saeed Dezfouli, a non-violent forensic patient in Long Bay Forensic Hospital, is one such person.

Saeed has been held indefinitely at the forensic hospital in Long Bay Jail since 2002, and is forced to take anti-psychotic medication on a fortnightly basis. Teams of doctors and nurses often have to physically restrain him, hold him face down and forcibly inject him. The use of forced injections, which would be considered battery in any other circumstance, is an unequivocal breach of Saeed's individual right to control of his body. Under the justification that he is incapable of making rational decisions, he has been given no opportunity to make decisions or question his treatment plan without running the risk of his opposition being used as evidence of his mental illness. Any sign of resistance has been used to mark him as non-compliant. In turn, this has been used as a justification to keep him incarcerated longer.

The unfortunate reality is that health professionals and doctors are de-sensitised to the plight of their patients, with a focus on financial and other outcomes instead of patient wellbeing. In addition, health professionals in forensic facilities must not forget that the prescription of medication to a person should meet the health needs of the person and should be given only for therapeutic or diagnostic needs. It should not be given as punishment or for the convenience of others as it is in Saeed's case. [89] Saeed's experience demonstrates the ineffectiveness of the Mental Health Review Tribunal and Supreme Court in providing a supposed avenue of appeal for involuntary patients. [90]

This abuse of individual rights is highlighted by the extreme case of Michael Riley. Despite the fact that Michael has never been charged for an offence and does not have a record of violent behaviour,

he has been in and out of mental hospitals as an involuntary patient for the last twelve years. During this time, he has been subjected to a whole host of involuntary treatment plans.

It is one thing to arbitrarily restrict individuals' autonomy because they might be dangerous to society; it is another thing entirely to take the last thing that matters to them after liberty – the control of their very body. Patients like Michael are trapped in a system where, by virtue of their mental disorder, they have been coerced into 'choosing' a specific treatment plan. This may consist of sedatives to make them more compliant, or being taken to hospital where the treatment plan is forced upon them. Michael has consistently been assessed as not being a danger to either himself or others, but due to his condition, he has been pre-emptively locked up. Unsurprisingly, this flagrant abuse of his rights feeds into the patient's existing sense of paranoia and distrust of the system, which further complicates recovery efforts.

Forced medication, which is trauma informed, is at odds with the principles of recovery-focused person-centred care. Forced medication reinforces the trauma of the high proportion of mental health consumers who have a past history of being abused.

The reality for many patients in forensic mental health facilities in NSW is that, if they accept psychiatric treatment, they are deemed to have the 'capacity' and will be admitted to a voluntary treatment program. However, if the patient is opposed to the treatment, they are subjected to a longer incarceration and involuntary treatment. Ultimately, this creates a situation where patients are only given the illusion of choice, which is at best coercive and at worst non-existent.

6.1 The Practice of Sedation

The practice of sedation of involuntary patients, particularly in NSW, highlights the abuse of rights and lack of respect shown to some of the most vulnerable members of society. Almost all forensic patients in and out of institutions are medicated against their will. It should be noted, however, that research has shown that psychosis symptoms are best treated with psychological therapy and medication should only be used alongside psychological therapy. [91]⁴

The NSW Health Policy Directive gives guidance to the sedation practices and clearly outlines the circumstances in which sedation may be used on a patient. The Policy Directive states that these 'chemical restraints' can only be used in 'extreme circumstances when other forms of management of a least restrictive nature have been proven unsuccessful'. [92] Furthermore, 'an injection without consent should be given only in the interest of the immediate physical safety of the patient or those in his or her vicinity'. [93]⁶ As noted above, any other unauthorised IV sedation that does not comply with this Policy Directive may be considered assault.

The Policy Directive also gives direction in relation to restraint in psychiatric in-patient facilities. Again, 'restraint should only be applied for the minimum time necessary and its application must take into account the principle of care in the least restrictive manner'. [94]⁶

On the surface these principles of care within the Policy Directive are safeguards for vulnerable patients. However, when read in conjunction with the *Mental Health Act* (NSW), the safeguards that protect patients can be easily abused.

When patients are held down and injected with a syringe, which functionally knocks them out, this should be classified as an IV sedation, and thus governed by the directives which states sedation should only be used in 'extreme circumstances'. However, the legislation has given treating doctors the ability to hide behind the notion of 'treatment'. If a patient complains that they are being sedated without justification, the treating doctor merely classifies the injection as 'treatment' and therefore is not bound by the Policy Directive. Thus the NSW Health system does not adequately protect the patient's rights. Power is placed in the hands of the treating doctor. Even with restrictions on sedation, the doctor has ultimate discretion in the treatment of the patient.

Criminal charges of assault can be laid for breaches of the Policy Directive and should act as deterrence to abusive doctors. The problem arises from the difficulty in separating 'sedation' from 'treatment'. The NSW health system needs to update its guiding principles of patient care and remove the ability of doctors to abuse the authority they wield over mental health patients. As well as collecting episodes of seclusion, the NSW health system should collect data on staff initiated PRN [95] medication as this could be argued as being another form of chemical restraint.

6.2 Discriminatory Nature of Forced Treatment

'The delivery of a non-discriminative, autonomy-based legal framework for all treatment has been the goal of many reformers'. [96]

It has increasingly been recognised that 'wherever possible the principles governing mental health care should be the same as those governing physical health'. [97] It has been argued that mental health legislation discriminates against a category of people because of their mental disorder.

Reviews have demonstrated that legislation governing involuntary patients demonstrates a lower degree of respect and patient autonomy than is afforded to other patients. [98] The *Mental Health Act 1986* (VIC) and the *Mental Health Act 2007* (NSW) remove a patient's ability to refuse treatment in allowing the treating psychiatrist to override lack of consent by the patient. [99] Although there is a right to a second opinion, the ultimate decision lies with the treating psychiatrist.

The differential treatment of involuntary patients should require further justification than merely their 'involuntary status'. It has been found that the increased risk arising from mental disorders is low in comparison to other factors such as age, gender, socio-economic status, drug or alcohol usage, or family breakdown. [100] Thus it is difficult to argue, as a general proposition, that the risk involved with involuntary patients justifies the restriction of civil and human rights. The right to autonomy may be impeded for a number of reasons such as 'intense pain, anxiety, temporary lapses in consciousness, or other forms of vulnerability'. [101]

Undeniably there may be more patients with a mental disorder who are impeded in their decision-making by the underlying disorder than those suffering a physical illness. However, this does not provide justification for a legal system that denies treatment decisions to those suffering a mental illness. [102] Furthermore, the assumed inability to make a 'correct' decision for mental health patients about treatment is not in line with other social standards. The potential of a patient to self-harm does not justify an institution's interference with the individual's right of autonomy. [103] Courts in the United States have recognised that individual autonomy in treatment decisions extends 'equally to mentally ill persons who are not to be treated as persons of a lesser status or dignity because of their illness'. [104] It can be inferred that any legislation that removes all treatment decisions from patients, purely because of their involuntary confinement status, is in fact discriminatory.

7. Opposition to Involuntary Treatment

So, what are the normative justifications for involuntary treatment that go beyond the principles of state intervention? The three justifications for involuntary treatment often provided are:

1. That the individual poses a threat to themselves and/or others; [105]
2. That the individual lacks competency in making rational decisions about their treatment plans; [106]
and
3. That there is a necessity to treat an individual's illness. [107]

In our view, the only valid justification is the first; that involuntary treatment is only ever justified in preventing immediate and tangible harm to others or the self. Thus, when a patient is a clear danger to themselves or other individuals, the use of medical practitioner discretion to apply involuntary medication to calm and treat the patient is supported.

However, with respect to the second and third justifications, there are significant principled and practical problems. The theoretical rationalisation is that the individual, by virtue of having a mental disorder, is unable to consent to treatment that would ultimately be in their best interest. Thus the government has the right to suspend their autonomy and forcibly treat them for their own good. This argument makes sense when the individual is a threat to others or themselves in a direct and clear manner. These situations provide a mandate for the state to take some form of evasive action to avoid greater harm. However, it is unsustainable in many other cases. The reality is that not all mental disorders are equal, and they do not affect individuals in the same way. Mild bipolar disorder is not equivalent to paranoid schizophrenia. Nor is it the reality that a weakened ability to make rational choices is equivalent to no capacity for choice by the patient. Hence, children in palliative care are given limited control over pain medication and treatment plans despite the state's view that they are not competent to vote or make independent Do-Not-Resuscitate orders. The ability of mental health patients to make this choice is particularly important given the nature of the medication which, despite their proven benefits, also have serious proven side effects.

We therefore reject the idea that a mental disorder completely removes the individual's agency or capability to make valid decisions. The erroneous belief that mental illness negates the ability of patients to act rationally is a major contributing element in the debate on involuntary treatment. [108] Research has shown that mental illness does not make a person incompetent to make decisions about their treatment. The *MacArthur Treatment Competence Study* has shown that, in relation to the ability to make treatment decisions, there is little difference between those with a mental illness and those without. [109] This has led to the push for involuntarily detained persons with a mental illness to be assumed competent unless proved otherwise, and therefore to be given the right to refuse or consent to treatment. Furthermore, the use of advance directives demonstrates the absurdity of the current policy; if medication can be used to stabilise a patient and to make them more capable of interaction, why can they not then issue an advance directive in their supposedly more stable state, when they are better equipped mentally at assessing the relative value of their treatment plan?

The absurdity of patients being denied the ability to choose their own medication is demonstrated by the use of the anti-psychotic medication Clozapine. Clozapine is very effective anti-schizophrenia medication, but also results in a wide variety of side effects ranging from weight gain, drooling, constipation, muscle stiffness, sedation, tremors, hyperglycaemia and many others. [110] It also highly reduces the amount of white blood cells in the human body, resulting in greater vulnerability to infections, with potentially fatal effects.

Consequently, Australian facilities are required to monitor the side effects on patients taking Clozapine on a regular basis. [111] They even require patients to sign a consent form waiving the liability of the hospital for any physical or mental detrimental consequences arising from the treatment.

This then begs the question of how patients, apparently not rational enough to choose their own treatment plan, are considered competent enough to sign a legal document waiving their rights. Three forensic patients spoken to, who must remain unnamed as per section 162 of the Mental Health Act, [112] noted that, due to the other medications they were forcibly treated with, they had no idea what they were signing or its significance. Those who were reluctant to sign and be treated with Clozapine were threatened with indefinite detention in the forensic hospital.

Furthermore the notion of incompetence is also associated with the idea of a 'need for treatment', implying a duty or an obligation to meet those needs. [113] Some jurisdictions justify compulsory treatment on the notion of treating that, which is 'dangerous'. It could be argued that 'dangerous' could be seen as a weaker requirement, merely permitting the state to interfere as opposed to an obligation to interfere. Although both standards are used in different jurisdictions, changes in such wording have not been shown to affect commitment rates. [114]. Appelbaum concludes that lawyers and judges bend the wording so as to conform to 'fixed' or shared moral assumptions. [115] Therefore, regardless of the justification for compulsory treatment in either a 'dangerous' or a 'need to treat' approach, there is a lack of security and minimal safeguards of the rights of the patient. When determining whether patients have the capacity to decide on their own treatment plan, those involved must examine the specific context of each situation. Appelbaum found that, out of the mere 10% of inpatients who refused treatment, most did so for a short amount of time and their reasons for refusal were often dislike or distrust of their medication's side effects. [116]

We also note that the therapeutic benefits of involuntary medication are questionable. According to Dr Penny Weller, involuntary treatments can 'mask, rather than relieve the symptoms of mental illness'. [117] She argues that such treatments often have sedative effects, which are used as chemical restraints.

At other times, they have disabling side effects that mimic symptoms of mental illnesses, which lead to interpretations by medical officers that patients' behaviours reflect escalations of mental illness. These findings are complemented by other studies done in this field. In the Cochrane review entitled 'Compulsory Community and Involuntary Outpatient Treatment for People with Severe Mental Disorders,' it was revealed that there is little evidence that community treatment orders are effective for competent health care. That study concluded that, statistically, it takes eighty-five community treatment orders to prevent one re-admission, 27 to prevent one case of homelessness and 238 to prevent one arrest. [118] This evidence is just another indication of why involuntary treatment is normatively inappropriate for mental health patients. It also indicates a clear waste of public expenditure in mental health treatment. Instead, such funding could be used to promote effective mental health care in accordance with fundamental human freedoms, such as treatment with free and informed consent.

Ultimately the trade off of benefits against side effects is a decision that must be left to the individual. They alone are qualified to assess the comparative benefits and detriments of the medication as it affects them. The problem with the status quo is that it goes too far in assuming that a mental disorder gives the state a blank cheque to disregard the choices of patients. With the exception of those who are a clear threat to themselves and those around them, there is no part of social contract theory which suggests that a surrender of one's own agency and autonomy is justified by notions of either empowering individuals or utilitarian notions of the greater good.

The National Mental Health Consumer and Carer Forum has taken a similar stance in calling for an end to seclusion and restraint (for further reference please see Appendix B or <http://tinyurl.com/audbspa>).

8. Alternatives to Forced Treatment and their Therapeutic Benefits

There has been a push for involuntarily detained persons with a mental illness to be assumed competent unless proved otherwise. They should be given the right to refuse or consent to treatment. Just as the legal system assumes innocent unless proven guilty, so too should the burden of proof favour the presumption that involuntary patients are competent unless proven otherwise. Patients are the suitable party to make evaluations on both the effectiveness and side effects of the medications, and independent groups such as the Consumer Organising Committee of the Mental Health Services Conference 2000 (COCMHS) have made attempts to facilitate communication between mental health patients in formulating viable solutions away from forced medication.[119] In order to review a patient's capacity in the specific context in which it occurs, a medical practitioner independent of the treating team should be required to assess the patient and provide an opinion of patients capability of being involved in decisions that affect them.

Giving patients the ability to refuse treatment is seen by some as therapeutic as it recognises the right of the patient to privacy, competency and autonomy. Giving patients the right to refuse treatment has also been seen to encourage practitioners to communicate more effectively with patients and to be more patient oriented. In turn, this may encourage a patient's compliance. [120] Ignoring a patient's right to refuse treatment can lead to disempowerment. Allan argues that 'there is evidence that practitioners take more care when the medication they recommend is appropriate, [when they] monitor its effects well, and [when they] listen to the concerns of the patient'. [121]

Ignoring a patient's right to refuse treatment can entrench a sense of resentment with authority that impedes future rehabilitation and recovery. Greater transparency in the treatment process contributes to the overall recovery of the patient. As psychiatric medication is often accompanied by severe side

effects and can be highly invasive, allowing patients to make treatment decisions utilises a patient's ability to understand themselves and their body's reactions. [122]

Consensual treatment is the ideal form of therapeutic care. Allowing patients to make decisions enhances the psychiatrist-patient relationship and patients gain greater trust and confidence in the treating psychiatrist. It increases motivation for rehabilitation as patients are said to respond better to treatment if they are explicitly involved and internally motivated to comply with treatment as opposed to being coerced.[123] When determining whether patients have the capacity to decide on their own treatment plan, each patient must have his or her specific context and situation analysed by those involved.

To address the infringements upon human rights associated with involuntary treatment plans, mental healthcare authorities should provide voluntary alternatives that act as either:

- 1 a) an intervention program before involuntary treatment, and/or
- 2 b) allows patients access to their rights, including medication, beds, meals etc.

8.1 Alternative Proposals from Patients

Patients who have been subjected to forced medications have suggested some alternatives as a way of avoiding the impacts of forced medication on mental health patients. These include:

1. Refuge where patients are serviced and kept privately and safe in a non-judgmental environment;
2. Access to a trusted organisation or person whom they nominate in advance so that when they suffer a period of mental illness they have agreed support;
3. A nominated primary carer, with the legal power to intervene when necessary;
4. An Advance Directive, which is a document that sets out what patients want to happen if they are deemed incapable of making decisions in the future. It can include what treatment is to be given and whether particular drugs should be given. Advance Directives are not yet recognised by legislation.

This means that the Advance Directives of involuntary patients may be overridden in favour of the Mental Health Act. A Court would therefore be unlikely to overturn any decisions made by the hospital for the patient's treatment and care.

Further the COCMHC 2000 noted the lack of available information on prescribed medications and their side effects as a barrier to patients making informed decisions about their health. Through discussion groups among consumers, the committees proposed the following solutions: [124]

- I. Consumer advocates at point of prescription;
- II. 2. More focus on therapies which involve discussing issues and information about alternative therapies with patients;
- III. 3. Information and explanation provided to patients about side-effects which may occur every time a prescription is administered. Consumers/patients can
- IV. be advised to ask certain key questions of their clinicians;
- V. 4. Doctors to be made more aware of drug reactions and interactions – a checkbox scale tool can be used to gauge patients' quality of life following medication; and
- VI. 5. Consumers can unite and raise awareness of medical prescription issues through online communication. [125]

It is essential to look at these alternatives from the perspectives of patients themselves; their suggestions are vital to ending forced treatment.

As highlighted by the *Not For Service* report, [126] there is expressed concern that clinicians are placing too much emphasis on medication as a means of mental health treatment while patients feel that they are not offered alternatives to medication. This gap is caused by the lack of patient and carer participation in the planning, implementation and evaluation of mental health services. What is required is greater attention to the patients voice as an essential means of resolving issues in our current system.

The options mentioned above would create an environment in which patients' rights are prioritised.

These alternatives would provide a chance for people with a mental illness to choose their treatment and provide a step between being uncared for and involuntary medication.

Ultimately, giving patients the right to choose is beneficial for their state of mind and allows them to assume control over their lives.

9. New Directions

The evidence documented in this report has been obvious to insiders for some time, but there has been no focus or levers to force changes in the culture and practices. The status of those controlling the industry has been above challenge despite the facts. The significant literature of Bracken *et al* [127] and Rosen, Rosen and McGorry [128] acknowledges that social inclusion should be the primary response to social disturbance, while the practices continue.

Recently, as a response to the upcoming publication of the DSM 5 (Diagnostic and Statistical Manual of Mental Disorders), the British Psychological Society's Division of Clinical Psychology (DCP) issued a statement expressing its concern for psychiatrists' over-reliance on the biomedical model of mental distress, and calling for a 'paradigm shift' in how mental health is understood. [129] Allen Frances, a psychiatrist and former chair of the DSM-IV Committee has further emphasised that this model is unsafe and scientifically flawed [130]. He asserts that the weak methodology of DSM-V trivialises mental health orders and will lead to unnecessary diagnoses and over-medication. This is a bonus for the pharmaceutical industry but a huge cost to people caught in the excessive model. Essentially, according to Frances, the DSM-V model is a reckless course that will ultimately result in mislabelling potentially millions of people with unsupported mental disorders.

The significant role organisations play in advancing the status of mental health must not be ignored, despite their dependency on Health funding. The NSW Consumer Advisory Group Mental Health Inc has continued to monitor the responsibility of State governments to uphold the standard of care set out in the United Nation's *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care*. Notably, the Victorian Mental Illness Awareness Council (VMIAC) and the Mental Health Coordinating Council (MHCC) continue to advocate on behalf of mental health patients and facilitate their empowerment.

The VMIAC has contributed enlightening research in their recent report "Zero Tolerance for Sexual Assault: A safe admission for women" [131], which consists of research, including survey results from the women themselves, that highlights the need for a stronger support network for women in the mental health care system and a zero tolerance towards instances of sexual assault. Although it is based in Victoria, the VMIAC does not limit its efforts to its own state, with reports submitted to federal government bodies such as the Department of Human Services, participation in national mental health committees and forums, as well as contributions towards academic journals.

In NSW, the MHCC, the peak body representing community-managed organisations [132] proposes legislative reform and policy development through submissions, and empowerment of the mental health community by training, research and advocacy. These organisations are valuable in that they

provide a well-organised voice for those who suffer due to injustice in the mental health system. They have enough support, funding and public recognition to be able to bring to light issues surrounding mental health that would otherwise be ignored.

9.1 National Recovery Framework in Australia

Currently the dominance of the medical model and the discretionary powers within it are overwhelming. However the recovery paradigm for mental health has now been officially accepted by the Australian government. It offers an alternative to the medical model, providing the individual with the opportunity to take control over their lives.

Recovery is the ability for people with a mental illness to restore their social functioning by reducing the severity of symptoms experienced, while also “being able to create and live a meaningful contributing life in the community” (AHMAC, 2013 p. 33-34) [133]. It is a consumer-driven movement that allows the individual to define and determine the extent to which mental illness will impact upon their daily lives. This is a major shift from previous ideas on how to address mental illness at a social level as it shifts the power and authority from the mental health professionals and institutions, back to the consumers. “What started as a grassroots movement led to government policy” (AHMAC, 2013, p. 1). [134]

The recovery-oriented framework, as developed and implemented by the Australian Health Ministers Advisory Council (AHMAC) and the Coalition of Australian Governments (COAG), is a new way of viewing the issue in Australia, allowing the people who live with the illness to define and determine how the illness will be treated and managed. The AHMAC launched a national recovery-oriented framework as a part of fulfilling Priority 1 of the Fourth National Mental Health Plan 2009-14: Social Inclusion and Recovery. [135] This framework displays an effort to “adopt a recovery culture” [136] in how services are provided. In adopting this culture, the AHMAC hopes to provide support to people with a mental illness to live and participate in the community and break down the barriers which lead to this group of people being socially excluded.

Such reforms have been growing internationally over recent decades. For example, the closure of Trieste’s psychiatric hospital and the “development of an integrated network of community services designed to meet health *and* social needs of the severely mentally ill (p. 7)” was the landmark shift towards a recovery-oriented approach to mental health in Italy and similar approaches were adopted throughout the country. Scotland and New Zealand have also made similar progress in the 1990’s in response to service-user movements (Smith-Merry, Sturdy & Freeman, 2010) [137]. This resulted in calling for a form of recovery that would “empower consumers, assure their rights, get the best

outcomes, and increase their control over their mental health and wellbeing” (Mental Health Commission in Smith-Merry et al, p. 7) [138].

With the re-oriented view of the individual possessing the knowledge and strength required for recovery, mental health service providers will be required to deliver their services in a way that reduces the risk of people falling through the gaps by adapting services to the needs of consumers rather than limiting the consumer’s wellbeing as a result of accessing services that are either inappropriate or only partially meet the consumer’s needs. This is will be ensured by providing “evidence-informed treatment, therapy, rehabilitation and psychosocial support [and] work[ing] in partnership with consumer organisations and a broad cross-section of services.” [139]

A recovery-oriented framework will force service providers to reconsider the weight that is placed on medication to ensure ‘recovery’ of people with mental illness. The AHMAC’s main comment on the place of medication in the framework is that it needs to be viewed as “one potential recovery support among many”. [140] With this in mind, the possibility for alternate therapies to be incorporated into the treatments for involuntary patients is on the horizon. The possibilities of this framework to change the entire mental health field is staggering. It is a positive development to acknowledging the rights and experiences of people with a mental illness as well as reducing the reliance on medication and isolation by health services. By giving power back to the consumers of mental health, Australia is taking steps towards creating an effective and inclusive mental health industry.

10. Conclusion

Mental health is an area where the uniqueness of human beings should be celebrated and protected. The opposite has occurred in practice, with daily brutal attacks on the integrity of vulnerable fellow citizens, degrading ourselves and our civilisation in the process. Saeed Dezfouli and Michael Riley are just two of the many consumers subjected to this abuse, who have contacted Justice Action asking for assistance, with no where else to turn for support.

The principle of the *National Disability Insurance Scheme* with consumers choosing their support providers provides recognition of the problem and its solution. An independently funded body that is democratically responsive to consumers’ concerns needs to be established as proposed by the *OUR PICK Report*. [141] We recommend it should have the power to oversee policies and give direction to mental health services.

11. Appendix

NMHCCF Advocacy Brief

Issue: Seclusion and Restraint in Mental Health Services

Background

Seclusion is the confinement of the consumer at any time of the day or night alone in a room or area from which free exit is prevented. There are three distinct types of restraint – physical (e.g. manual, handcuffs, harnesses, straps), chemical (e.g. sedative medication) and emotional (e.g. fear of expressing views, coercion, threats).

The key factor that differentiates seclusion and restraint from other forms of care or medical treatment is intent. Seclusion and restraint are often used to restrict the movement or behaviour of a person because of a failure to provide proper mental health care. Seclusion and restraint are being used on a daily basis, despite evidence that they can contribute to negative health outcomes.

In the NMHCCF position statement 'Ending Seclusion and Restraint in Australian Mental Health Services,' Professor Ian Hickie notes, 'The frequent requirement to seclude and restrain people with an acute mental illness highlights the ongoing failure of the mental health system to provide high quality care'.

While protection from harm may be one reason for implementing measures to restrain someone, there are clinical, ethical and legal issues which practitioners must consider before restraining a patient.

- Impact of physical restraint on a patient and their family/carer
- Consumers' rights and autonomy;
- Myths and misconceptions about the use of restraints;
- Ethical aspects of restraining people;
- Legal and legislative aspects of restraint use and restraint minimisation;
- Dangers involved in the use of physical restraints resulting in adverse outcomes; and
- Considering alternatives to restraint.

Unless alternative locations for care and services are established, people requiring mental health care will be forced to attend psychiatric units which are notorious for their use of seclusion and restraint - not as a measure of last resort, but as the default means of keeping order.

Prepared by National Mental Health Consumer & Carer Forum May 2012

A combined national voice for mental health consumers and carers

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Key Points for Mental Health Consumers and Carers

The NMHCCF released its position statement 'Ending Seclusion and Restraint in Australian Mental Health Services' in September 2010.

It is available at www.nmhccf.org.au/Publications-info.

It is the position of the NMHCCF that involuntary seclusion and restraint is:

- Currently used at unacceptably high levels in mental health services;
- An avoidable and preventable practice;
- Highlighting a failure in care and treatment when they are used;
- Commonly associated with human rights abuse;
- Not an evidence-based therapeutic intervention;
- A cause of short and long term emotional damage to consumers and/or their family/carer;
- An inhibitor of developing trust and respect between consumers, carers and clinical staff;

The trauma of seclusion and restraint contributes to consumers' fear of treatments and they are much less likely to seek help again if subjected to seclusion and/or restraint. Similarly families and/or carers may feel reluctant to seek treatment for a consumer.

Attracting and maintaining a dedicated mental health workforce will be hindered if the care provided continues to be associated with patient harm rather than positive health outcomes.

In under-resourced and inappropriate mental health services, seclusion and restraint are the accepted practices. This is totally unacceptable and there are alternatives available for the safe management of dangerous behaviours.

Recommendations for Change and Key Issues for the Future

The NMHCCF has identified six key strategies to end seclusion and restraint in Australian mental health services:

- 1) Better Accountability
- 2) Implementation of Evidence Based Approaches to Ending Seclusion and Restraint
- 3) Adherence to Standards and Public Reporting
- 4) Support for Mental Health Professionals Towards Cultural and Clinical Practice Change
- 5) Better Care Planning
- 6) Review Relevant Mental Health Legislation

Name of Nominated NMHCCF contacts on this issue

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Prepared by National Mental Health Consumer & Carer Forum May 2012

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