



## WITNESS STATEMENT OF ELIZABETH PORTER

I, Elizabeth Porter<sup>1</sup>, say as follows:

### My background

- 1 I have a Master of Public Health.
- 2 I have experience working as a health professional and in policy roles in various public sector departments, including working on policy relating to the National Disability Insurance Scheme (**NDIS**).
- 3 I currently work in a senior policy role in the public sector.
- 4 I have a number of mental health diagnoses including bipolar affective disorder type 1, post-traumatic stress disorder and borderline personality disorder. I have experienced significant mood instability and intermittent depression since I was 13.
- 5 In 2007 a man raped me. The matter was unable to proceed to trial due to lack of evidence, however I received financial assistance from the Victims of Crime Assistance Tribunal.
- 6 I have previously worked at Neami National (**Neami**), prior to receiving any diagnosis. I knew at the time that there was something going on with my mental health, but I did not want to engage with the clinical system so I thought I'd work in the community mental health system to see what it was like. The community mental health sector equipped me with valuable life-saving skills and supported me to manage my conditions.
- 7 Having borderline personality disorder sometimes means having a very black and white view of things, and sometimes I haven't seen the nuances to a complex system, with lots of individuals having different levels of empathy, compassion, and ways of practicing. And so in my early 20s I uniformly resisted clinical mental health services.
- 8 My experiences with the clinical mental health system have included three separate compulsory admissions to public hospitals for psychotic episodes, and interactions with the private mental health system, including private hospital admissions, psychologists, many psychiatrists, and a five year treatment relationship with my private psychiatrist - a medical doctor who uses talking therapy as her primary treatment modality.

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<sup>1</sup> The name and details of the witness referred to in this statement have been changed to protect their identity.

- 9 All of my psychotic episodes and subsequent compulsory admissions were preventable.
- 10 The first time I went into hospital I was 25. In the lead-up to my first psychotic episode, I went to a psychologist and a GP, as I hadn't slept for days. I felt high, my thoughts were racing, and I was distressed. They both said I was fine and dismissed my concerns, including when I asked the GP for help to sleep. Days later I was sectioned and had my first admission to a public hospital. During this admission I felt very unsafe and was very distressed by the behaviour of male patients.
- 11 In the lead up to my second psychotic episode, I called the CAT team 11 times and asked for help, telling them that something was not right and that I was scared. They told me to go back to sleep and consistently dismissed my concerns. After not sleeping for days, my condition deteriorated to the extent that my family had to stay with me to prevent me from harming myself, for instance from running across roads with no awareness of cars. When my parents called the CAT team they were taken more seriously than when I had called, and the CAT team eventually visited me. By that stage, I was psychotic and unaware of my surroundings. The CAT team determined that I would not willingly get into an ambulance and called the police. Four police officers attended and escorted me into the ambulance.<sup>2</sup>
- 12 Most of the time my internal experience is different to my outward behaviour and functioning. As part of my ongoing condition I experience regular feelings of intense panic, despair, rage, and suicidal thoughts. I work hard to keep my condition invisible in my day to day life.
- 13 Due to the level of functional impairment my mental health conditions cause I am an NDIS participant with a psychosocial disability.

### **My approach to my wellness**

- 14 A few years ago, when I was 26 years old, I came close to suiciding. As I considered my options I thought to myself, *'I'm 26, I haven't had much of a decent innings yet, and I also haven't exhausted all my options. I hadn't gone begging to my family for money to pay for treatment, and I hadn't tried all of the possible treatments. It wouldn't be logical to kill myself yet.'*
- 15 The public mental health service that had sectioned me had told me in a reductive and dismissive way that all I needed to do, and actually all I could do for my mental health, was take medication to treat bipolar affective disorder. For me though, this was a very incomplete picture as I was aware I had significant mental health issues related to

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<sup>2</sup> I was a 27 year old unarmed woman. I have read [Victoria Police's submission to the Commission](#) and note that I am not alone in receiving a police response to a mental health issue, and note that this is not an efficient use of resources.

trauma and attachment. Importantly, despite taking all medication as prescribed, I was still intensely suicidal. Through my own research I identified that I needed talking therapy urgently, and that this was just as important as medication to address my ongoing suicidality. If I hadn't had this awareness, and undertaken my own research to identify and access the treatment I needed, I wouldn't be alive. The public health system was completely ill-equipped to recognise that I had other co-morbid conditions.

- 16 Instead of ending my life, I made a spreadsheet. I went to the College of Psychiatrists database and searched for doctors. I populated the spreadsheet with possible doctors, using my own criteria of what I wanted in a doctor, and I called through the list, noting down which doctors I thought would be most suitable for me. That's how I found my current doctor. I was lucky to find her because she is an experienced psychiatrist who is skilled in psychodynamic psychotherapy. She had the skills to unravel my complex and atypical presentation and diagnose the other conditions that were present: PTSD and borderline personality disorder, as well as severe bipolar disorder.
- 17 The main thing that has contributed to my wellness is twice or thrice weekly psychodynamic psychotherapy sessions with my psychiatrist, which I've been doing for five years. Psychodynamic psychotherapy is an evidence-based treatment for borderline personality disorder which focuses on helping a person find patterns in their feelings, thoughts and beliefs to gain insight into their current self. It requires a strong relationship between the therapist and the patient. I was familiar with the therapy because of my Master of Public Health and my capacity to research effective population level interventions for specific diagnoses. I had tried some dialectical behavioural therapy (DBT) and it wasn't effective for me. I identified psychodynamic psychotherapy as a treatment that can improve symptoms of borderline personality disorder significantly within a five-year period. It's been effective in helping me manage my behaviours, align my behaviours more with my values, and not act in anger or in problematic ways.
- 18 The therapy is expensive. I am about \$8,000 a year out of pocket as a result of attending this therapy (I recently added up my medical costs the other day and I'm about \$12,000 a year out of pocket after Medicare and private health insurance rebates for all of my treatment). I could instead do psychodynamic psychotherapy with a psychologist to get the 10 rebated Medicare sessions and access additional sessions through my NDIS funding, but I think that would be life threatening for me at the moment because having a rapport with my practitioner, who knows me, is essential to my health. But there is no other option to pay for treatment. I have borrowed before from my family and if I hadn't been able to do that, I wouldn't be alive. I currently work enough hours to carefully balance my budget so that I can manage my health care costs independently.

Working enough to pay for the medical treatment I need and manage other expenses such as housing is hard, given my ongoing challenges.

- 19 In my view it shouldn't take a masters level qualification to navigate the mental health system and access effective treatment. I am a highly capable and intelligent person and I have found the mental health system absurdly difficult.
- 20 DBT is gaining more awareness as an effective treatment for personality disorders and I understand there are some options to access it through the public system; however treatments such as psychodynamic psychotherapy are not accessible. I think that's one factor that contributes to very high suicide rates among people diagnosed with personality disorders.
- 21 It is also important for me to state how debilitating psychiatric medication has been in terms of my physical health. The medications I take have caused obesity and damaged my thyroid. I was in a healthy weight range my whole life until my first compulsory admission, where I gained 7kg in 14 days. I received no follow up care about lifestyle factors, losing that weight or improving my physical health – this in turn was a major disincentive to continue taking the medication that was prescribed.
- 22 A reformed mental health system should integrate medical and social care related to the physical impacts of psychiatric medications as part of routine care; for example, support with diet and exercise. The only way I have been able to lose weight – after several years of attempting to – has been with the assistance of an appetite suppressant medication. This counteracts the daily impact of the psychiatric medications I take that increase my appetite. The appetite suppressant medication I am accessing is not available on the PBS and costs \$400 per month for the full dose. Medications to support physical health should be routinely available for people who are on obesogenic psychiatric medications, particularly people who are forced to take obesogenic psychiatric medications. As I gained weight during admissions I felt that the mental health system was blatantly disregarding my physical health, and as a survivor of rape feeling that I had no control over my body distressed me significantly.

### **The dignity of risk**

- 23 For me, personally, the dignity of risk is why I am alive. Simply put, people with mental health conditions should be able to make informed decisions to take risks, take responsibility for our choices, and come to terms with the effects of our actions. The dignity of risk is about both not being prevented from having agency; and being enabled to exercise agency.

- 24 Recently, I decided to try to come off my medication. I made this decision for various reasons, including the debilitating side effects my medication has had on me such as loss of creativity, increased appetite, weight gain and impact on my thyroid health. I was grappling with the possibility of being on the medication for an indefinite period of time, so I decided this was something I needed to do for myself.
- 25 My doctor and I weighed up the potential consequences including psychosis, debilitating depression and death, versus long term health deficits, major loss of meaning in life, not wanting to live and also possible death.
- 26 My doctor, who has an understanding of agency and risk, was willing to support my choice and go through this with me – to support me over a year coming off my medication. If my doctor had refused to support me in doing this, suicide was a real possibility for me.
- 27 If I had been unable to access private psychiatric care, and wanted to go off my medication, there's a real possibility that I would have had a doctor in a public clinic that said: "No way, we're going to section you, we're going to put you on a community treatment order."
- 28 I spent a year coming off the medication. Initially, it had positive aspects including a rekindling of creativity and improved physical health, however as the year progressed, I became increasingly manic and depressed. But what was important was that I had a supportive manager at work at the time, and that my doctor was there to support me; who I could call and ask for help. She never said *'No I'm refusing treatment because you wouldn't follow my instructions, rack off'*. She would say *'Okay, let's talk about your starting dose. Let's talk about your blood tests. Do you need other medications while you're still feeling really impulsive? Let's make a plan and check in every day.'* So having a doctor who respected my choice made it possible for me to live. I think that sometimes a meaningful life is not possible without agency, and without the dignity of risk.
- 29 The dignity of risk plays out beyond decisions around medication – including around decisions like sectioning a patient; physically restraining someone or confining them to a space, or requiring someone to attend a hospital or be detained in a treatment facility.
- 30 For example, my experience of being sectioned and having compulsory treatment was a feeling of being incarcerated. I felt confused because I was pretty sure I hadn't committed a crime - so why was I being locked up? Hospital was a distressing place, where male patients touched me and assaulted me; and there were clinical staff who were trying to make me do confusing things that I didn't want to do, and I didn't



understand why they wanted me to do them. I didn't get to see a lawyer, and no one explained to me why I was there or how long I would be there for.

- 31 In my first compulsory admission, when medical staff eventually explained they had diagnosed me as having a manic episode, I actually said, 'Oh, is that all?' I had thought I must have been accused of a serious crime to have been incarcerated, restrained, secluded, refused phone calls to my family, refused visitors and refused legal help.
- 32 I understand there is a tension because compulsory treatment has a place particularly in the current system. The system lacks preventative care and early intervention to such an extent that acute episodes are generally accompanied by behaviours that present dangers for staff. Violent behaviours by people receiving mental health treatment can stem from feelings of frustration and futility, which the current system engenders. I think we need to give people options other than being sectioned, particularly people who present risk to themselves as opposed to others. Understanding that yes, if you don't section this person they might die, but sectioning this person could be ineffective or cause trauma that can also result in death.
- 33 I don't believe all suicide is preventable. Obviously that is a hard concept because we know that people with mental illness can be depressed, not think rationally, see suicide as a rational idea for them, and that's why we have treatment to intervene and challenge this thinking. So there is that tension. I know that in Australia there is not a lot of appetite for people with mental health conditions dying or choosing to die.<sup>3</sup> The prevalent view is that if someone is sick, we need to fix them; that they might want to live.
- 34 I have a different view; one that is intimately coloured by my experience of chronic suicidal thoughts for half of my life. I don't think that suicide is only ever a symptom of an illness - I see suicide as a valid choice because for most of my life there was nothing available that could make my life better. I look back at my life and think that if I had killed myself when I was 26 or 27, it would have been a completely valid and understandable choice, even a rational choice. It has only been since I've been an NDIS participant that I've had the level of support needed to make my life bearable. So it's one thing to say "Oh but when people get better they'll realise that there's hope and they'll realise that life can be really good". I see that as being a privileged view that is not cognisant of entrenched inequity in our society.
- 35 A mental health system that espouses suicide prevention while not providing equitable access to high quality, evidence based mental health care is a system that is asking people to suffer indefinitely – to stay alive, and keep choosing to stay alive - without the support needed to increase quality of life to the point where it is liveable for the person.

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<sup>3</sup> [In the Netherlands, voluntary assisted dying is available for people with psychiatric conditions.](#)

Health systems also do not exist in a vacuum – they are tied to other social determinants of health such as education, employment, housing, childhood experiences, trauma, social support, physical environment and so on. Primary prevention initiatives for family violence are incredibly important for mental health, as are effective early childhood interventions.

- 36 I envisage a mental health system that is trauma-informed and integrated with other essential services such as housing. A key feature of trauma informed system is a system that is minimally coercive, which will require new resources that are used differently.

### **My experiences at Neami**

- 37 I worked at Neami over several years. While I was there, I met a peer worker, with whom I became friends. I learnt so much from how she operated in her peer work.
- 38 At the time, and prior to the introduction of the NDIS, Neami received state funding and was able to provide support work for something like \$90 to \$100 per hour. That price point enabled Neami to employ support workers at salaries above award rates and fund extensive training in their primary operating model, known as the collaborative recovery model (CRM).<sup>4</sup> Neami provided regular and extensive supervision and reflective practice for their workforce, including their peer workers. Reflective practice provided a safe space for staff to understand how their work impacted their own emotions and mental health, build their skills and consider different ways of responding to situations that they found challenging.
- 39 Not only have I worked at Neami, I have also worked with Neami workers as a consumer at different points. My Neami workers were great. However, for me with my level of functional impairment, I needed more than what Neami could offer. With the operating model Neami had at the time, the support workers were only able to visit once or twice a week. At some points with the NDIS I've chosen to engage support workers every day, which has helped me stay out of hospital and helped me de-escalate my symptoms.
- 40 Neami's service model has changed drastically because of the introduction of NDIS. I understand that it has lost a substantial proportion of its funding. Community mental

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<sup>4</sup> The CRM was [developed by the University of Wollongong](https://www.neaminational.org.au/about-us/our-approach/evidence-informed-recovery/) and is a person-centred strengths based coaching model to support people towards mental health recovery.  
<https://www.neaminational.org.au/about-us/our-approach/evidence-informed-recovery/>  
 Oades, L. G., Deane, F. P., & Crowe, T. P. (2017). Collaborative recovery model: From mental health recovery to wellbeing.

health is a function that needs to be government funded, and I don't think it is covered by the NDIS in its current form.

## NDIS

- 41 I now get an NDIS package and I have been able to have the level of support that I need to make my life bearable. However, it seems like in part because I'm capable, I can make the scheme work for me – I once worked as a policy officer on government NDIS policy and so in a sense I know how it was designed and how it works.
- 42 At first, my NDIS plan was plan-managed. This is when the NDIA provides funding to pay for a Plan Manager, who is a registered provider under the NDIS, to help keep track of funds and take care of financial reporting. However, the NDIA Price Guide is limiting when you plan manage. I could only spend about \$50 to \$52 per hour on a support worker – and in my experience many of them don't know what borderline personality disorder is. And so at that price, I'm not going to be able to get anyone who has a specialisation like social work training.
- 43 I understand the NDIS rate of \$50 per hour was designed for carers providing personal care for physical disability in general. As a participant I have engaged support workers at this price point to help with household tasks such as cooking, shopping, folding, washing etc, and some support to access the community such as going to yoga classes, reminding me to keep in touch with my friends, etc. The support workers I've engaged have been hit and miss – some are fantastic, others (mostly sent through agencies rather than me engaging the worker directly) have been less than suitable. The support workers I've engaged have no training or particular knowledge of mental health – one support worker I've engaged regularly is a makeup artist between jobs, another is a silk scarf designer and yoga teacher. I've engaged these people based on their values and interpersonal skills. I am conscious that the workers I've engaged do not have access to supervision or training.
- 44 It would be beneficial for me if there was structured training available, something like: Level 1 – mental health first aid, basic overview of common mental health conditions, suicide prevention training, Level 2 – 1 plus more in depth overview of mental health conditions, trauma, personality disorders, and training about emotional attunement to the client, and Level 3 – 1 and 2 plus in depth training about collaborative recovery, coaching, motivational interviewing. In my view the NDIS pricing is not sufficient to provide training, support and supervision that would improve the quality of care provided for NDIS participants with psychosocial disability. Although Neami's pricing was significantly higher than what is provided through the NDIS, it was the supervision and training that delivered better care.



- 45 The NDIS could be improved by adding a line item specific to psychosocial disability to fund 'recovery workers' or as they were called at Neami, 'community rehabilitation support workers', for a price of approximately \$100 per hour. This would enable organisations and individuals to offer CRM-style recovery and wellbeing coaching services that are evidence-based and effective. The NDIS could also offer tiered psychosocial worker price points to reflect levels of training. I realise this is a complex multijurisdictional space, and that it is market driven. The main thing is at the moment as a participant I need to be high functioning and proactive to utilise my NDIS plan in an effective way, and it's a lot of work to recruit and engage suitable support workers – noting that the people I've engaged are great but have no mental health specific knowledge or training. And support workers working with someone like me can sometimes really need that, because dealing with my behaviours can be hard. When I'm distressed, I can manipulate people.
- 46 If I didn't have my doctor and I was fending for myself with the NDIS with support workers, I think that could be harmful as I wouldn't have someone to help me hold those boundaries with them. So I think that the NDIS could be harmful for many people with psychosocial disabilities because there aren't the resources within its structure to get the level of skill they may need. I am essentially subsidising my NDIS plan by paying \$8,000 out of pocket to pay for a highly skilled doctor who is supporting me in my interactions with support workers.
- 47 In the last couple of weeks, I've started self-managing; that is, I am managing my own NDIS funding, which is a lot more effective for me, and I have the capacity to do it. I've budgeted at the moment for about eight hours of support work per week, and I'm spending my capacity building funds on financial advisers and career coaching. I'm still working out how to use the funding and looking for providers – for instance I want to find a specialist mental health occupational therapist with expertise in assistive technology. This would help me to reduce my mental load through automating things like reminders to take medication, and even remembering to turn off my heating.
- 48 There are some basic things that are working very well at the moment - cleaning and gardening, and things like meal delivery services and a support worker to help me cook at home, which means that I can do as much paid work as I currently do. While I'm a high functioning employed person, I feel contradictory sometimes – my support worker helps me fold washing, open my hard copy mail and get other basic tasks done. This support with basic activities frees up my capacity to undertake paid work. Combined with the support I've received to access community activities, the NDIS is drastically improving my life.

### ***The broader impact of NDIS***

- 49 In my view the NDIS has resulted in the Victorian Government stripping funding out of community mental health. I have observed that for some people with mental illnesses who don't qualify for NDIS, there is no other support available to them – particularly if they have exhausted their Medicare funded psychologist sessions. If you can't afford the gap fee for a psychiatrist, and if you can't afford private health insurance, there is nothing anymore and nowhere for you to go.
- 50 I think the NDIS has had a lot of unintended effects on the mental health community sector. In terms of prevention, de-escalating situations and avoiding the need for acute admissions, the community mental health system is vital. I know that there are people out there who are more than capable of stepping up and running services.
- 51 I can see a way forward where more NDIS participants self-manage and can use the funding flexibly to employ recovery coaches for psychosocial conditions – or the price guide could be expanded with additional psychosocial line items. It's not clear to me though if this would be best funded through community mental health or as a mainstream service.

### **Safety and quality of care**

- 52 One thing that I would prioritise, and which is most important to me, is the safety and quality of care provided in the mental health system.

### ***Safety for women***

- 53 The mental health system is not safe for female patients. There is a lot of sexual harassment and sexual assault by male patients against women in compulsory admissions. In all three of my admissions, I have had a male patient come into, or try to come into, my room.
- 54 During my second admission, I had a male patient try to come into my room and he was pulled back by staff members. It triggered nightmares and flashbacks of sexual assault. I have a history of rape, and that is largely a trigger of my psychosis and a lot of my delusions are around rape. When a male patient leers at me, makes sexually inappropriate comments, or touches me, it would feed into delusions that the man was still in my room, and that I was being assaulted. These nightmares persisted for months after my admissions. I appreciate that this might seem simple, but I do not want to be in confined quarters with a male, whether they are psychotic or not.
- 55 One of the hospitals did have a mental health unit across two storeys, and they were able to make one of the units a female only unit, and they moved me upstairs to be with

two other women. The remainder of my admission was a lot less distressing because I was physically separated from men.

- 56 My experience though was that the hospitals didn't always respond adequately. Despite having an advance directive that talked extensively about safety and the need to feel safe, and the need to not be around men, I was put into a locked ward with men because the hospital didn't have any space where they can physically separate men and women.
- 57 During a couple of my hospital admissions, I was put into seclusion to keep me away from men. I don't remember how long for but I would say between two and four hours at a time, mostly during night shifts when there were fewer staff and fewer options with what to do with me. At the time, I was psychotic and terrified about being in a ward where I didn't feel safe, so I would run around a lot, screaming and trying to wake up the male patients to give them a hard time. I would quite openly say to the staff that I was aiming to make their shift as hard as I possibly could.
- 58 Being in seclusion was incredibly distressing for me. My borderline personality disorder is pronounced when I'm psychotic, and I will often experience intense feelings of abandonment and intense suicidality. While I was in seclusion, I felt abandoned and suicidal. As a result, I have about 20 different suicide plans about how to end my life in preference to being back in a public mental health unit. I am in fear for my life if I have to go back to a public hospital.
- 59 I have been through an extensive complaints process about these experiences: with the hospital, the Mental Health Complaints Commissioner and the Victorian Minister for Mental Health. I've had several meetings with the hospital about how I didn't feel safe. The hospital essentially said *'We can't do anything about it'* because they couldn't physically separate me from men, they didn't have any capital funding, they couldn't rebuild their locked ward, and they didn't have the budget for extra staffing.
- 60 I'm aware of some jurisdictions that have female only wards, or a secured locked female ward, such as the United Kingdom. In my view this model has strengths, particularly as the incidences of assault have plummeted.<sup>5</sup>
- 61 For me, given my cluster of conditions and history of symptoms, a female only ward is the only way in which I would feel safe. When I'm not psychotic enough to be in a

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<sup>5</sup> New figures obtained by the UK Health Service Journal (*HSJ*) show there have been [at least 1,019 reports of sexual assaults](https://www.hsj.co.uk/patient-safety/revealed-hundreds-of-sexual-assaults-each-year-on-mixed-gender-wards/7026629.article) between men and women on mixed wards since April 2017 to October 2019. This compares to just 286 reports of incidents on single-sex mental health wards over the same period. <https://www.hsj.co.uk/patient-safety/revealed-hundreds-of-sexual-assaults-each-year-on-mixed-gender-wards/7026629.article>

locked ward, I can be around male patients, even if they are aggressive or violent. But when I am acutely psychotic, and acutely sick, I don't have the capacity to be around male patients, and I don't have the capacity to remove myself from a situation to make myself safe. I am self-destructive and non-rational. I often sought to deliberately provoke the male patients around me as a form of self-harm, and as a way of expressing anger about being in proximity to men. That's the whole point of being psychotic and why I am detained; I don't have capacity.

- 62 In terms of staff, generally the inpatient units had female staff. But sometimes overnight the only nurses on shift were men. During my last admission in an open ward, I had a male nurse open my door and shine a torch on me, which is what they would do during their night-time checks. The fact that it was a strange man – I hadn't met him before – scared me. I had only just gotten to sleep, and then I was awake for hours and distressed, finally falling back into more nightmares of rape.
- 63 Other hospitals have had more capacity to have female staff on and so I would often ask to be given female staff to look after me. Generally they would give me a female contact nurse during the day, but not always at night.

### **Quality of care**

- 64 My experiences with the private hospital system have been variable – I would like to see much more vigorous safety and quality standards, and standards of duty of care, for private hospitals. At the moment it seems like they are able to make a lot of money and then wash their hands of people who they don't like, or who they think are too hard, or whose needs are deemed to be too high risk for the private sector. So what we are paying private health insurance for? In my view the mental health system has inconsistent quality across its workforce. From my own observations, nurses in private hospitals appear to have a lower level of skill than nurses in public hospitals – perhaps because they're dealing with less acute presentations.
- 65 Before my third psychotic episode, I recognised that I was not well. I admitted myself to a private hospital for a week and during that week I felt like I received wholly inadequate care. I was not adequately assessed, and I asked for more medication which I didn't get. I met the doctor who admitted me twice. He assessed me over the phone or via the nurses. He didn't pick up that I was manic. No-one in the private hospital picked up that I was becoming ragingly manic, even though I was telling them that I didn't feel okay, that I didn't feel safe, that I needed more medication and was asking them '*can you please help me?*'.
- 66 I remember being discharged on a Sunday morning. I was really quite mad. I asked whether and how I could stay because I didn't feel safe. The admitting doctor, via

phone, said *'no, you've got to get out of here'*. So he discharged me into the care of my parents, when I was 28 or 29 years old, and I had to sign a form saying that I was being discharged into the care of my parents. I actually crossed out 'parents' on the form and wrote 'self', because in reality, when I'm manic, my parents can't do anything except call the police or the CAT team. And that's exactly what happened two days later.

- 67 After I was discharged that Sunday morning, I was wild – at large, wandering the community. When I'm manic I love to get up at 3am and walk like 20km around the inner city and do various things like go swimming, go to cafes, talk to people, take people experiencing homelessness out for brunch, all while increasingly under the impression that time isn't real and no longer exists. My parents had to follow me, preventing me from running into the middle of the street, which I was happy to do because I didn't think cars were real. My parents then left me alone because I threatened to smash glassware if my dad stayed with me – I did this in part to demonstrate to the doctor who discharged me exactly how effective it was to be under the care of my parents. Eventually on Monday night two friends asked me if I wanted them to drive me to hospital, and I reluctantly agreed. I was in an awful position – I knew I needed help, but I knew that the public hospital wasn't safe, and I hadn't been able to stay at the private hospital. I was admitted and sectioned for two weeks – two days after I'd been discharged from the private hospital. I again experienced sexual harassment.
- 68 This was my third psychotic episode that could have been prevented. I know that psychotic episodes can have a neuro degenerative effect which could impact my livelihood. All the resources the public hospital used for my two week admission could have been prevented.
- 69 I reflect on these three compulsory admissions with sadness. I wonder how my mental health trajectory could have been different if the GP I'd seen in the lead up to my first episode had organised an urgent psychiatric referral and I'd been supported to sleep; if the CAT team had come the first time I'd called them and helped prevent my second episode; if the private hospital had treated me adequately rather than discharging me and prevented my third episode. Despite my presentation being complex and atypical, at each turn there were many lost opportunities to intervene early, to prevent my condition from deteriorating. This could have hugely improved my quality of life, prevented many life-threatening situations, avoided the massive disruptions and loss of friendships I've experienced, and used public resources much more effectively. In total I've been sectioned in public hospitals for close to two months, and had ambulances and police repeatedly involved.
- 70 As another example, I had had a psychotic episode and been sectioned on 29 September for three years in a row. On the fourth year, I went to a private hospital in Queensland and admitted myself there. I said, *'Look, I'm really anxious. Every year at*



*this time I've had a psychotic episode. It's a heightened time of anxiety for me, and I just need to feel safe.'* I picked Queensland because it's warm and there was a pool on the hospital grounds. While I was adequately treated there, the doctor proposed to treat me with high doses of a combination of two medications. I told him I wanted to wait and talk with my doctor when I got back to Melbourne. When I got back, my doctor told me these recommendations were potentially unsafe and not evidence-based: experimental at best and irresponsible at worst. I have a Master of Public Health, and I used to be a health clinician. I pick my doctors carefully. I consider their advice in a measured way before I consider taking it. And I thought at the time – how on earth could any lay person know what is evidence based and what isn't, and what is dangerous and what is not? We are so vulnerable and we have to trust doctors. But in my experience I have seen many being less competent, and less than capable and Machiavellian in their practice with no consequences.

- 71 One friend once nearly died after she took an overdose. In the lead-up to her suicide attempt, she sought extensive medical care in private hospitals. She had had several courses of electronic convulsive therapy (ECT) and it was impacting on her memory and on her life, while not improving her depression significantly. When I talked to her, I asked her how she had ended up with ECT. I asked her how many SSRI's she had tried, and that I was sorry they hadn't worked for her, or that the side effects had been unmanageable. She told me she'd never taken an SSRI, because her doctor had told her the risk of hypomania was too high. She had never experienced mania and I also understand she had never experienced any major negative consequences from her brief hypomania. I had a discussion with her about treatment and she reflected that it was time to access other options. My friend ended up going to see a new treatment team who indicated SSRIs would absolutely be a reasonable option and on trying her first SSRI, my friend's depression immediately lifted. I wondered: why did my friend not receive information about all of her options so that she could make her own decision? How do doctors get away with this? She should have had the dignity of risk; she should have had the choice and it was inexplicable that she was offered ECT as a frontline treatment with no exploration of other options.
- 72 As another example, a friend has Dissociative Identity Disorder. She had recently had a prolonged suicidal crisis and was getting picked up by the police or the CAT team, going to hospital and getting discharged after less than 24 hours. Then the situation would repeat. She told me that they kept discharging her, telling her that she was acting out; being childish; and wanting attention. She was profoundly distressed and suicidal, in a high-risk situation with impulsive and dangerous behaviours. In my view the public mental health system didn't have the faintest idea how to respond to her. The public hospital also did not elicit the source of her distress, which was that she was going through civil court hearings related to childhood sexual assault. It was obvious to me

after talking to her for twenty minutes that her suicidality was a trauma response. It made a huge difference to my friend when I called her to check in and see how she was doing the day of one of her court hearings.

- 73 I supported my friend to look at other options and she decided to get private health insurance. She had to do a lot of work to research clinicians who might be able to help her, and to organise an admission. She was admitted into a private hospital and over three weeks she received an hour of treatment every day with a professor who specialised in dissociative identity disorder. After that, she was able to keep herself safe and stop her suicidal behaviour.
- 74 As another example, at one stage I was very depressed. I wanted to go to hospital for respite because I couldn't get out of bed, make my bed or eat. I had been seeing a doctor at a private hospital who said she'd be willing to admit me. When I called her rooms and asked for an admission, I was told she was on leave for a few months. I asked if they could put me through to her locum and the staff told me that no one was covering for this doctor and they couldn't help. I called my GP and said *'Hey I need a hospital admission here, I'm really struggling'*. My GP asked me to call all the doctors who admit to that private hospital to see if any would admit me. I thought *'Are you kidding me?'* I can't tie my shoelaces, I can't open my mail, and I can't remember to eat. It had taken all my functional capability to get to my GP. And my GP is pretty good, but she's not funded to call around to private hospitals to organise an admission.
- 75 It was my director at work who didn't want me to come into work until I'd sorted out my private admission. She supported me to take the time to go onto the hospital's website and eventually I found a phone number for an intake coordinator whose actual job it was to organise an urgent admission for me. Reflecting on that experience I feel like the doctor at the private hospital should have helped me to seek care – at the very least, her reception staff definitely should have been able to let me know that there was an intake coordinator for the hospital who could help. I also think my GP should have some sort of capacity to coordinate an admission – for when I'm at the end of my tether and need some support, and I can't organise it myself. Now I have an NDIS support coordinator who can do that, but the majority of people don't.
- 76 It's also worth noting that respite in a private hospital is a very expensive option, and the NDIS can offer essentially what I needed while highly depressed at a much lower cost. I needed someone to cook me healthy food, do the housework, be nice to me, and say comforting things while I cried. I'm able to access this with my NDIS funding on a regular basis. It means I don't get woken up at night every two hours by someone shining a torch in my eyes, and I can still hang out with my dog.

- 77 My experience of public inpatient mental health facilities has been universally bad, and consistent across two hospitals and three admissions. I have found the quality at private hospitals with mental health facilities to be variable. Some have quality programs and caring staff but others don't. Some seem to have high nurse to patient ratios, which I would like to see mandated to be lower. Often nurses are running around so much all they can do is talk to you for two minutes – in other places though, they seemed to have more time and spend 20 or 30 minutes talking and checking in.

### **Phone helplines**

- 78 I will briefly mention phone helplines, particularly their effectiveness for people with personality disorders. Many organisations currently recommend people experiencing mental distress contact Lifeline or other helplines such as Beyond Blue. There are also other services such as the suicide call-back service. In general these services are not suitable for me and I have to manage my distress in other ways. I have called helplines dozens of times and I've found the quality within services to be variable. I often find I am talking to minimally trained volunteers who have to follow scripts that aim to assess acute suicide risk. The frequent suicidal thoughts I experience are generally chronic, rather than acute, and I am not at immediate risk.
- 79 What I need is emotional validation and support to regulate my feelings of intense distress to de-escalate impulses to self-harm. In my experience, most helplines are not able to provide this – often once ascertaining that I am not at acute risk of suicide they seek to end the call as soon as possible, which intensifies my distress, and in a catch 22 can lead my thoughts of suicide to become more acute. Beyond Blue is probably the most helpful phonenumber I have found in that it is staffed by qualified clinicians and they are able to provide brief counselling, which includes validating feelings.
- 80 I (and many others) would benefit from a helpline that specialises in providing emotional validation and support for people experiencing significant distress or panic, accompanied by chronic thoughts of suicide and impulses to self-harm. I am generally alone with these thoughts and feelings in the small hours of the morning, and interrupting harmful behaviours can be very challenging. I still experience this regularly in spite of years of taking medication, undergoing twice weekly therapy, and learning techniques to tolerate distress. I've looked into whether purchasing phone support like this with my NDIS funding is possible, but I haven't found anything suitable. I think it would be best as a publicly funded service aimed to complement other treatments for personality disorders.

### **The peer workforce**

- 81 As part of my experiences with the mental health system, and due to my previous experiences as a health professional, I have had a lot of distrust of doctors, medication, and hospitals. Hospitals are places where I have been assaulted, dehumanised, physically restrained, secluded, and chemically restrained.
- 82 Peer support has been a major support in helping me to choose to be alive. Having that different power dynamic, where someone is a peer, helps me trust that they are not trying to control me; they're not acting from a duty of care; they're acting from care and compassion. Having a knowledgeable peer support worker helps me to appraise treatment options and understand what I want, and to understand how to advocate for myself.
- 83 In my view, peer support needs to feature prominently in any mental health system reform, because it's an alternative pathway to treatment, and form of intervention in and of itself. For peer work to be effective, there needs to be supervision, training and support for peer workers. For example, if peer workers are in a situation where they are working with clinicians, peer workers need active supervision to maintain a peer perspective to stop them from being assimilated into a clinical perspective.

### ***Bringing elements of the peer workforce into the clinical workforce***

- 84 To some extent, some of the qualities and values of the peer workforce can be adapted more broadly by anyone, including clinicians and other mental health workers. The types of qualities and values of the peer workforce that stand out are basic human empathy, compassion, open mindedness, a lack of judgment of those they are working with, relating to people in an informal, kind and human way. Even if someone is experiencing severe delusions or hallucinations, still just relating to them as a person, and to some extent, normalising the feelings and emotions behind the person's delusions, because very often they are fear based, and the fear is often very valid and often arises from trauma.
- 85 One of the stark differences I have experienced between peer workers and clinicians is the responses I get when I am experiencing delusions. If I say something like '*I can read the future*' or '*I can control the weather*', a response from a clinician may be '*You're delusional*'; '*We're putting you in a locked ward*'; or '*We're increasing your antipsychotic medication*'. But if I say that to a peer worker, a response is more likely to be '*Wow. What an interesting thought to have. Tell me a bit more about that. How are you feeling when you're thinking that?*'. So I think sometimes that clinicians can take a slightly different approach, adapted from the peer workforce, while still engaging in evidence-based clinical treatment.

- 86 In my experience, what peer workers do is bring their lived experience into an interaction with the consumer where that lived experience is helpful and relevant, often for the purpose of providing empathy and understanding, and interacting in a human way. It's not about telling me that I'm out of reality; that I need to be diagnosed or medicated. It's about empathising with me; asking me what it's like and how I'm feeling and thinking, and how they can help me feel safer. Peer workers help me work through some of the things I am experiencing in different ways.<sup>6</sup>
- 87 I've seen a number of effective ways of educating the non-peer workforce to develop an understanding of the experiences of people with mental illness. While I was at Neami, they had a peer workforce train their new workforce. Part of that training involved storytelling, and sharing lived experiences— for example, *'Hi, I'm your trainer today. We're going to talk about your role here, and I'm going to tell you about this time that I was sectioned, and what happened, how I felt, and how it could have been different'*.
- 88 Another way of developing that understanding is by reading people's stories – reading people's individual perspectives of lived experience and discussing them, or by undergoing activities where you get to experience what a person with lived experience has.
- 89 For example, a prominent consumer advocate, Merinda Epstein, made a board game called 'Lemon Looning', which was kind of like Monopoly. You rolled the dice and if you landed on particular squares, you suddenly found yourself in a psychotic episode. Then you rolled the dice again and various things happen – like you met police, or a clinician, or then you found yourself in hospital. There was lots of detail; for example, in hospital you need to make a phone call so that your mum can look after your dog but you don't have any coins, and the nurse tells you that you're having delusions about making phone calls and there are no dogs here, and gives you drugs and sends you back to bed. There were other situations where you wanted someone to bring your own clothes into hospital because you hated the hospital clothes, or you wanted someone to bring in apples, but you couldn't speak to your loved ones because you didn't have access to a phone.
- 90 A player of the board game, having had no experience with mental illness, gets to the point where they're like *'Hang on. That's frustrating and stupid. I should be able to make a phone call so that someone can care for my dog and the system should be able to accommodate that'*. And so by playing this game, you have this personal experience of these frustrating emotions in dealing with the system. The board game conveyed the minutiae of some of the frustrating and arbitrary experiences that you come up against in the system.

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<sup>6</sup> For an example of peer work, refer to Indigo Daya's article "Creating a new voice".  
<http://www.indigodaya.com/creating-a-voice/>.



- 91 I particularly liked the feature of the board game of rolling the dice because it showed how mental illness can be random. It can affect everyone. You can find yourself suddenly in a locked ward having delusions, so you don't know what is real and what is not real. You don't know who to trust and who not to trust. You might have paranoia. You might not be able to contact your family. You might not understand why you are being held there or what you are being diagnosed with, or what your treatments are, or you might not understand that your treatments are not radioactive poison. It was an effective way of putting people in a "patient's" shoes. The board game would be a useful training tool for clinicians.

## **Reform of the mental health system**

### ***The peer workforce***

- 92 In my view, at least 80% of the staff in peer organisations<sup>7</sup> should have some form of lived experience. Clinicians on staff without lived experience can potentially dilute the model of peer support.
- 93 Separately, I think we need to acknowledge that being publicly identified as a peer worker can act as a barrier. You're kind of stamping yourself with the label – like *"Hey I'm a mad person and I'm willing to go publicly identify myself as a mad person in my professional role."*
- 94 In one organisation, I knew that a member of a leadership team had significant lived experience, and she didn't feel safe to disclose that to the lived experience team. We need to acknowledge that this can be a barrier for some and it's something that is complex and needs to be worked through over a period of years. We need to acknowledge those barriers are there – there are fantastic clinicians who may be reluctant to work with peer services because of potential stigma and impact on their careers.

### **Resources**

- 95 In my view there is a need for resources that speak to consumers. After I was first diagnosed and first going through the mental health system, my case manager was my only interface to the mental health system and I didn't have a rapport with her. At the time, I had access to a newsletter written for Our Consumer Place<sup>8</sup>, a place run by consumers for consumers. That newsletter was critical for me to understand that there were different perspectives out there, and there were people who had gone through this

<sup>7</sup> I'm referring to peer staffed crisis respite facilities. Here is a write up of an international centre with some information on cost effectiveness: <https://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.201700451>

<sup>8</sup> <http://www.ourconsumerplace.com.au/consumer/resources>

before, and survived it, and had found different ways of managing their mental health, engaging with the world, and deciding what was important to them.

- 96 As well as their monthly letter, Our Consumer Place made a number of resources available. One of them was a little booklet distributed by Neami, which is still available online.<sup>9</sup> It was called, 'So you have a mental illness, what now?' And there were comics inside which brought a bit of humour and different perspectives – positive and creative perspectives. There are a number of other resources available on the Our Consumer Place website and they are excellent. There is also *MadQuarry Dictionary 2013 – a Consumer's Guide to the Language of Mental Health*; *The Company We Keep – a user's guide to mental health clinicians*; *Psychobabble – the little red book of psychiatric jargon*; and *The Consumer Movement in Australia a Memoir* by Merinda Epstein.
- 97 As another example, I went to a workshop run by Mary O'Hagan, a New Zealand peer recovery expert. Mary has written a book called 'Madness Made Me' and it's such an excellent resource, and Mary is an excellent speaker and trainer.<sup>10</sup>

### **Respite services**

- 98 A lot of my colleagues from Neami and friends more broadly would welcome an opportunity for genuine peer respite services. By genuine peer respite I mean places where people can go that are non-clinical, and peer run. There are successful models of this overseas.<sup>11</sup>
- 99 I feel like these kinds of models are hard for the current system to comprehend, because the system is so focussed on pathologising, medicating and getting people out the door. So it is hard to convey how different and transformational it can be to have a non-clinical space where people can physically go and take themselves away from whatever chaos is happening in their lives. A key feature also is that peer spaces are not coercive.<sup>12</sup>
- 100 I have recently set up networks to run informal peer respite. By way of example, I have a friend who has borderline personality disorder and who experiences significant chronic suicidality. She is also a talented musician and artist and somatic therapist. We decided to go on a retreat, where we went to a cattle farm in the country where there's a studio, and camped, sang, and went for walks in the bush. I paid her a stipend from my

<sup>9</sup> <http://www.ourconsumerplace.com.au/files/MentalIllnessbook.pdf>.

<sup>10</sup> Mary O'Hagan's writings are publically available on her website:

<http://www.maryohagan.com/publications.php>

<sup>11</sup> <https://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.201700451>

<sup>12</sup> Gooding, P., McSherry, B., & Roper, C. (2020). Preventing and reducing 'coercion' in mental health services: an international scoping review of English-language studies. *Acta Psychiatrica Scandinavica*.

NDIS funding. That experience is something that would not have been possible for me before NDIS, because neither of us could afford to do it.

- 101 Setting people up to be able to resource their existing community connections and organising things like this would be great. We should help people to set up their own networks, to set it up for themselves. This takes a lot of skill and experience. I have a graduate diploma in art therapy and background in healthcare, and I have worked at Neami. Since I was 13 I have known that I have had very significant emotions and significant experiences of distress and so that's something I have had to plan for and address throughout my life. There are different ways by which I have accumulated these skills. But there are many people who don't have that level of resourcing or capability.

### ***Not having a solely medical approach***

- 102 I also think we would see a reduction in violence if we had a more humanised system; a more compassionate, empathetic system. In my view, one way we can do that is not adopting a solely medical approach. I don't think we can justify authoritative medicine in particular. I don't think we know enough about the human brain, and for the overwhelming majority of mental health conditions, diagnosis is still consensus-based because no definitive biomarkers have been identified. Scientific understanding of mental health conditions is in its infancy.
- 103 Eleanor Longden is a psychologist in the United Kingdom and created an incredible TED Talk.<sup>13</sup> She has severe schizophrenia, and chooses not to take medication. She hears voices all the time – daily. In her TED Talk, she talks about how she manages that, and what it's like, and how she's even made friends with some of the voices who help her with exams, and tell her what to write and help her with her TED Talk. And then she talks about how she has loud, angry voices shouting at her, and how she manages that, rather than letting them interrupt her day and distress her.
- 104 In her talk, Eleanor talks about how she met a psychiatrist who encouraged her to think about her condition differently. She came off her anti-psychotic medication which helped her to have the cognitive capacity to be able to study and work. She talks about how lucky she was to have met this doctor.
- 105 As another example, Open Dialogue in Finland,<sup>14</sup> adopts a different approach to treating psychosis through the use of talking therapy in a group. They talk about their dynamics openly and in front of their friends and family, and the approach has had impressive recovery rates. A recent study on 19 year outcomes for Open Dialogue has found the

<sup>13</sup> [https://www.ted.com/talks/eleanor\\_longden\\_the\\_voices\\_in\\_my\\_head?language=en](https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head?language=en).

<sup>14</sup> Bergström, T., Seikkula, J., Alakare, B., Mäki, P., Kögäs-Saviaro, P., Taskila, J. J., ... & Aaltonen, J. (2018). The family-oriented open dialogue approach in the treatment of first-episode psychosis: Nineteen-year outcomes. *Psychiatry research*, 270, 168-175.



approach was associated with a decreased need for treatment, better work capability, the outcomes were more sustained over decades as compared to other treatments, and the approach showed no significant difference in its ability to prevent suicides (Bergström et al, 2018).

### ***Living a meaningful life***

- 106 I'm aware that we have high suicide rates, yet people end their lives sometimes when they're receiving structured, intensive clinical treatment. And people also end their lives in peer support spaces. I think that suicide is part of the human experience and has been throughout history. I don't think that zero suicide is a desirable goal,<sup>15</sup> and suicide prevention should focus on equity, addressing the social determinants of health, and providing access to high quality, evidence-informed treatment and support options.
- 107 From a human rights perspective, if we try to stop people from ending their lives in a way that's not empathetic; not compassionate, then it ends up being coercive. We could have a 0 per cent suicide rate if we are locked up all the time in handcuffs. That's not desirable – we don't want a society like that.
- 108 Instead, we need to have a different approach. I think we need to look at the social determinants of health, at economic participation, and at social participation. We need to understand why people want to live, and how people can build a meaningful life. We need to look at whether people have the resources to build a meaningful life, and whether they have the support to do so. For me, it's about far more than the absence of symptoms or the treatment of a medical condition. With or without symptoms, it's about living a meaningful life.

27 April 2020

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<sup>15</sup> <https://blogs.canterbury.ac.uk/discursive/zero-suicide-an-idea-whose-time-has-not-and-should-not-come/> University Academic Director John McGowan considers the 'Zero Suicide' initiative and the strengths and weaknesses of assertive suicide prevention approaches.