Carer and friend for Anonymous

Hello, my name is , and I'm here to talk to you about the draft report in the context of a friend with severe mental health issues I have been caring for over the past couple of months, who has given me permission to speak to you on their behalf. It's been an absolute baptism of fire, learning about the way the mental health system in Sydney works.

I will be touching on in volume 1 the role of the GP as per page 28 and 205, prospective universal care plans as described on page 26, the role of stable housing as per page 31, interactions with the justice system as per page 33 and 589, my friend's experience of treatment while being employed as per page 37, isolation, trauma and socioeconomic disadvantage at page 121, and the mental health workforce at page 367.

So I'll tell you a bit about my friend, they're in their mid 40s, was formerly a successful senior sales manager at an international organisation, had a house, a spouse, and a child. However due to the rapid decline in their mental health over the last 7 years without the correct support, or indeed much support at all, they are now unemployed on Newstart, in debt, goes in and out of homelessness, and has a pending criminal charge.

So how does someone who was so successful fall from such a great height? Surely someone who was earning over $120,000 a year would be able to access the best healthcare that money can buy in this country, right? Wrong. I was looking through their GP's medical records the other day, and I was quite unimpressed with what I saw. I noted that there does not seem to have a definitive diagnosis or diagnoses, despite having employed psychologists and psychiatrists, and being in and out of private and public mental health care a number of times over this time period. This year, this lack of mental health advice and management has resulted in a serious criminal charge for them. Let's unpack the various issues I've mentioned previously to see how each have played a role in their undoing.

GPs and their front line role in delivering mental health care to the patient

It is noted on page 28 that 'GPs are the front-line service for mental healthcare in most urban and regional parts of Australia, representing a key referral gateway into services and an important point for the ongoing monitoring of individuals' physical, and potentially mental, health'. and on page 206 that 'many GPs have received only limited training in mental health'.

In the case of my friend, their GP has carried the majority of the work in looking after them over the last 15 years, with the last 7 years also taking on the role of mental health practitioner. In our last consultation, their GP said to us, in the middle of writing referrals to private psychiatric hospitals, that he was not trained adequately to deal with their situation, and I can see that from looking at the medical records. It is in no way the GP's fault, as GP stands for general practitioner. They are indeed the first port of call. My friend has a complex history, which has

included prescription medication and alcohol abuse while going off their prescribed psychiatric medication in an attempt to self manage their symptoms, as well as incontinence possibly arising from one of the prescribed psychiatric medications that seems to exacerbate their condition. This is the direct result of them not feeling that their medication was working, but not knowing what to do about it, as simple as letting the prescribing practitioner know. This has also resulted in multiple voluntary and involuntary hospitalisations over the years, at great economic and social cost to the patient but also to the morale and confidence of the general practitioner, who is unable to make the degree of difference to my friend's life that they need to return to stable mental health.

Therefore I do think that GPs do need to focus on ensuring that patients with complex mental health conditions are seen regularly by a psychiatrist so that they can be managed as effectively as possible, and that the patient needs to understand the role of the psychiatrist and clinical psychologist in creating and maintaining stable mental health to a greater degree than a GP can provide. I feel that while educating GPs to become more aware of poor mental health symptoms and the effects are useful, but they should not be required nor expected to carry the lion's share of the mental health care the patient needs. Yes, they can prescribe psychiatric medication, but they should not be recommending psychiatric medication and managing complex psychiatric patients intensively in the place of a psychiatrist.

Universal care plans

As per page 26, the idea of a universal care plan sounds like a great solution, but does not comprehensively cover the holistic view that I have come to see as vital to the management of a mental health patient's physical and mental health. The concept of 'A single care plan developed by the individual's primary treating clinician and covering physical and mental health can help address the issues raised by comorbidity.' hits it nail on the head, because a major reason why patients stop taking their medication is because they do not like the side effects.

In the case of my friend, they have been prescribed antipsychotics that have retarded their speech, mind and movement, which negatively affected their performance at their high paying job. They have caused them significant weight gain, which has been a particular sore point as my friend used to play sport extensively and had a six pack, and now has a tyre of fat around their belly and has had to spend money on purchasing new clothes. It has made them lose confidence and has decreased their self worth. As you know, significant weight gain is also associated with other physical health conditions such as diabetes type II and pancreatitis, as well as heart attacks, placing further drain on the physical and mental energy available to the patient.

At no point in time has my friend ever been suggested to see an endocrinologist to monitor them for endocrine disorders, nor a dietician to advise them on the foods to eat and to avoid to counter the side effects of the medication, nor an exercise physiologist to encourage them to

perform appropriate types of exercise to mitigate physical poor health but also to increase good mental health.

They have never been advised they are eligible for NDIS, nor that a community organisation can support them in applying for NDIS for them and managing their plan, a crucial support for complex mental health patients who may find it hard to get out of bed, perform routine such as eating, grooming and attending appointments. In the case of my friend, NDIS would support them immensely by providing equipment and social support for self catheterisation, as my friend does not void their bladder regularly often enough as it takes up a lot of mental energy and as a result contracts UTIs regularly, relying on antibiotics when this occurs.

They have never been recommended a guardian, nor power of attorney, two important people to make life decisions for them when they cannot make decisions for themselves and to ensure their human rights are not breached while in involuntary or voluntary care.

They have never been explicitly advised nor given the support to stop smoking, nor eliminate caffeine intake, nor alcohol intake, nor abusing prescription medication. Most importantly, patients do need to be advised of the legal implications of the status of having been diagnosed with mental illness, such as the obligation to keep society safe (but nowhere is the obligation for society to keep the patient safe).

They have also never been informed that they will require regular visits to a psychiatrist or clinical psychologist for the rest of their life, as these are the key people that can be spoken to by other medical professionals when the patient is going through challenging and vulnerable times. They have also never been told to maintain top level private health insurance so that they can check into a private psychiatric hospital when they feel unwell, or that DBT is available for them to manage their emotions.

In sum, while the original proposal for a care plan is good, it needs to be more thorough in order to support GPs comprehensively.

Suitable housing and the role it plays in good mental health

It is acknowledged in the report that ‘suitable housing (housing that is secure, affordable, of reasonable quality and of enduring tenure) is a particularly important factor in preventing mental ill-health and a first step in promoting long-term recovery for people experiencing mental illness’. My friend does not have family in Australia, so there is no one to lean on upon discharge.

When my friend was discharged from involuntary care at a major public hospital, they were given minimal accommodation support. Housing NSW provided 2 nights’ worth of motel accommodation, and then was cut off as my friend has $11,000 in the bank, most of which is apportioned for legal fees for their criminal case. My friend then slept in their car in the secure parking area of my apartment block, using my apartment for resting, eating and grooming during

the day. I have housemates, who were initially fine with this arrangement, but unfortunately two police officers came to check they were at my residence when one housemate was home. After learning my friend had been charged with a criminal offence, they were no longer welcome inside my home. My friend, who had been doing quite well within my quiet four walls and had been improving in their outlook in life took many steps backwards.

We arranged for more motel accommodation, but they cried and stressed the importance of stability, as the stigma of mental illness with a pending criminal charge was debilitating for them. Two days after this, I took them to the emergency ward of another major public hospital where they were cared for for two nights and then turned loose again. In those two days, they had recovered quite significantly, but after discharge instead of letting me know they were available to collect, my friend was found on the lawn outside my apartment, saying they had nowhere to go. We mentioned this to my friend's social worker at their community centre, whose only option was a shared room in the CBD, which we rejected due to potential noise levels and lack of privacy which would have exacerbated my friend's condition. An NGO run organisation on the Northern Beaches rejected my friend on the basis that they had abused prescription medication and alcohol but instead of explicitly telling them they said they were full.

Can I stress stable, self contained, long term and quiet accommodation is extremely important in order to increase and stabilise mental health patients, as I have had significant trouble in assisting my friend appropriately, and it has been heartbreaking to see this support is not offered.

Interactions with the justice system

While I welcome the statement that 'State and Territory Governments should continue to develop and implement Disability Justice Strategies to ensure the rights of people with mental illness are protected in their interactions with the justice system', I have not seen this.

In my interactions with police, I was firmly told that their job is to get a statement from my friend. When I said they needed to show compassion to my friend as they were gravely unwell from not receiving appropriate treatment, I was informed that there were 'real victims' involved. I replied that poor mental health has consequences for everyone, particularly the person being charged. My friend is a victim of poor mental health treatment, and I see this approach as victim blaming, as with appropriate treatment and advice, I believe they would never have been in this position.

A statement is cornerstone to a criminal charge, and because my friend was an involuntary patient they were not able to seek external legal advice. I had to advise to be firm in return in not giving a statement and to reject all questions to protect their defence. After an hour, my friend was turned loose. I and my friend's other carer had been advised to go home by an officer as my friend was expected to be there for five hours, so when I came to the station my friend was nowhere to be found. When I expressed my grave concern for my friend's wellbeing, I was told by an officer that because they have been released from the mental health facility that they must

be all right. I told them that could not be further from the truth, and that they should not be left to wander on the streets as I feared for their safety.

Moreover, the report does not cover in the least the limited rights mental health patients have civilly, criminally and in family law. Mental health patients cannot sue medical practitioners for negligence, such as prescribing medications that damage their mental and physical health further, nor failing to inform them of side effects so that they may make up their mind on appropriate medication. This protection needs to be removed. There is a limit of one year to sue for emotional distress, which needs to be removed as the manifestation of trauma may not be detected for years after the events. As part of the criminal justice system, mental health patients can apply for section 32, meaning that a criminal conviction can be waived. However, the conditions for this seem to be inadequate to the medical needs of the patient such as seeing a psychiatrist, but does not specify why. My friend spent tens of thousands of dollars seeing a psychiatrist who my friend felt did nothing to improve their condition. Finally, a mental health patient has limited rights in being able to form and maintain relationships with their children as they are deemed unstable, and recourse through the Family Court when the other party limits access or removes access without consent is too onerous for the mental health patient to bear. This increases isolation, which my friend has continually expressed regret over given that they have no other family in Australia.

Mental health treatment and employment

While the report touches on good points, it does not take into account the restrictions placed on patients who have been given instructions by the courts and the Mental Health Review Tribunal. My friend has had a community treatment order while being employed full time as a senior manager. This involved one injection of Abilify Maintena once a month at a community treatment centre. The initial centre was close to their workplace, enabling them to receive treatment on their lunch break. However, this was changed to a treatment centre in the patient's accommodation area as apparently that was the rule. This change caused them to miss half a days' work, which was not suitable for someone with their level of seniority.

The role isolation and trauma play in mental illness

The report mentions that 'Discrimination can create a sense of isolation' which we have seen as per my friend's experience with my housemates above. Also, 'some people are more likely than others to be exposed to a high level of trauma, and therefore are at higher risk of mental illness.' in the case of my friend, they were exposed to intergenerational trauma over a sustained period of time as a child. However, I feel concerned that the report does not address explicitly that mental illness and addiction comes about as a result of trauma and isolation. We do need to acknowledge the cold, hard truth that abuse at home, the workplace and the wider community has devastating effects long term or indefinitely for the victim, which in turn has negative social and economic impacts on family, friends and wider society. We need a long term campaign to explain to the Australian population what trauma is, how it manifests itself and the economic and

social costs to society, and to promote ways of dealing with people that is not borne out of violence or oppression. Very often, perpetrators (including perpetrators who are victims of trauma themselves) do not realise what constitutes abuse and it is this lack of knowledge that contributes to the cycle being repeated again and again. If you want prevention of mental illness and addiction, you need to consider this approach.

My friend's experience with their last stay as an involuntary patient at a public hospital and their human rights

Finally, I would like to talk about my patient's experience as an involuntary patient at a major public hospital. The report unfortunately does not mention as part of reorienting care to the patient that respect needs to be given to the patient and treatment given without prejudice to their background. I visited my friend regularly over the 6 weeks they were in care and the following happened:

- Repeated failure to enable my friend to give informed consent over medication, tests conducted and speaking to external parties
- Their treating team regularly telling my friend not to speak to me and constantly asking if I am trustworthy
- Staff speaking to them with disrespect, telling my friend they were whining when they were asking for leave constantly. There was an apology over this, however the damage was done
- Initial refusal to provide a Carer Nomination Form and consistently refusing to speak to me despite being on the form
- The social worker consistently refusing to perform their duties expected for my friend, for example leaving them alone with the Newstart application form on two occasions
- A registrar telling the Mental Health Review Tribunal that the treating team did not want me to be part of the hearing, and that the treating team were of the view that I am over involved in my friend's affairs, that my friend does not agree with me, that I am not an appropriate person to associate with, that I am complicating their care and that I am going to be removed from the list of their nominated carers
- The day after I informed the treating team I applied for guardianship, they woke my friend in their bed around 9:30am telling them they were going to oppose the guardianship and that if I am their guardian I can do whatever I like with them
- Finally, the Mental Health Review Tribunal that was conducted shortly before my friend's release into police custody was a disgrace. It started late, there were two versions of the paperwork with differences that the Tribunal nor the registrar were aware of until I pointed them out, and then it was closed hurriedly as they were running behind. This is someone's life they are playing with.

None of this is in the least acceptable, and falls far short of professional behaviour expected of mental health staff. However there seem to be no effective remedies apparent to the behaviour my friend has experienced that will ensure that this behaviour does not occur not only to them

but to others ever again. I will say that if mental health professionals behave in the ways outlined above, they should exit the industry and find something else to do. It is challenging and exhausting to care for mental health patients, as there is no immediate reward, but we cannot entrust vulnerable people to mental health professionals who have no compassion nor respect for those they are responsible for. The legal protection that the public mental health system is given in reference to involuntary mental health patients needs to be removed for this reason.

In conclusion, the report is a good beginning into public mental health reform. However, we have a long way to go, and I am prepared to part of ongoing discussion as I have no confidence whatsoever that NSW Health's involvement in my friend's mental health management will improve their quality of life.