1st March 2022

Mental Health Select Committee

Parliament House

George Street

BRISBANE QLD 4000

Submission for the inquiry into the opportunities to improve mental health outcomes for Queenslanders.

Contact information – [redacted] and [redacted]

Background

I am a 26-year-old female with recurrent contact with the mental health system in Queensland. Since I was 14 years old, I have experienced bouts of severe feelings of hopelessness, sadness, shame and spent long periods in inpatient facilities with major depressive disorder, anxiety, borderline personality disorder, PTSD and described as chronically suicidal. I have been seeking treatment for my mental health since I was a teenager and until I finally found a combination of treatments that worked for me it was a long journey to recovery through a confusing, expensive and at times distressing mental health system. My lived experience places me in a unique position where I have experienced all stages of the mental health system ranging from primary care to crisis care.

It is important to acknowledge that there is no simple solution to improve the Queensland mental health system. My focus for the submission will be on the stages of the mental health system in Queensland and the experience of a patient in each stage. While I understand that the Queensland Government has little input into the primary stage and the missing middle stage as these are primarily Commonwealth funded all stages of the mental health care system intertwine. My submission will also focus on the idea that the main message in mental health awareness is 'just ask for help'. Although this message promotes awareness the process of 'just asking for help' in the stages of the mental health system is convoluted, confusing, expensive and in no way simply just asking for help ensures receiving it. The 'just ask for help' message fails when the system does not have the resources, integration and is financially unable to be accessed for many Australians' resulting in asking for help but not getting the help they need. I have outlined some sections I think my submission directly relates to the scope of inquiry by placing a letter next to it that correlates to the scope of inquiry letters.

Primary Care – C (a, b)

The first step in asking for help is expensive

We know that 1 in 5 Australians experience a mental health disorder in their lifetime. In Queensland this figure is consistent with the national figure however it has doubled since 2001 [1]. This means a lot of Queenslanders present at the GP looking for a mental health care plan. Generally, this is considered one of the first steps to seeking help for your mental health and the first step to 'just ask for help'. A mental health care plan is not a simple process and it often time consuming and expensive. Most GP practices require long appointments for starting a mental health care plan generally putting the patient about $65-75 out of pocket depending on individual practice fees. The start of a mental health care plan only entitles you to six sessions before you must return to the GP for a review of this plan to receive your further 4 with another GP appointment being around $40 to $60 out of pocket.

GPs as the first point of contact lacks evidenced based care

For patients unless you have a psychologist in mind the plan is generally written out to the one closest in your area or one the GP knows of that is 'good.' For different types of mental health issues there are multiple different therapies with the most common CBT. A GP writing a plan out to the closest psychologist in your area although convenient can lack evidence-based care for the mental health issue depending on the therapy needed. I spent many years in CBT therapy and eventually found ongoing remission with a DBT approach at the time though finding this approach relied on my family researching providers as our GP wasn't sure who could provide this.

Most GPs have mental health training and are aware of multiple different psychiatric medications, but they are not a psychiatrist, and we can't expect them to be. I remember telling my GP my new medication prescribed by my psychiatrist in an inpatient setting and her replying 'never heard of it' even though I had been told that this was a regularly used medication for anxiety. Although GPs are aware of most psychiatric medications, they are not a specialist in this and sometimes it can be outside their scope of practice which can have the effect of lacking evidence-based treatment for the patient.

GP's when studied against psychologists and psychiatrists have the highest rate of negative attitude (stigma) towards patients with a mental health disorder (stigmatizing attitudes towards people with mental disorders). Considering GPs have generalised training in prescribing psychiatric medication and have highest rate of negative attitudes towards patients are they our best point of first contact?

Recommendations on Primary Care

- Further training to support GPs in prescribing psychiatric medication
- Use of allied health workers like social workers to support patients to find the best resource to use with a Mental Health Care plan. For example, the GP identifies the patient had OCD so requires Acceptance and commitment therapy but doesn't know any therapists with this training in the area. The allied health worker works with the patient to find a psychologist that meets this training and meets their personal circumstance.

[1] Queensland Health. (2020). The health of Queenslanders, Report of the Chief Health Officer Queensland, available online: https://www.health.qld.gov.au/__data/assets/pdf_file/0019/1011286/cho-report-2020-full.pdf.

The missing middle – C (a,b)

The missing middle although gaining significant traction in the media, politically and throughout mental health spaces is not a new phenomenon and I have spent most of my life wading through the missing middle to try and support my mental health disorders. There's no real definition of the missing middle and it is a spectrum from being too sick for primary care and 10 sessions with a psychologist but not being sick enough to require inpatient care. Its important to acknowledge that the missing middle doesn't just go away after experiencing crisis care or inpatient care discharged patients comprise the end of the spectrum wavering tentatively on being not suicidal enough.

'Just ask for help' relies on the patient searching for hours to be told its two months away

When I identified that I needed help again I had been out of contact with my mental health professionals for a while as I was considered recovered and didn't need regular sessions to support my mental health. The health professionals I saw lived in Brisbane and I moved to the Sunshine Coast so when I identified I needed help again I tried to find someone close to my new home. I had several situational stressors at the time I'd started a new degree, moved cities, and developed chronic pain and I was struggling to adjust to my health conditions. I rang my local headspace explained the stressors and they told me the earliest appointment was three months away I rang five other psychologist practices, and the wait was around two months. I felt like I was asking for help, and no one was helping me, and it was up to me and relied on me researching multiple psychologist practices to find one with the earliest appointment. I finally received an appointment from a cancellation but it meant I had to cancel a shift to make it work.

How long is two months? A (b)

I remember being terrified to wait two months because I knew how quickly based on my earlier mental health experiences things could go downhill. Two months may not seem like a long time but it's an excruciating long time when you are experiencing mental health challenges. When I was 19, I realised I was at the start of a bout of depression, so I got more intensive support. Within two months of getting more intensive help my mental health went downhill fast I was in deep depression, I had multiple panic attacks a week and I'd engaged in self harm a behaviour I'd successfully stopped since the age of 15. When I was 14, I began seeing a psychologist after I thought I was a little depressed within two months I had severe suicidal ideation, my mum slept on my bedroom floor to support me during the periods of night I woke up crying and was engaging in self harm regularly. It's important to highlight my experiences of the long two months are all whilst I was seeking help so imagine how long it feels for someone not getting any help.

At present 61% of Queensland psychologists reported a waiting list more than three months or are not taking new clients.[2] Although some say this wait time is due to the mental health effects of the COVID19 pandemic the long wait of the missing middle has been around for years. As the missing middle is a spectrum the patients on the 'not suicidal enough end' have often just had contact with inpatient treatment often due to suicide attempts and sometimes on ITOs. I've met countless patients in my contact with the mental health system that fit into this category, one story stands out. On an admission to the RBWH a fellow patient was being discharged with an appointment made for headspace two months away as she had never had contact with a mental health professional before so that was the earliest and she couldn't afford another service. She was recommended the public DBT program however that had a three month wait. Research suggests that after a suicide attempt,

[2] Australian Psychological Society. (2022). Submission for Inquiry into the opportunities to improve mental health outcomes for Queenslanders, 063.

patients are at their highest risk for suicide and we support them by discharging them into the missing middle into the long three month wait. Two months doesn't seem like a long time but when you are experiencing depression two months can be the difference between life and death for some.

The missing middle is an expensive place -A

Help is expensive and inaccessible for a lot of Australians due to affordability, Australians with depression, anxiety, and other mental health conditions in one study were found to pay 95% more out of pocket costs compared to a person with no long-term health conditions [3]. That 95% more just to manage my mental health condition in practice is around $10,000 to $15,000 a year and that's just the estimated cost of my psychologist appointments. I'm one of the lucky ones to have the financial backing of my parents when I was mentally ill, and that estimated cost was a cost my mum estimated for when I was relatively well, only needing weekly or fortnightly psychology sessions which excludes medication and the private health insurance premium they paid. During periods of my life where I was in crisis you could estimate my parents paid around $20,000 to $25,000 in out-of-pocket costs for sometimes two weekly therapy, group therapy, private health insurance premiums, medication, fortnightly psychiatry and at time private hospitals fees.

Money is arguably one of the main predictive factors to recovery, it's not how hard you work in therapy, it's not whether you respond to treatment its whether you can afford long term help. When the average gap fee for psychology or psychiatry is approximately $170[4] even with 10 Medicare rebated sessions that's $1170 a year, its money that's the difference between recovering and not. When your part of the missing middle you need more than 10 sessions you need psychological therapy that is consistent, ongoing, and often intensive. Each session after your 10 Medicare rebated sessions costs out of pocket $267[5], if the psychologist is following the national schedule of recommended fees. So being part of the missing middle and paying $267 is the about the same as buying two weeks' worth of groceries for an average Australian couple[6]. The pure expense of out-of-pocket costs demonstrates why some Australians with mental health conditions are likely to skip care because of the cost [7].

The problems in the missing middle is why people don't recover

Often people comment on my ability to recovery that 'it was all the hard work I did', I respond to the rare few that I know can handle my honesty and say, 'it had nothing to do with hard work I had money and a mum that had the time to research therapists in my area that specialised in a different therapy'. That's what recovery relies on, the missing middle relies on patients to be responsible to find an affordable, short wait time and treatment appropriate health professional. It relies on

[3] Callander EJ, Corscadden L, Levesque J-F, Callander EJ, Corscadden L, Levesque J-F. Out-ofpocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost? Aust J Prim Health. 2017 Mar 15;23(1):15–22.

[4] Australian Psychological Society. (2022). Submission for Inquiry into the opportunities to improve mental health outcomes for Queenslanders, 063.

[5] Australian Psychological Society. (2022). How much does seeing a psychologist cost? https://psychology.org.au/psychology/about-psychology/what-it-costs

[6] The New Daily. (2020). This is how much the average Australian spends on groceries every week. https://thenewdaily.com.au/finance/your-budget/2020/12/08/sacrifice-dinner-food-budget/

[7] Callander EJ, Corscadden L, Levesque J-F, Callander EJ, Corscadden L, Levesque J-F. Out-ofpocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost? Aust J Prim Health. 2017 Mar 15;23(1):15–22.

patients in their most difficult period of life, who are hopeless, worthless, and helpless to their own feelings to seek help in a system that makes them feel the exact same things due to cost, wait time and the search to just find a professional that can help in the first place.

Recommendations for the missing middle

- It is crucial for the state to support interventions in the missing middle as this takes pressure off the crisis stage of care and supports patients who have just come out of the crisis stage of care from returning to it. The state supporting interventions in the missing middle supports patients to have a long-term recovery. The state needs to fund interventions in the missing middle that make psychological support affordable. - F
- Wait times need to be decreased in both private and public psychology. One way to alleviate for patients to receive support in long wait times is through upskilling and training more peer support workers and funding peer support services.

Crisis Care

"We Just need more beds" – A (b)

When the patients on the end of the missing middle spectrum final tip over into needing crisis care there is no alternative to the emergency department. Often patients are turned away from the ED for being 'not suicidal enough' this happened to me on multiple occasions. Although I was at risk and had come to the ED for feeling suicidal, I was deemed to be not 'at risk enough'. I was discharged into my own home the place I had just come from, for not feeling safe for feeling suicidal. When your discharged into the place you just came from for feeling at risk it makes you feel like the saying 'just ask for help' is redundant because you ask for help and don't receive it.

When you're feeling at risk or you're feeling like you really need help right that minute there's only two options the ED or back to the missing middle. There is no other option then the ED on the weekend or outside of business hours which means we have a system where the focus is availability of beds and not supporting the patient. Often patient perceptions in the need for going to ED are at odds with emergency department staff. With the pressure for availability of beds and the mismatch in perceptions for needing the ED this results in staff responses of 'they are not at risk enough or could maybe wait till Monday' but considering they are not the patient they can often turn people away that are at immediate risk. This is evident in the statistic that 25% of people that present to the ED die by suicide within 7 days of presentation. [8]

So, is it just a problem of needing more beds? Lack of beds leads to a reactive system that is crisis driven and not based on patient need but immediacy of risk and whether you have a bed for them. The lack of beds also leads to early discharge and discharging people that have not improved with 43.5% of children aged 0-17 discharged from a psychiatric ward not significantly improving[9], this is our most at risk population for suicide and we discharge them early due to lack of beds. Although the lack of beds leads to a system based on crisis funding more beds is only part of the complex solution. We need to provide alternatives to the ED that patient can attend on weekends, outside

[8] Queensland Mental Health Commission. (2022). Submission to the inquiry into the opportunities to improve mental health outcomes for Queenslanders.
[9] Roses in the Ocean (2022). A submission for the Mental health Select Committee inquiry into the opportunities to improve mental health outcomes for Queenslanders.

business hours and when they are feeling they just can't cope anymore. One alternative is 'safe spaces' that employ peer support workers as one study demonstrated that in the first three months of an Australian mental health peer support service 300 beds were saved, equating to saving around $19,850. [10]

Recommendations for alternatives to ED

- Provide alternatives to the ED that are open on weekends, outside of business hours and for patients that are needing crisis support but can be seen in a non-ED setting.
- These alternatives need to have an aspect of peer support. Peer support is a nonjudgmental, healing way to talk through crisis rather than being assessed by a doctor whose perceptions of crisis may be vastly different to the patients. Peer support is unique because peer support workers have often been through crisis so they can empathise.

Treatment in ED

I was aware my disorder of borderline personality disorder had some stigma associated with it as being attention seeking and manipulative however I did not expect to receive this stigma from health professionals often in the ED. I experienced a lot of stigma on presentations to ED the things that were said to me over time were 'that's not that bad so you must be fine (in relation to self-harm)', 'you're not like one of the ones that's going to like run off or hit me', 'it's not that you seek attention all the time but people like you always do' and 'you will always be like this people with BPD will always be hospital frequent flyers'. These are just some statements there is plenty more, by far the worst statement was you will always be like this it provided me with little hope and drive to recovery as this was said by a doctor.

My experiences of stigma from mental health professionals are not unique or unusual. In SANEs stigma report 80% of participants agreed they had been discriminated against when trying to get help for their mental health.[11] In the same report 81.5% of patients reported they had stopped themselves from seeking emergency mental health care for fear of stigma of mental illness. The fact patients are so fearful of being stigmatised for their mental illness that it stops them for seeking emergency mental health care demonstrates yet another reason we need alternatives to the ED. Please stop telling us to 'just ask for help' when the people we ask for help from stigmatise us, judge us and do not take our concerns about our safety seriously.

Recommendations for improving treatment in ED

- Further training for all health professionals that encounter mental health patients in a hospital setting, on responding to mental health crises and mental health disorders. -G
- Further training for all health professionals that encounter mental health patients on bias, unconscious bias, stigma, and discrimination of mental health patients. -G

The inside of an inpatient mental health facility - G

I once tried to explain what the inside of an inpatient mental health facility was like to a friend and she said, 'sounds like prison'. This is an effective way to describe it as its locked doors, bars on windows and the overwhelming fear you might be hurt by another patient, are what I imagine prison

[10] 8 Lawn S, Smith A, Hunter K. (2008). Mental health peer support for hospital avoidance and early discharge: An Australian example of consumer driven and operated service. Journal of Mental Health ;17(5):498-508.

[11] SANE Australia. (2022). National Stigma Report Card. https://nationalstigmareportcard.com.au/

is like. Some studies reveal that patients experience high trauma in a psychiatric ward with 31% of patients physical assaulted, 8% of are sexually assaulted and 63% of patients reported witness traumatic events.[12] The inside of a psychiatric ward is not a place of healing often it results in more trauma for patients and a reason they do not seek help in the future.

Along with the risk of trauma from other patients then there's the risk of trauma for the seclusion and restraint. I understand that at times there is a need for restraint and seclusion. I'm currently a teacher and I've worked in schools where violence is an everyday occurrence, police are called and I'm the one breaking up the violence or the violence is directed towards me. I've been bitten, kicked, hit, punched, and had large pieces of furniture thrown at me, so I can emphathise with the experience of violence in a workplace setting. In no way am I saying that my experiences of violence in the workplace makes violence in a mental health workplace okay, but I do think that there are little to no de-escalation strategies used before using restraint and seclusion. It is often used as a first resort rather than last.

When I was an inpatient at 14, I met another patient who was admitted as she has just experienced a gang rape. Late one night she wanted to call someone and was told she couldn't she became really agitated and started screaming at nurses. The nurses told her they would get security if she didn't go back to her room, she was just screaming and crying about how she desperately wanted to call someone. Security arrived and she was told if she didn't return to her room they would 'escort' her. She refused to return to her room and security grabbed her arms to start walking back to her room, she started flinging her arms around hitting them they pinned her to the ground and the nurses gave her an injection of sedatives she woke up in seclusion. This would have been the most harmful thing to recovering for a rape to be pinned to the ground by large men. In this incident there was no de-escalation tactics, my experience is the use of threats is used to deescalate situations 'if you don't calm down, we will call security'. Patients in psychiatric care need support and help to assist them to use strategies to calm themselves down not threats and if they don't 'comply' restraint and seclusion are used.

The use of threats to calm down was one of the most common de-escalation strategies I saw. Patients were often threated with 'if you don't calm down, we will call security' which meant one of two options restraint or an injection or oral taking of sedatives to be put in seclusion. In 2020/21 there were 17,359 incidents of seclusion in psychiatric hospitals across Queensland[13]. Seclusion is incredibly hindering to treatment and recovery as it does not encourage use of coping strategies to support a patient to calm down. Threats also often included threats of being moved to other wards or hospitals that were considered more violent or where other patients had 'severe issues. At 14 I remember being told if I didn't change my behaviour on the ward I would be moved to the Mater where the patients were mainly from juvy and they all had severe issues. Its important to acknowledge that not all staff used threats or security or seclusion and restraint there were plenty of staff who really tried to suggest strategies to calm down. However, the overall majority and the culture within an inpatient setting is very risk adverse where overreactions of restraints and seclusion are used, and it is used as a first resort.

[12] Frueh, B. C., Knapp, R. G., Cusack, K. J., Grubaugh, A. L., Sauvageot, J. A., Cousins, V. C., Yim, E., Robins, C. S., Monnier, J., & Hiers, T. G. (2005). Special section on seclusion and restraint: patients' reports of traumatic or harmful experiences within the psychiatric setting. Psychiatric Services, 56(9), 1123–1133.

[13] Roses in the Ocean (2022). A submission for the Mental health Select Committee inquiry into the opportunities to improve mental health outcomes for Queenslanders.

Along with restraint and seclusion patients often experience high amounts of chemical restraint or the use of psychiatric drugs to often subdue with antipsychotics even though the patient does not have a diagnose of psychosis. The use of chemical restraint is also a demonstration of the culture of risk adverse as patients were often handed pills when they were feeling the tiniest bit upset. We do not collect data on chemical restraint in an inpatient setting, so it is difficult to know how often it occurs. From my experience every patient no matter their diagnosis was prescribed a PRN of an antipsychotic drug that was very sedating, and patients could ask for this drug when feeling upset. The use of chemical restraint prevents patients learning any effective coping strategies to assist with their distress that will be effective when discharged rather the patient takes a medication to dull the distress rather than learn how to cope with it. When patients are discharged, they are no longer prescribed this PRN and need to rely on coping strategies to manage their distress. Even though they had no practice in using coping strategies during their admission as PRN is the first resort. Patients often do not have access to a psychologist to teach them effective coping mechanisms in an inpatient setting as the ward psychologist only sees certain patients.

The use of threats, seclusion, restraint, and chemical restraint are not conducive to support recovering from a mental health disorder as they do not teach coping skills to cope with distress. It is well known these practices have little therapeutic benefits and are often associated with harm of a therapeutic relationship and can increase trauma in patients who are already at their most vulnerable, the WHO supports eliminating these practices in psychiatric settings. [14]

<u>Recommendations for improving inpatient facilities</u>

- Further training of mental health inpatient staff on accurate risk assessment to not overreact, de-escalation strategies, coping strategies to support patients to calm down and when to use restraint and seclusion. -G
- Research into why the use of restraint and seclusion was used by Queensland health staff on patients to support understanding of what de-escalation strategies were used.

Queenslanders' mental health system has been messy, expensive, disjointed and crisis driven for years now, this is not a new phenomenon based on demand from COVID. The problems in the mental health system have for patients caused trauma, severe heartache, a feeling of helplessness and likely countless lives. It is crucial that the state of Queensland takes steps to improve its mental health care system by further training for GPs in mental health, investment in the missing middle as this it the only way to relieve pressure on a strained crisis system. In the stage of crisis Queensland need to provide alternatives to the ED that are peer- led so ED is not 'the new front door of mental health', further train staff in stigma, de-escalation and when to use last resort options. Mental health patients are tired of the messaging to 'just ask for help' when its expensive, has long wait times, is difficult to find and we are often turned away from. Mental health patients are tired of waiting to be sick enough to get the help they deserve.

[14] "Guidance on Community Mental Health Services: Promoting Person-Centered and Rights-Based Approaches," World Health Organization, 10 June 2021, p. 216, 7,6.