

Submission for Senate Community Affairs References Committee regarding their inquiry and report on ***Indefinite detention of people with cognitive and psychiatric impairment in Australia.***

I am the mother of an adult son (now 30 years of age) who has experienced both the forensic side of involuntary detention and the non-forensic side of involuntary detention over the past six years (2010-2016), spanning both the old and new Mental Health Acts in WA.

My son was under the 'care', and I use this term very loosely for the services provided (prior to his involvement with forensic involuntary detention), by the Community Mental Health Services from the Bentley Clinic in WA. Whatever the mitigating factors behind the lack of services provided, the services were far short of what was needed for my son at the time. He was diagnosed with drug induced psychosis initially in about 2008-2009 and was under the Bentley MH Clinic for voluntary community treatment. Needless to say his condition both medically and mentally deteriorated over a two year period and was directly contributing to his, 1st offence and, Forensic Involuntary Detention in December 2010 at the Frankland Centre of Graylands Hospital in Claremont WA.

I believe that the interface between Community services, forensic, and Involuntary detention is non-existent to limited at best. There is no ongoing involvement of Community based services (peer support) or support for individuals with psychiatric impairment while in detention and no smooth transition from detention back to the community (discharge planning). The individual systems are closed and have few pathways for meaningful helpful interaction for the best outcome for the individual. Once the person has forensic status there are few places available for them to re-enter the community. Release back to family is not considered as an option due to the forensic background, so unless there is an available place in a live-in rehabilitation facility (of which there are few) there is no other alternative for release available which is a discriminatory practice. Recovery was not the focus of the medical system in detention, rather sedation and medication compliance was the norm. Some activities were available for the patients, but none were compulsory, so a lot of time within the daily routines was given for each to dwell on their own particular demons. There were certainly no diversion programmes in place in 2010, which would have been of benefit to our son, we believe.

The detention (forensic) of a mentally unwell person with a group of equally mentally unwell people is not a therapeutic environment that promotes good health practices or individual recovery.

My son's forensic detention was under the old Act in WA and family inclusion was not a requirement under the Act. This meant that we were excluded from any decision making process, or even part of the discussion for his care. Individuals within the system who are recovery focussed and inclusive by nature have always been helpful and took the time to explain and assist our son and us as parents to navigate the system and it's challenges for our son. However, this was done on an individual basis as there were no processes in place for them to utilise as part of the system, to assist my son or ourselves. The social worker for the Frankland centre (Janet Hicks) deserves special recognition as she gave us contacts to

support groups (*Mental Health Matters 2*) for ourselves, and liaised with the lawyer representing our son, as we were not permitted to directly speak to him, and was supportive of our son and ourselves during the entire process. Janet is the one who applied for the Disability Pension for him, which has been a great help to him, as employment post detention has not been possible with his state of mental ill health and low general health due to the debilitating effects of high doses of medication. Our son was in Forensic Involuntary Detention for approximately three (3) years. This is an extraordinarily long time at a crucial period of a young man's life! The effect of being in a locked ward with other acutely unwell co-inhabitants made him withdrawn and emotionally shut down, with his Voices dominating his life. The outcome (legally) was the best that we could have hoped for given the restrictions that the Judge had to work with. He was released without a criminal charge, however, with a life sentence of the label of paranoid schizophrenia.

It took several years post detention and living back at home, within a normalised living environment, to bring him back to being a semi-social person who was happy to go out with family or trusted friends. The effects of the medications prescribed whilst in detention, had a considerable toll on his general health and did not provide relief from the Voices that were at the centre of his psychiatric impairment. After two more years of struggling with the significant adverse effects of the medications and once again under the "care" of Bentley Community Mental Health Services, my son requested a review of his medications. This review was supposedly conducted, but neither my son or either of us were present at this review and no review paperwork was made available. He was simply told by the treating psychiatrist, that the number of medications (7) and levels of medication (725mg Clozapine/day) were what was required to "keep you well" despite the obvious crippling impact on his life. Aside from the condescending attitude of the psychiatrist toward an intelligent adult, who is quite capable of having an informed discussion about treatment options, no discussion of what was in my son's best health interests was even remotely considered.

Out of pure frustration with having tried to work within the MH system that will not listen to the individual's needs and is excessively risk averse, despite state and national policies citing the importance of the Recovery approach, and life restricting issues of sleeping 18-20 hours/day, weight gain of some 15kgs, pre diabetes medication, and anti psychotic medications that are known to shorten his life expectancy to mid 50's, was not in his best long term health interests and my son was left with no other option if he wanted to improve his quality of life, but to withdraw from his medications himself. Unfortunately, there is no mechanism or state programme in WA that aids someone who wants (based on empirical evidence) to alter their medication levels (downwards) with any medical oversight or monitoring, especially for someone with a background as a forensic client, in this risk averse (rather than recovery focussed) approach applied to any reduction in medications. Hence, the inevitable "cold turkey" approach led to withdrawal psychosis developing at the end of 2015. This leads us to my son's second Involuntary Detention at Smith Ward at Graylands Hospital in January of 2016. I would like to point out that prior to the psychosis developing over a few months we again had our outgoing, humorous, compassionate, intelligent son back in our midst, who was coping exceeding well with the Voices, and was

exercising and taking care of his health and wellbeing for the short euphoric period of no medications and no reactions to medication withdrawals.

In January 2016, my son took himself voluntarily to Graylands seeking help, NOT detention, but was held under the new MH Act involuntarily for a total period of seven (7) months (January to July 2016). He had not been violent or threatening but was most definitely confused and agitated, and the decision was made by the registrar and on call psychiatrist to hold him involuntarily. Although the new Act has purposefully written in conditions for family inclusion, the previously ingrained behaviour of clinicians of exclusion appears to still prevail. My son was quite psychotic when admitted but was obviously in sound enough mind to take himself for treatment. I feel that the guidelines around Involuntary detention are not onerous enough on the clinician to find alternative ways to treat an individual that presents in a psychotic state, rather than the first and most used course of Involuntary detention for no fixed period. Again, our son was exposed to a living space filled with acutely unwell co-inhabitants in a locked ward with very little open air space or private areas for seclusion if needed. He developed patterns of thinking that had not been observed previously and began smoking again whilst in detention, as there was virtually nothing else to do. Early in his detention he was still engaging with us when we visited and was discussing real world events and enquiries about family and friends (still relatively normalised). After a month or so of detention and pharmaceutical treatment he began to become suspicious and withdrawn and moving further and further into the Voices world and more and more suspicious of his co-inhabitants (un-therapeutic environment). To have equally unwell people sharing a locked ward situation where no one can remove themselves from any unsettling situation is not conducive to recovery and is not a therapeutic normal living environment and in fact is quite traumatising.

The effects, physically over the involuntary period whilst the treating team were varying his medications without the requisite time given to see the interactive effects of the medications caused our son to be rushed to emergency at a nearby hospital because of a reaction to the prescribed drugs, that was of a life threatening nature. He also developed Akathisia while being treated involuntarily, and the treating team were not open to any other methods of treatment other than pharmacological. Medication was the only 'treatment' made available despite our requests for alternative methods to be considered (psychological counselling, Hearing Voices approaches, art therapy, CBT) which have been known to have beneficial impact. They were unwilling to release our son from Involuntary status until they felt the medications were having an effect and he was virtually a "guinea pig" with no avenue for resistance, or cessation, if he was unhappy with the prescribed drugs and no practical recourse to influence his involuntary status. This is all solely dependent on the treating psychiatrist's recommendation. Please remember that these people are already in a fragile state and sometimes not capable of being strong within a severe, isolating and traumatising environment, that locked wards are. No individualised plan (with regard to community based services and programmes) for discharging of patients back to the Community is completed. It is left to family/carers to investigate and source help on their own if the person has such a support network, many do not.

Australia's dependence on pharmacological treatment in locked wards is not conducive to recovery in any way. Overseas models with high recovery rates (Open Dialogue Approach

in Finland/Western Lapland) are not even discussed let alone contemplated as an appropriate form of treatment in Australia. It appears that the best interests of the individual for recovery are not the priority and that locked wards and forced drug administration is the only method of treatment, even though the failure rate is extreme and the recurrence rate high. This type of treatment has a high individual and community cost, and is an inhumane way to treat one of the most vulnerable sections of our community.

The more normal the living environment for a mentally unwell person, the more beneficial that will be to their recovery, as the Open Dialogue Approach have proven, over more than a decade now. I would like to see the Senate Community Affairs References Committee seriously look at other more humane models for treatment and look to implement these in Australia in the quickest timeframe possible . We are supposed to be the "lucky country" except if your psychiatrically impaired then that's just "unlucky"! It is hard not to become somewhat cynical after repeated contact with this inflexible system.

I have compiled this submission for several reasons, firstly that this sidelined section of our community deserves far better 'treatment' (in all senses of that word) than they are currently receiving, as I have a very close connection to what is happening in this area through someone I love and want to see have a future full of un-fettered possibilities. Secondly, I feel I have a duty to utilise my education to be able to give 'voice' to the practices and attitudes that I see happening within the Mental Health service supply for the others that are unable to and for those that no longer have support from family or others to advocate for them. Our family has been supported by members of the Mental Health Matters 2 Group, who have made us feel that we are not alone in these circumstances and that our loved ones deserve the best possible care to help them to recover and resume their contribution to their and our nations growth.

This illness and the ineffectual 'treatment' forced on my son (involuntary) by the Mental Health system has affected all areas of his life, health (compromised) family (anguish/helplessness), friends (alienated), education (university halted), employment (limited/mental), relationships (none), independence (restricted), personal growth/future (hopelessness), not to mention that his Voices still dictate his actions and interactions as the pharmacological approach has NO positive effect. Then you can get a feel for the ripple effect this has for the vast number of people that mental ill health effects. If you looked with unconditioned eyes at the practice of involuntary indefinite detention and forced medical 'treatment' of a person simply because they are unwell, you would think you were living in the dark ages, not a supposed enlightened, forward looking, humane society. Surely we can and have an obligation to do better and in fact should be striving for best practice worldwide. Involuntary indefinite detention for people suffering mental disturbance is not humane or in the best interests of the person or the community, it is just institutionalised segregation and silencing of a vulnerable section of our community, who have been labelled and dismissed accordingly.

Thank you for receiving and considering my submission.

Regards