



WITNESS STATEMENT OF NINA EDWARDS

I, Nina Edwards,¹ say as follows:

- 1 I make this statement on the basis of my own knowledge, save where otherwise stated. Where I make statements based on information provided by others, I believe such information to be true.
- 2 This statement is about my experiences with the mental health system and my subsequent experience working in mental health. I am now 40 years old.

Nature of my illness and my experiences with the New South Wales mental health system

- 3 I started having crippling panic attacks and constant anxiety when I was 16 years old. I remember thinking I was losing my mind or going crazy. I felt ashamed and paranoid about people learning of my altered reality. Sometimes the panic attacks lasted for 24 hours without physical or mental respite. They were there more than they were not there, and they defined every moment of my life.
- 4 I was living in various share houses at the time and going to school. It was hard to go to school or shopping, or to do anything. I started binge drinking on weekends as a response to my panic attacks and generally altered reality. Some days when I would go grocery shopping and would have to retreat with a single item and leave. It felt like a terror constantly rattling and gripping my bones, my body and my mind. Like a deep excavation site or an industrial drill making the inside of my head shake and tremor with disorientation, dizziness and nausea whilst trapped on an underwater roller coaster.
- 5 The spiral of terror, voices and random jungle beat orchestra made daily life really hard. Often the spirals of utter terror felt like there was no bottom and when I hit the bottom the noises in my head and panic dropped to further dimensions of torture. The purpose of this description is to try to share my experiences of being trapped in mental illness long term.
- 6 This continued until my thirties with occasional short-term respite. Whilst still a teen, my GP recommended that I see a counsellor. I went three times, but I was too poor to keep seeing the counsellor. I was on the funded homeless allowance of \$218 a fortnight because I could not live at home.

¹ The name and details of the witness (and others) referred to in this statement have been changed to protect their identities.

- 7 I finished high school and as a full-time university student, I was still having constant panic attacks. It slowly was accompanied by depression. I was bed-bound for roughly a year and had hallucinations of nooses everywhere I looked. I had night-sweats, mind-altering terror and an inability to leave the bed without crying. My family did not know any of this as I maintained very minimal contact. My mother had died when I was six and my father moved overseas when I was 15. My best friend became my carer for about a year until they nearly broke from the pressure.
- 8 I went from share house to share house and then lived alone in isolation and things went from bad to worse. At 20 years old, I was periodically self-harming and I was actively suicidal.
- 9 I saw a number of GPs and told them I wasn't coping and couldn't face it anymore. I had unsophisticated language with regards to a clinical analysis of mental illness but the doctors should have seen the warning signs. I was prescribed a few different antidepressants after brief conversations at medical centres but there were no follow-ups and nothing else was done to pursue clinical or non-clinical treatment and diagnosis, or inquiry. I felt like the antidepressants were making me elevated in mood in a terrifying way which retrospectively I perceive as mania. This problem was not followed up.
- 10 When I was about 22, I was couch-surfing. The anxiety and depression and occasional punctuations of elevated mood – fuelled by inappropriately administered antidepressants – took me to a new perch of being where the next step would be invariably off a cliff. I had insight into the guilt my death would pose on my family so I took myself to an emergency department (**ED**) in Sydney or else I knew I would kill myself.
- 11 I was what they termed depressed and having psychotic symptoms as I was convinced everyone was trying to kill me. I was hospitalised for a week and medicated with antipsychotics and some more antidepressants. The hospital stay felt incredibly shameful for me, akin to when I first came out as gay. The self-stigma also made me feel suicidal and alienated. The medication was amazing and proved to be able to take some of the edge off the terror and spirals of depression and anxiety. I was unable to work or study properly so stayed with my then-partner's parents who looked after me.
- 12 I was still trying to complete my degree, with variable success (I failed about six years out of nine at university). I also had sporadic part-time jobs. I just pushed through. I flipped between bedridden and functional and completely unable to participate in the workforce most of the time due to the side effects of antipsychotics and illness. I worked in the sex industry for six months so I could pay rent and avoid having to accept any

money from my family. I see this as directly due to my mental illness and lack of available support from the mental health system.

- 13 While in New South Wales, I visited the ED easily 100 times within a year or two. I had pretty much no formal support, except for one mental-health clinical nurse practitioner (**MHCNP**) from the ED who would help de-escalate crises, give PRN antipsychotics and ad-hoc psychosocial support.
- 14 I called a national crisis telephone line regularly, who gave me emotional CPR, but they did not suggest further help even when actively suicidal.
- 15 My dependency on the ED went on for 10 years up to 2013-2014. When I was working full-time, the ED was fortuitously situated up the road and I would stop at the ED sometimes almost every morning, but usually at least a couple of times a fortnight. I began full-time work in approximately 2008 and the ED helped me every week. They constantly supported me for drop ins, sent often daily check-in emails and phone calls at least once a week over ten years in total. I am guessing they knew I had few resources to pay for, or negotiate a NSW or Victorian mental health system. The MHCNP also referred me for dialectical behaviour therapy (**DBT**) which was really helpful. This was the only period – four months in total – out of nearly two decades that I had sufficient support outside of ad hoc ED care.
- 16 I moved to Melbourne permanently in 2015. I had very basic private health insurance for psychology, dental, and certain other services, but used it minimally over the years because it only covers a very small portion of the out-of-pocket expense. I tried about four psychologists in total but could not afford the cost. When I moved permanently to Victoria, I was in touch with a psychologist in Sydney. I told them I was constantly and actively wanting to kill myself due to the symptoms of my illness, but they didn't really respond, suggesting cognitive behavioural therapy and later left their job. In hindsight I don't think they were giving me the urgent support I needed such as acute CAT team or urgent psychiatric assessment.

My experiences with the Victorian mental health system

- 17 While I was living in New South Wales, I went to Melbourne periodically for a couple of months at a time, roughly between 2001 and 2013. I saw a few GPs during that time as I was having really bad episodes and needed scripts. They gave me scripts, but they didn't ask any questions, provide mental health plans or refer me to a psychiatrist. I feel like it partly was ageism – I was young and perceived as undergoing common experiences of youth. I was saying "I am not coping", "I don't know what to do", "I really need help, this is too much, my head's exploding with insects crawling in it", "I feel like I

have ants in my head”, “I am not in the world”, “Please help me”. They would give me my script usually within minutes.

- 18 After I moved to Melbourne permanently and stopped communicating with the last psychologist in Sydney, I was profoundly sick. I was often terrified of leaving my apartment and hid in bed to escape from being heard or found. I did not tell anyone how I felt.
- 19 I went to a random GP and he spent an hour and a half with me engaging in diagnostics. He said that he thought I had a serious mood disorder, potentially bipolar, and recommended that I see a psychologist and a psychiatrist urgently. He spent a lot of time understanding my view of reality and the extremes of cognitive and affective torture I was feeling.
- 20 I felt like apart from the hospital stay, the MHCNP and the short term DBT clinicians, he was the first practitioner of any kind to really see and hear my reality and my increasing inability to sustain life. I believe his ability to engage in critical diagnostics and the need to engage with allied health services outside his own skill-sets and clinical discourse ultimately started my recovery. I recognise the role of psychosocial, spiritual and personal tools I had developed over the years, but my illness and its symptoms outweighed the remedy they could provide. A type 1 diabetic may recognise the importance of monitoring insulin and caloric and carbohydrate intake, however the baseline and inherent pathology cannot be addressed without underpinning diagnostics and a management plan.
- 21 I saw a highly experienced doctor of clinical psychology and a private psychiatrist and within six months my life started coming together, due to appropriate and specialised pharmacotherapy. I was informed that my mood disorder is biological and too severe to be remedied with psychosocial support alone. The psychiatrist started a regime once she got to know me and it turned everything around. The benefits of a therapeutic relationship also shaped the new treatment – something an unstable, ad hoc history of clinical and psychosocial service delivery could not offer me apart from the ED.
- 22 However, I would see the psychologist more than the psychiatrist because she was cheaper. I would have recovered faster if I could consistently afford both. My panic, anxiety and mood disorder have been managed well since I have been in Victoria getting proper treatment. Compared to my earlier 20 years, I now occupy a mind and body that is liveable. My psychiatrist is now retiring but I am sure I will find someone of their calibre. They kindly offered support to me free of charge leading up to this hearing.

- 23 I initially saw the psychiatrist weekly or fortnightly pending her retirement. I also saw the psychologist fortnightly at first, and now I see her once every one to three months, depending on my wellness and status of my mental health plan.

My work in the mental health system

- 24 I now work in mental health in the community sector for a non-government organisation that provides advocacy, education, consultation and information to people with mental health issues. My role is as a National Disability Insurance Scheme (**NDIS**) information support worker. I support people who fall in the gap between allied health, continuation of care programs and the NDIS. Business is booming.
- 25 I support people in building their literacy and efficacy around NDIS access and service engagement. I work with roughly 25 people a week. Every day I get phone calls where people say they are suicidal and in crisis. I receive these calls from people in regional, rural, and metropolitan areas. I think that the people engaging with my organisation and others like it are, absurdly, 'the lucky ones' when I reflect on my own history.
- 26 In my work, I often seen people with mental or psychosocial health issues use charity services for food and accommodation, or move back into abusive situations (such as moving in with abusive parents) to avoid homelessness and other unknown risk. A Prevention and Recovery Care centre or psychiatric unit tragically doubles as a warm place to sleep.
- 27 In my work, I have seen that there is incoherence and lack of information about the services that exist. I have found that many staff at all levels within the allied health and NDIS-focused services have little insight into what services exist, for whom, and where. In my experience, allied health services are stretched to their limits with massive waiting lists to get on to the waiting lists.

Problems with the mental health system

Treatment needs to be more affordable

- 28 I think that access to mental health treatment needs to be more affordable and free services should be expanded exponentially. I could easily fall through the cracks again if I could not afford ongoing treatment. The public system needs to have capacity to service all of us, especially those who have limited means. Out of pocket cost in the private mental health system is a major block to receiving proper and appropriate treatment. I would have recovered more quickly and would not have been incapacitated for 20 years if I had been able to access care. The cost for a psychologist is \$120 out of pocket and the psychiatrist is \$220 out of pocket. I did reach the Medicare threshold once or twice which is indicative of the cost. At times in Victoria when I haven't been

able to afford to see anyone, I have retreated to bed and relied on increases in antipsychotic medication which can periodically inhibit my skill-set at work if not directed by a psychiatrist.

Disconnect between services and lack of information

29 The Victorian mental health system is not working, partly because of the disconnect between services. It is very difficult to navigate the system; in my experience, both workers and consumers in the sector find this difficult. The mental health services operate in silos and consumers are not given the tools to navigate the system. In my opinion, the current shift of services towards the NDIS is compounding this disarray, resulting in many ad hoc short-term programs for transitions and continuity of care. These need secure funding in two-year blocks to both attract skilled workers and allow consumers to engage. The Victorian public mental health system therefore is currently a disaster. Even if you can afford to pay, it is difficult to find practitioners because the information is not readily available.

Services operating in silos

30 The mental health system is also not working because clinical (and non-clinical) services are largely operating in a siloed way. Many clinicians, especially GPs, need to recognise that referring on can be life-saving. This requires a conceptual and practice overhaul, so that interagency work and referrals to specialists can be increased. My recovery was sparked by a moment in service provision where a referral took place. Current trigger systems for referring are not working.

Stigma

31 Stigma associated with mental illness and using the mental health system has impacted my life and is present in the Victorian mental health system and society at large. Before I worked in the community sector, I worked in retail. For the vast majority of time, I concealed my illness with varying success. I was concealing it because of shame and stigma. I would not take time off work even if I was feeling on the edge of psychosis and I had no concept of a good working life. The shame compounded this. Being hospitalised nearly drove me to the edge due to shame and I hear many clients say the same.

Ineffective response to spectrum of experiences

32 The mental health system is currently not equipped to effectively respond to and support the spectrum of experiences such as acute care through to chronic management and episodic variables. Luck is needed when trying to get the right type of

support. People are often either too sick or too well for different services and are therefore exited, disengaged by services or don't find anything.

Difficulties with accessing NDIS

- 33 In my view, the NDIS access and service provision model for psychosocial participants is currently failing the philosophical and practice principles from which it was conceived. In my experience, an NDIS access request requires an almost professional level of discourse analysis – this is beyond the scope of any other service delivery access requirement and is by no means reasonable or necessary. When I have submitted access requests, I have found NDIA's responses to be inconsistent. I have also found NDIA's response to clinician's recommendations to be inconsistent. As a result, I am at a loss to understand what the rubric for NDIS entails.
- 34 In my view, a major flaw is the lack of understanding of the interaction and complexity of dual disability and the ways different types of disability can compound with psychosocial disability. In my experience, clients who attempt to access NDIS commonly refer to all other disabilities as primary, such as cognitive, physical or sensory. Psychosocial disability is often deferred to a secondary disability or not included. In my view, this potentially further displace psychosocial disability as peripheral both systemically and economically.
- 35 Finally, many of my clients who are lucky enough to access the NDIS are having widespread problems with service delivery. In my view, part of the reason for this is that the NDIA workforce has different skills to the skills used by mental health workers. The NDIA workers are not able to support people in the same way mental health workers could.

Accepted into evidence at the Royal Commission into Victoria's Mental Health System public hearing on 26 July 2019.