



## **WITNESS STATEMENT OF INDIGO DAYA**

I, Indigo Daya, Consumer Academic, Centre for Psychiatric Nursing, University of Melbourne, of 161 Barry Street, Carlton VIC 3053, say as follows:

### **Note about respectful language use**

- 1 There are terms in common use within the mental health system which are considered offensive by many, but not all, consumers/survivors. Critiques of this language have been written about for decades in consumer/survivor literature. I have attempted to strike a balance between respectful language use, and broader accessibility, in this witness statement. I use the term 'consumers/survivors' in place of 'consumers' to pay respect to different personal preferences. I use the term 'emotional distress, trauma and mental health challenges' in place of 'mental illness' to signify that there are different ways of understanding our experiences. Terms which are particularly disputed, but difficult to avoid, such as 'schizophrenia', are written in inverted commas to denote that these are concepts under challenge.

### **Background**

#### ***Current roles***

- 1 I am a Consumer Academic at the Centre for Psychiatric Nursing, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne. This role involves both teaching and research responsibilities.
- 2 I hold a casual academic position at the School of Global, Urban and Social Studies at RMIT.
- 3 I hold several casual academic and teaching roles at the University of Melbourne, in nursing and social work.
- 4 I am an Honorary Fellow at the Melbourne Social Equity Institute, Faculty of Law, University of Melbourne.
- 5 I am an Ordinary Member on the Committee of Management for VMIAC (Victorian Mental Illness Awareness Council).

*Please note that the information presented in this witness statement responds to matters requested by the Royal Commission.*

6 I have a private consulting business as a Consumer/Survivor Advisor, which includes ad hoc lectures at various universities, public speaking, training and specialist advice across the mental health sector.

7 Attached to this statement and marked 'ID-1' is a copy of my curriculum vitae.

### ***Background and qualifications***

8 I have 15 years' experience working as a consumer/survivor leader across the mental health sector, including in service delivery, program management, advocacy, research, education, government policy, executive and governance roles. Prior to working in the sector I had a mostly very poor personal experience of mental health services, and so my focus has always been to use my lived experience to improve human rights and outcomes for all consumers/survivors.

9 My personal experience of trauma, emotional distress, the mental health system, recovery and healing are described in paragraphs 117-152 of this statement.

10 I have worked in mental health service delivery as a Support Worker, Peer Worker and as Program Manager (lived experience) of the Voices Vic Peer Support Program at Uniting Prahran Mission. During these roles I attended training with international leaders in recovery, peer support work, the hearing voices approach and trauma.

11 In the area of governance, I was a Board Director at Uniting Prahran Mission.

12 I have worked in advocacy roles in the mental health sector, including as General Manager of Consumer and Carer Advocacy at MI Fellowship (now WellWays) and as Human Rights Advisor, Policy and Communications Manager and Strategic Projects Manager at the Victorian Mental Illness Awareness Council, where I led systemic advocacy campaigns and projects and coordinated organisational communication strategy.

13 I have worked in mental health policy and practice leadership roles, including as Senior Policy Advisor, Consumer and Carer Relations in the Mental Health Branch of the Department of Health and Human Services ('DHHS'), and as Senior Consumer Advisor in the Office of the Chief Psychiatrist, DHHS. These roles involved providing expert lived experience advice on sector policy, practice guidelines, participating in service audits, investigations and statutory committees and project work. During this time, I co-delivered training across 12 clinical mental health hospital services.

14 In my consulting work I have delivered guest lectures to occupational therapy students at Australian Catholic University, social work students at Latrobe University, University of Melbourne and RMIT, psychology students at Swinburne University, education and

training to mental health workers on trauma informed practice, recovery oriented practice, group facilitation and using lived experience. I have consulted with the clinical sector about resource development. I also write an online blog about my experiences of trauma, emotional distress and recovery.

- 15 I have a Bachelor of Business (Communication) from the Queensland University of Technology and a Diploma of Management from Monash University.
- 16 Across all of these roles, I have applied my lived experience as a consumer/survivor of complex childhood trauma, from nine years of using mental health services and my personal experience of recovery and healing. My work is also informed by knowledge gained from the consumer/survivor movement including its history and literature and many lived experience mentors.
- 17 I am giving evidence in my personal capacity and not on behalf of any organisations with which I am associated.

## **Supporting recovery from trauma**

### ***Defining trauma***

- 18 Trauma is often misunderstood, and so it is important to define it before moving to the issues and needs. Trauma is a personal and painful experience of being harmed, and having little or no power to prevent it.
- 19 Traumatic harm can be direct by being threatened, or be indirect by witnessing harm to others (e.g. a child witnessing family violence). Traumatic harms can be physical, mental, emotional, cultural, intergenerational, spiritual, social or ecological in nature. Many traumas include multiple types of harm. Trauma is not so much located in the 'events' that happen, but in an individual's experience of those events, including deep and lasting emotional impacts (i.e. fear, shame, despair) and can have profound impacts on personal identity and beliefs about the world. Sometimes trauma occurs through a single, major experience. Sometimes it occurs through the cumulative effects of long-term adversity or harms.
- 20 Trauma can include intentional interpersonal harm (i.e. sexual violence), intentional collective harm (i.e. genocide), accidental interpersonal harm (i.e. car accident) and environmental harm (i.e. natural disaster). It is sometimes argued that intentional harms are the most injurious, however this is not always the case, because the impact of trauma occurs within unique personal and cultural contexts.
- 21 Historically, much research into trauma has focused on war veterans and Post Traumatic Stress Disorder ('PTSD'). Increasingly, academics and practitioners have

differentiated other types of trauma, with many now describing 'complex trauma' as being a different experience to 'PTSD' or to 'single incident trauma'. Complex trauma is usually interpersonal, intentional, extreme, ongoing and can be particularly damaging when it occurs in childhood. However, complex trauma can also occur in adulthood in sustained and extreme traumatic experiences such as in family violence, war trauma or genocide. Complex trauma can impact people in more diverse ways than PTSD.<sup>1</sup>

- 22 Some examples of trauma include child sexual, physical or emotional abuse, child neglect, sexual violence, physical violence, family violence, bullying, hate crimes, war and torture. However long-term experiences of adversity like poverty, extreme inequity and discrimination can also constitute trauma. Not all kinds of trauma have a name or are well understood.
- 23 It should also be noted that research into trauma varies significantly in how trauma is defined and measured. Some studies, like the Adverse Childhood Experiences ('ACEs'), only look at a narrow list of predefined trauma events, occurring only for children. Other studies define sexual violence in very narrow ways. Few studies include a deep and broad definition of trauma. This is, in part, why trauma prevalence rates vary in the research.

### ***Recovery needs for people who have experienced trauma***

- 24 Recovery, as it is described in the trauma literature, has a different meaning to recovery as it described in the mainstream mental health context. Recovery in the mental health context is described in the next section. In order not to confuse the terms, in this section I have used the word 'healing' instead of recovery. There are different perspectives about trauma and healing. Trauma healing work can occur through peer support, talking therapies, or both.
- 25 A common message by consumer/survivor leaders who specialise in trauma is that the first step in supporting trauma survivors is for workers to shift from asking '*what's wrong with you?*' to asking '*what's happened to you?*' In Intentional Peer Support ('IPS'), this question is part of the peer support task called 'worldview'.<sup>2</sup>
- 26 Some of the peer-led approaches to working with trauma include Intentional Peer Support,<sup>3</sup> the Hearing Voices Approach<sup>4</sup> and Alternatives to Suicide.<sup>5</sup> The hearing

<sup>1</sup> Blue Knot Foundation, "*Complex trauma and mental health*," <https://www.blueknot.org.au/Resources/Information/Understanding-abuse-and-trauma/What-is-complex-trauma/Complex-Trauma-and-mental-health>.

<sup>2</sup> Intentional Peer Support. *IPS Core Materials*. (West Chesterfield: US, 2019).

<sup>3</sup> Intentional Peer Support, <https://www.intentionalpeersupport.org>.

<sup>4</sup> Hearing Voices Network, "*HVN: A positive approach to voices and visions*," <http://www.hearing-voices.org/about-us/hvn-values/>.

<sup>5</sup> Western Mass Recovery Learning Community, "*Alternatives to suicide*," <https://www.westernmassrlc.org/alternatives-to-suicide>.

voices approach, as an example, begins with the premise that hearing voices is a normal human experience which is meaningful (as opposed to a meaningless symptom of illness). People are supported to explore the content and the character of their voices, in the context of their life history, in order to make sense of the experience. Typically, people working with their voices will come to understand aspects of trauma which have not been addressed, and this can lead on to further peer support or talking therapies to process trauma. Some people will lose their voices during this work, or the character of their voices will change. For others, peer support or therapy can help to improve the relationship with the voices, so that they are less distressing, or even not distressing at all.

- 27 The most widely accepted approach to trauma and healing proposes three stages: (1) establishing safety and stabilisation, (2) processing and resolution of trauma memories (what Herman calls 'remembrance and mourning') and (3) reconnection or integration, or applying what has been learned in phases (1) and (2) into daily life.<sup>6,7</sup> These stages are underpinned by a healing relationship. Rothschild's approach to trauma and healing suggests that not every person needs to undertake phase (2), involving the processing of trauma memory. Instead, she proposes that this should be the choice of the person.
- 28 These three phases of trauma treatment can map roughly into short, medium and long term healing needs. Each of these phases can be achieved using a variety of different therapeutic approaches such as narrative therapy, psychodynamic therapy, feminist therapy, arts therapy, cognitive behavioural therapy, Eye Movement Desensitisation and Reprocessing (EMDR), group work and family therapy.<sup>8</sup> Intensive peer support work, and coproduced supports like the hearing voices approach, can also support people through these healing stages. People can require vastly different types of therapy, and different amounts of support intensity and duration, depending on individual circumstances. These stages are not necessarily linear.
- 29 Current mainstream mental health services provide little of these options to support people to heal from trauma. At best, it can be argued that some people may learn some coping skills, such as through sensory modulation work, and there may be a role for some use of traditional psychiatric medication, for some people.
- 30 Psychiatric medication, at best, can only be an adjunct to therapeutic trauma work, rather than a primary treatment. Some people do find medication useful for relieving distress. However, the benefits to trauma healing would be largely undone if processes

<sup>6</sup> Herman, J., *Trauma and recovery: The aftermath of violence—from domestic abuse to political terror*. (New York: Basic Books, 1992).

<sup>7</sup> Rothschild, B., *The Body Remembers: The psychophysiology of trauma and trauma treatment*. (New York: W.W. Norton & Company, 2000).

<sup>8</sup> Victorian Centres Against Sexual Assault (CASA), "Standards of Practice." 3<sup>rd</sup> ed. Accessed May 4, 2020, <https://www.casa.org.au/about-us/standards-of-practice/>.

of informed consent and supported decision making were not properly upheld. In particular, medication may be helpful for some people during the phase of safety and stabilisation or during times of crisis. In trauma recovery, medication would always be a choice and never a sole treatment strategy. Trauma specialist Bessel Van Der Kolk notes: "...drugs cannot 'cure' trauma; they can only dampen...".<sup>9</sup> A useful metaphor for this issue is to think about physical pain from a back injury. Medications to suppress pain may be useful for some, but they come with serious risks, and pain medication will not resolve the underlying injury. The same is true for psychiatric medication and trauma—even though medication is very often the only treatment people receive.

- 31 It is important to note that the majority of literature about trauma and healing is focused on a single psychiatric diagnosis: PTSD. This is despite good evidence that almost all psychiatric diagnoses have a high prevalence of past trauma. In particular, people diagnosed with 'schizophrenia' and 'borderline personality disorder' have a high prevalence of child sexual abuse, child physical abuse and/or sexual or physical violence as an adult.<sup>10,11</sup> This means that sometimes, leading advice about working with trauma fails to consider how to work with experiences outside the realm of PTSD, such as hearing voices, having unusual beliefs or using self-injury. In the area of 'psychosis' and trauma, there has been a growth in literature about psychosis, trauma and recovery from consumer/survivor perspectives and in using the hearing voices approach, but no evidence this has translated into practice change in Victoria's mental health system.

### ***Features of a 'recovery-oriented approach'***

- 32 Recovery is one of the most important yet most widely misunderstood concepts in mental health. Recovery in a mental health context has a different meaning to any other health context in that it does not refer to 'remission of symptoms' or other clinical concepts. Recovery is individual and defined by each person; recovery cannot be defined or assessed by a clinician.
- 33 The CHIME model of recovery<sup>12</sup> (based on a meta-analysis of 87 papers that asked what consumers/survivors said recovery meant to them) provides a helpful breakdown of the five key processes that are most often considered to comprise recovery:

<sup>9</sup> Van Der Kolk, B., *The body keeps the score: Mind, brain and body in the transformation of trauma*. (Penguin Books, 2015.)

<sup>10</sup> Everett B and Gallop R., *The link between childhood trauma and mental illness. Effective interventions for mental health professionals*, (Thousand Oaks: Sage Publications, 2001).

<sup>11</sup> Department of Health., "Service guideline on gender sensitivity and safety: Literature review." Victorian Government, 2011, <https://www2.health.vic.gov.au/about/publications/researchandreports/Service-Guideline-on-Gender-Sensitivity-and-Safety-literature-review-PDF-570kb>

<sup>12</sup> Leamy, M., Bird, V., Le Boutillier, C., Williams, J., and Slade, M., "Conceptual Framework for Personal Recovery in Mental Health: Systematic Review and Narrative Synthesis." *The British Journal of Psychiatry*, 6:445 (2011). DOI:10.1192/bjp.bp.110.083733.

- (a) **Connectedness:** includes peer support and support groups, relationships with friends and family of choice<sup>13</sup>, support from others, being part of the community and having a sense of belonging;
  - (b) **Hope:** includes belief in the possibility of recovery, motivation to change, having dreams and aspirations;
  - (c) **Identity:** includes rebuilding a positive sense of identity and overcoming stigma;
  - (d) **Meaning:** includes two different but related processes: (1) making sense of (or /finding meaning in trauma and mental health experiences and (2) having a meaningful life including spirituality, social roles and a good quality of life.
  - (e) **Empowerment:** includes personal responsibility, having control over one's own life and being strength-based.
- 34 Recovery-oriented mental health services are focused on understanding what is important for each person to live the life they want, rather than only being focused on diagnosis and treatment. While the above processes are broadly accepted, what they mean in the context of different people's lives may vary significantly.
- 35 Recovery emerged out of international consumer/survivor led advocacy efforts, and is about being supported to live a great life, regardless of emotional distress or mental health challenges. Victoria developed a 'Framework for Recovery Oriented Practice' in 2011, recovery is recognised in the *Mental Health Act 2014* (Vic) and it was a priority in Victoria's 10 Year Mental Health Plan (2015). However, there are no Key Performance Indicators ('KPIs') established for the sector relating to recovery-oriented practice.
- 36 From a consumer/survivor perspective, it is fair to say that recovery-oriented practice has never been fully implemented in the Victorian clinical mental health sector. There are recovery courses, and an online Recovery Library of resources, and most services probably have a recovery plan template that is completed with people. However, in practice, services are driven by clinical recovery and the 'remission of symptoms'. This means their focus is assessment, diagnosis, treatment and risk management – not supporting people to find hope, connectedness or empowerment. Services are measured on clinical outcomes using Health of the Nation Outcomes Scale ('HoNOS'), and it is hard to see what motivation the sector might have to broaden its focus.
- 37 Since the current Victorian government launched annual reports for the mental health sector, there have been no system-wide measures for recovery-oriented practice (or for trauma informed practice). Alarming and confusingly, each year's annual report includes measures under the heading "*services are recovery oriented, trauma informed*

<sup>13</sup> Note: "Family of choice" is the preferred language for survivors of childhood and family violence. For people who have survived these types of trauma, "family" is not always safe or wanted. However, trauma survivors can and do create "families of choice" through partners and close relationships.

and family inclusive”<sup>14</sup>, which are well-understood to measure neither recovery-oriented practice nor trauma informed practice. Instead, the annual report lists five HoNOS figures, which are measures of clinical outcome, completed by a clinician without the consumer/survivor. Research has found that clinical measures, including HoNOS, do *not* assess recovery-oriented practice, because clinical and personal recovery are different things.<sup>15,16</sup> This seems to be counter-productive to embedding recovery-oriented practice, and sends problematic signals to the sector, and to consumers/survivors.

- 38 There is considerable scope to advance recovery-oriented practice by developed performance indicators, and using evidence-based and widely accepted measures of recovery, such as the INSPIRE measure developed in the UK.<sup>17</sup> The INSPIRE measure is rated by the person rather than the clinician, and includes a rating of how important each item is, and how they were supported by the worker or service on those items. Because of the individualised nature of recovery, it may seem difficult to measure, however data could still be utilised to determine how well the sector is supporting people on the recovery needs that matter most to them.
- 39 In recent years, a critical survivor narrative has emerged in response to failures in the UK, and arguably here in Australia, to implement recovery-oriented practice. This is best exemplified by the UK group, Recovery in the Bin (‘RiTB’). These activists argue that recovery has been co-opted by the mental health system, and tools like ‘The Recovery Star’ have been used to pursue neoliberal agendas of individualising broader social problems, rather than responding to the real issues in people’s lives, such as trauma, poverty, discrimination or loss of rights.<sup>18</sup> This is a contested space. Many consumers/survivors would agree with these arguments; however many also want support for the original, un-co-opted version of recovery.

### ***Challenges to supporting recovery for people who have experienced trauma***

- 40 Recovery oriented practice remains relevant for trauma experiences, particularly because a large majority of mental health consumers/survivors have a history of trauma. However, much of the trauma literature, when describing recovery, refers to

<sup>14</sup> DHHS., “*Victoria’s Mental Health Services Annual Report 2018-19*,” Victorian Government, 2019, p.80. <https://www2.health.vic.gov.au/mental-health/priorities-and-transformation/mental-health-annual-report>.

<sup>15</sup> Macpherson, R., Pesola, F., Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. “The Relationship between Clinical and Recovery Dimensions of Outcome in Mental Health.” *Schizophrenia Research* 175,1–3 (2016): 142–47. doi:10.1016/j.schres.2015.10.031.

<sup>16</sup> Andresen, R., Caputi, P. and Oades, L.G. “Do Clinical Outcome Measures Assess Consumer-Defined Recovery?” *Psychiatry Research*, 177,3 (2010): 309–17. doi:10.1016/j.psychres.2010.02.013.

<sup>17</sup> Williams, J., M. Leamy, V. Bird, C. Boutillier, S. Norton, F. Pesola, and M. Slade. “Development and Evaluation of the INSPIRE Measure of Staff Support for Personal Recovery.” *Social Psychiatry And Psychiatric Epidemiology*, 50, 5 (2015): 777–86. doi: 10.1007/s00127-014-0983-0.

<sup>18</sup> Recovery in The Bin: “*A critical theorist and activist collective*.” 2015. <https://recoveryinthebin.org/>.



traditional notions of clinical recovery, focussing on the alleviation of distress or 'remission of symptoms', rather than the whole of life approach in recovery.

- 41 Clinical recovery could become a workable concept if specialist trauma understandings were improved. Consumers/survivors typically critique the concept of 'clinical recovery' because it's based in the idea that our experiences are symptoms of illness. This conceptual understanding results in biomedical treatments (medications and electroconvulsive therapy) and the harmful use of rights restrictions and breaches. However, if fundamental assumptions shift from physical disease concepts, towards seeing people's experiences as a meaningful response to trauma, then 'clinical recovery' changes in meaning, from 'remission of symptoms', to 'self-rated reduction of distress'.
- 42 Each process of recovery can be challenging for trauma survivors in the mental health system:
- (a) **Connectedness:** The recovery process of connectedness is a challenge in mental health services because peer support is still limited, and there are few, if any, processes by clinicians to address people's loneliness, isolation or other social barriers. Connectedness can be impeded rather than grown because of adverse effects of medication like excessive sedation, akathisia and, in intimate relationships, sexual dysfunction and excessive weight gain. Connectedness between consumers/survivors and clinicians is impeded whenever coercive practice is used. Shame is a common cause of emotional distress for trauma survivors, and the instinctive response to shame is to hide and isolate from others, making connectedness an important part of trauma healing and recovery.
  - (b) **Connectedness (with families of choice and carers):** A practice which I call 'family splitting' can further isolate consumers/survivors. Family splitting occurs when clinicians co-opt a person's family members into becoming an extension of the clinical team, by asking the family to convince consumers/survivors to consent to treatments, monitor people taking medications at home or report concerns back to the services without the person knowing. If the carer/family have been a strong supportive connection previously, this process of family splitting can be devastating because consumers/survivors will lose trust in their family and lose their sense of support and connectedness. Many times, I have seen this family splitting process occur after clinical services provide 'psychoeducation' to carers which teaches families biogenetic explanations for people's distress, and largely ignores consumer/survivor perspective.
  - (c) **Hope:** The recovery process of hope is a challenge in mental health services because of the current system's overreliance on compulsory treatment. People

on compulsory treatment lose significant fundamental rights and this makes hope much more challenging. The adverse effects of most psychiatric treatments also impede hope, by adding further disability and limitations to people's lives. Psychiatric language like 'treatment resistant' or 'noncompliant' also hurt people's hope. The former tries to place blame (for the failure of the service to be helpful) onto the person, while the latter gives consumers the message that we must be obedient and submit to whatever our doctors say, even if we know it's wrong and not helping. Finally, hope is damaged when services give prognoses of lifelong illness and disability.

- (d) **Identity:** Identity, or sense of self, can be particularly injured by trauma, especially when trauma occurs in childhood. Many survivors blame themselves for what happened, and this deep shame can result in low self-esteem, even self-hatred. The recovery process of identity is a challenge in mental health services, in particular because biogenetic messages about our experiences can cause people to feel broken and excluded, and disrespectful terms like 'lack of insight' can leave people feeling like they lack any self-efficacy to effect change in their lives. Emotional distress, trauma and mental health challenges themselves can transform our identities and the lack of access to talking therapies means that people have limited opportunities to explore or resolve these issues. Many consumers/survivors have unusual beliefs outside of mainstream views, including beliefs about spirituality. When these are pathologized as being symptoms of illness people can experience profound existential crises.
- (e) **Meaning:** Meaning is particularly relevant to trauma survivors because it can feel impossible to make sense of what has happened, particularly for complex and interpersonal abuse and violence. The struggle to make sense of trauma can express itself in hearing voices, unusual beliefs, despair and terror. The recovery process of meaning is a challenge in mental health services because no space or effort is made to frame people's experiences as meaningful responses to what has happened in their lives. Emotional distress and trauma is stripped of meaning and reduced to diagnostic labels, treated with pills and force, which can render these significant life experiences as largely meaningless.
- (f) **Empowerment:** The recovery process of empowerment is a challenge in mental health services because of mental health legislation and the system's focus on deficits in individuals. It is not possible to feel empowered when your fundamental human rights are restricted and sometimes severely breached. Even within the context of Victorian mental health law, the most basic aspects of supported decision making have not been implemented, further limiting the

potential for people to feel empowered. Only a small minority of consumers/survivors can access a lawyer for a Mental Health Tribunal hearing and many cannot access an advocate or even get frank information about their treatment pros and cons. I have been saddened over the years to hear several clinicians tell me that they intentionally don't inform their patients serious treatment side effects because then we may not take the medication. This doesn't just take away our power, it is unethical. It leaves people at risk of serious health problems, even shortened life expectancy, with no chance to protect themselves. Of all of the recovery processes, empowerment is the most unlikely to be supported in existing mental health systems. It is far more likely that consumers/survivors will feel profoundly disempowered, which is the opposite of recovery.

- 43 There are two underlying, major challenges to recovery and healing from trauma. The first is that the mental health system is based on a biomedical diagnostic framework that is subjective, lacking evidence, and which largely ignores the role of trauma. The second major challenge is mental health legislation, which strips away fundamental human rights, and forces people into a system that causes further trauma.

### ***Adopting a 'trauma-informed' approach to mental health services***

- 44 A service can be trauma specialist, trauma informed, trauma creating or neutral. Currently, there are clear indications that public clinical mental health services are neither trauma specialist nor trauma informed. In practice, most, if not all, of these mental health services are likely to be worsening the impacts of trauma and/or creating new traumas. In other words, our current system is 'trauma creating'.
- 45 Trauma specialist services exist to support people to heal from trauma. They usually offer specialist counselling and therapy by practitioners whose primary expertise is in trauma. Examples of trauma specialist services include the Centres Against Sexual Assault, Foundation House, women's refuges and family violence counselling services.
- 46 Trauma informed services provide support not directly related to trauma, to people who are likely to have experienced trauma. Examples may include housing or employment support services. Trauma informed services use a particular approach and set of principles.
- 47 A trauma informed approach includes 4 Rs: Realise, Recognise, Respond and Resist:
- (a) **Realise:** services realise the wide scale prevalence of trauma and its impacts and realise that many behaviours and signs that may otherwise be seen as symptoms of illness may instead be meaningful responses to trauma;

- (b) **Recognise:** services recognise the signs of trauma, and use supportive and therapeutic strategies to screen for trauma and support trauma disclosure;
- (c) **Respond:** services respond by applying the principles of trauma informed practice to every aspect of their service in all roles and aspects of service delivery. Staff are trained in trauma informed practice and the organisation shows commitment in policies, values, leadership and providing a safe space.
- (d) **Resist:** services actively resist retraumatising consumers/survivors and staff. They realise that coercive, compulsory and restrictive practices can retraumatise people and prevent healing from trauma.<sup>19</sup>

48 The above approaches are not well or widely understood in the mental health sector. It is my observation over years that many clinicians believe that trauma informed practice is simply the avoidance of retraumatising people (the 4th 'R'). This simplification is one barrier to trauma informed practice, which is much greater in scope than this. Preventing retraumatisation is essential, however if this is all we do then people will not have access to trauma recovery and healing.

49 There are six trauma informed principles which a trauma informed organisation will ensure are understood and embedded across every aspect of the service and organisation:

- (a) **Safety:** this principle ensures that all people at the organisation feel and are safe, including physical and psychological safety. Safety is defined by the people served by the organisation. Why does safety matter? Because trauma takes away people's physical and psychological safety, and so a supportive organisation must do the opposite.
- (b) **Trustworthiness and transparency:** this principle ensures that processes and decisions are transparent so that people can have trust in the service. Why does trustworthiness matter? Because trauma often feels like a betrayal, whether that is by another person, a group, or even by nature. After severe trauma, it can be hard to trust others, and so organisations must work hard to demonstrate they can be trusted. Why does transparency matter? Trauma usually begins as a shock, the danger can be hidden until it is no longer possible to escape. Organisations need to be transparent in their processes, plans and actions, so as not to replicate trauma.
- (c) **Peer support:** this principle means the organisation recognises that peer support is a key process in recovery and healing and peer support is an accessible part of the service offering. Peer support is inherently trauma-

<sup>19</sup> SAMSHA (Substance Abuse and Mental Health Services Administration). "TIP 57 on Trauma-Informed Care in Behavioral Health Services," Rockville: US Department of Health and Human Services, 2014. [http://www.integration.samhsa.gov/clinical-practice/SAMSA\\_TIP\\_Trauma.pdf](http://www.integration.samhsa.gov/clinical-practice/SAMSA_TIP_Trauma.pdf)

informed because it is grounded in consumers/survivors recognising that our experiences often stem from past trauma, and aiming to avoid pathologisation of experience. People often feel safer and more understood when disclosing and sharing with someone who has had a similar experience. This dynamic is not unique to mental health: in all walks of life, people have a tendency to seek out others who have walked a similar path. First time expectant mothers will seek advice from more experienced mothers. LGBTIQ+ people will often seek out other LGBTIQ+ people when coming out. And trauma survivors can feel safer with other survivors.

- (d) **Collaboration and mutuality:** this principle aims to break down power imbalances and encourage partnerships. A key focus of collaboration is in decision making, while mutuality helps to break the idea that some people are passive recipients of help and others are the helpers. These principles matter because of the way that trauma takes away people's power and agency. 'Doing to' people, rather than 'doing with' people, can unintentionally replicate the dynamics of trauma, and make people feel like powerless victims.
- (e) **Empowerment, voice and choice:** this principle recognises the strengths of consumers/survivors and a belief in people's ability to heal. Power differences are understood and it is recognised that power imbalances can diminish the voice and choice – and recovery – of consumers/survivors. Supported decision making is embedded, and staff recognise their role as facilitators rather than controllers. Staff feel empowered by an organisation that supports them. These principles are also about power, but explicitly about doing everything possible to support the person to have the most power in the support relationship.
- (f) **Cultural, historical and gender issues:** this principle is applied by the organisation actively moving past old stereotypes and discriminatory views and practices. People's culture and gender is respected and related safety needs are responsively supported. The service recognises and addresses historical trauma. This principle matters because much trauma is grounded in culture, history and gender. These are high priority areas in which to ensure trauma is not recreated.<sup>18</sup>

50 Substance Abuse and Mental Health Services Administration ('SAMHSA') is a branch of the United States Department of Health and Human Services. I acknowledge that the Australian trauma organisation, Blue Knot Foundation, proposes a different set of trauma informed practice principles. However, these principles are not as thorough or well aligned with consumer/survivor perspective and priorities as the original SAMHSA principles.

- 51 SAMHSA recommends 10 domains for implementing trauma informed practice including: governance and leadership; policy; physical environment; engagement and involvement; cross sector collaboration; screening assessment and treatment services; training and workforce development; progress monitoring and quality assurance; financing; and evaluation.
- 52 A trauma-informed approach, on its own, does not aim to support recovery and healing from trauma. However, it prevents further trauma, it can play a critical role in addressing people's needs from a service in the most helpful way possible, and by supporting people to disclose trauma and gain subsequent access to trauma specialist services (where recovery and healing can occur). Providing trauma informed services, without access to trauma specialist services, can open the door to healing and recovery, but leave people with no way to progress their journey.

***The link between unaddressed or untreated significant trauma and serious mental health challenges and suicide***

- 53 Trauma is a highly prevalent experience shared by most consumers/survivors of clinical mental health services. A significant body of research has found trauma is associated with most psychiatric diagnoses including 'PTSD', anxiety, depression, 'psychosis', 'personality disorders', dissociation and suicide.<sup>20</sup> In general, people seem to find it easier to understand how trauma might result in a diagnosis of depression or anxiety, and PTSD is always associated with trauma. However, the links can be harder to see for other diagnoses—although research has shown consistently strong associations:
- a) **Consumers/survivors in general:** In one study, 87% of public mental health patients report experiencing physical or sexual assault during their lifetime. For two-thirds it was as children.<sup>21</sup>
  - b) **Trauma and psychosis:** A meta-analysis of 41 trauma studies found that child maltreatment and adversity (abuse, neglect, parental death, and bullying) was strongly associated with psychosis.<sup>22</sup> Another review of 59 studies found that, of patients diagnosed with psychosis, 64.5% of women and 55.5% of men had been subjected to sexual or physical abuse as children, most often, but not

<sup>20</sup> Blue Knot Foundation. "Complex trauma and mental health." <https://www.blueknot.org.au/Resources/Information/Understanding-abuse-and-trauma/What-is-complex-trauma/Complex-Trauma-and-mental-health>.

<sup>21</sup> Goodman, L.A., Rosenberg, S.D., Mueser, K.T., and Drake, R.E. "Physical and Sexual Assault History in Women With Serious Mental Illness: Prevalence, Correlates, Treatment, and Future Research Directions." *Schizophrenia Bulletin*, 23, 4 (1997): 685-696.

<sup>22</sup> Filippo, V., Feikje, S., Marjan, D., Ritsaert, L., Tineke, L., Wolfgang, V., John, R., Jim, van O., and Richard P., B. "Childhood Adversities Increase the Risk of Psychosis: A Meta-Analysis of Patient-Control, Prospective- and Cross-Sectional Cohort Studies." *Schizophrenia Bulletin*, 4, 661 (2012). doi:10.1093/schbul/sbs050.

always, by family members.<sup>23</sup> Another meta-analysis found that people abused before the age of 16 years were between 2.5 and 9.3 times more likely to develop 'psychosis'.<sup>24</sup>

- c) **Borderline Personality Disorder:** People with this diagnosis have a high prevalence rate of childhood abuse 45% to 86%.<sup>25</sup> This abuse has frequently been prolonged and severe.<sup>26</sup>

- 54 Research has identified that many consumers/survivors have experienced multiple types of trauma during our lives.
- 55 Research has identified a 'dose response' relationship between trauma and emotional and mental distress ('psychiatric symptoms'). This means that more severe trauma tends to be associated with more severe distress, including for 'psychosis'.<sup>27</sup> This is particularly concerning because, based on my observations in the sector, the people with the most serious trauma histories are the most likely to have a traumatic experience in psychiatry of forced treatment, with trauma being ignored.
- 56 Despite the high prevalence, trauma is largely ignored in mental health services, particularly in the public clinical system. A small minority of clinical services claim to be 'trauma-informed' but I believe this is clearly disputable. On balance, most clinical mental health services are more likely to add to and worsen trauma, than to be a helpful support in trauma recovery.
- 57 Most people are rarely asked by mental health workers about their history of trauma, let alone provided therapy to support recovery – this would be easily evidenced by an audit of hospital records. Instead, services focus on symptoms and medical treatment, without addressing the underlying issues.<sup>28</sup> Even when clinicians ask about trauma, or the person discloses it, it is unlikely that trauma therapy will occur. Over my years of

<sup>23</sup> Read, John, Paul Jay Fink, Thom Rudegeair, Vincent Felitti, and Charles L. Whitfield. "Child Maltreatment and Psychosis: A Return to a Genuinely Integrated Bio-Psycho-Social Model." *Clinical Schizophrenia & Related Psychoses* 2, 3 (2008): 235–54. doi:10.3371/CSRP.2.3.5.

<sup>24</sup> Department of Health. "Service guideline on gender sensitivity and safety: Literature review." Victorian Government, 2011. <https://www2.health.vic.gov.au/about/publications/researchandreports/Service-Guideline-on-Gender-Sensitivity-and-Safety-literature-review-PDF-570kb>

<sup>25</sup> Everett B., and Gallop R., *The link between childhood trauma and mental illness. Effective interventions for mental health professionals*, Thousand Oaks: Sage Publications, 2001.

<sup>26</sup> Department of Health. "Service guideline on gender sensitivity and safety: Literature review." Victorian Government, 2011. <https://www2.health.vic.gov.au/about/publications/researchandreports/Service-Guideline-on-Gender-Sensitivity-and-Safety-literature-review-PDF-570kb>

<sup>27</sup> Read, J., J. Os, A. P. Morrison, and C. A. Ross. "Childhood Trauma, Psychosis and Schizophrenia: A Literature Review with Theoretical and Clinical Implications." *Acta Psychiatrica Scandinavica* 112, 5 (2005): 330–50. doi:10.1111/j.1600-0447.2005.00634.x.

<sup>28</sup> Xiao, Claudia Lin, Emorfia Gavrilidis, Stuart Lee, and Jayashri Ku karni. "Do Mental Health Clinicians Elicit a History of Previous Trauma in Female Psychiatric Inpatients?" *Journal of Mental Health* 25, no. 4 (3 July 2016): 359–65. <https://doi.org/10.3109/09638237.2016.1139074>; Kohen, D., McNicholas, S. and Beaumont, K. "Inpatient Psychiatric Services for Women". In *Women and Psychiatric Treatment: A Comprehensive Text and Practical Guide*, by Claire Henderson, Catherine Smith, Shubulade Smith, and Angela Stevens. Routledge, 2013; Riecher-Rössler, A., and García-Moreno, C. *Violence Against Women and Mental Health*. Karger Medical and Scientific Publishers, 2013.

working in the sector, countless consumers/survivors have told me about disclosing trauma to a clinician, only to be told that this was probably a 'delusion' and didn't really happen. About five years ago I spoke with an audience of clinicians from Victorian hospital services, at a public forum. One of the psychiatrists spoke during question time, claiming that trauma is routinely ignored, describing having seen patient files with trauma recorded years and years ago, but no record that anything was ever done. She described feeling like she didn't have the skills to work with trauma.

- 58 These types of trauma are not the only issues that impact mental health. Other types of trauma can include: childhood bullying, workplace bullying, child neglect, family violence, war and refugee trauma, racism, homophobia and many other painful experiences.

***Implementing effective system wide application of trauma-informed care and recovery-oriented approaches in Victoria***

- 59 I was a strong advocate for trauma informed practice for many years. I have delivered hundreds of hours of training in trauma informed practice. Despite this, I am increasingly unconvinced that public clinical mental health services can or should implement trauma informed practice. If this approach is pursued, then I suggest it will take at least 5 years to prepare and move towards trauma informed practice, and probably another 5 or more years to embed practice change. It will require major and sustained funding, and there will be significant barriers to success.
- 60 Another consideration is a need to determine whether Victorian mental health services should be trauma informed or trauma specialist. If the vast majority of consumers/survivors have a trauma history, and our experiences of emotional distress and mental health challenges are a consequence of that trauma, then we should be entitled to, we need to, access trauma specialist services. If these are not adequately funded and accessible in the community, then introducing a trauma informed mental health service does not go far enough. An even more fundamental question is this: if trauma is at the root of most consumers/survivors distress, and mental health services lack relevant expertise, are they even the right service? Or should we be able to attend trauma specialist services instead? These are fundamental questions for funding bodies and the sector, of an enormous scale.
- 61 Putting aside the question about whether we need trauma informed or trauma specialist practice, the next greatest issue for the sector is to confront the substantial barriers to trauma informed practice. These barriers include harmful contraindications, not least of which is the *Mental Health Act 2014* (Vic), a dominant biogenetic paradigm in psychiatry, a lack of adequate expert skill and knowledge in the workforce and the enormous scale of this change.



- 62 Today, it is not feasible for any public clinical mental health service under the Act to claim it is trauma informed, despite the fact that some services do claim this. It is not feasible because all of these services behave in ways which are wholly contraindicated by trauma informed practice.
- 63 For example, a trauma informed service cannot achieve the principle of safety while sexual violence, seclusion and all forms of restraint (including physical, mechanical, chemical and psychological restraint) remain in widespread use. They cannot achieve the principle of trustworthiness while privacy breaches, coercion, punitive measures and unlawful practice (such as denying leave to voluntary patients) are common practice. Neither collaboration, nor empowerment, are possible while compulsory treatment and detention is common practice. Even voluntary patients witness restriction and compulsion and this damages trust, safety and recovery. All of these practices are in direct contradiction to trauma-informed principles. It is difficult to understand how a mental health service can be genuinely trauma informed while the Act remains in force—unless we proceed with a tokenistic approach that risks doing more harm to people who've been hurt enough.
- 64 The significant structural contraindications to trauma informed practice must be taken into account in any review of the Act, and in any commitment made to trauma informed practice. Too much activity in the mental health sector is already superficial and tokenistic. It is better to have no trauma informed practice than a co-opted version where trauma survivors are told they will be supported, yet are actually hurt. One potential strategy is to commit to 'moving towards' trauma informed practice for the first period of time, but to do so with clear targets, deadlines and genuine accountabilities.
- 65 Reform needs to commit to implementing all of the 4Rs of a trauma informed approach. And while 'resisting retraumatisation' (the 4<sup>th</sup> R) is the one least likely to progress recovery and healing, it is probably the first one that needs to be tackled. Currently the mental health sector retraumatizes people in so many different ways, on such a frequent basis, that the other parts of the approach are not yet feasible. Enabling reform would ideally begin with the elimination of seclusion and all forms of restraint (physical, mechanical, chemical, psychological), and this needs to be supported with funding, training, KPIs, oversight, clear and transparent accountabilities – and a deadline.
- 66 Victoria has been a poor performer in this area in recent years. It is important to note that Victoria's KPI for the maximum rate of seclusion is three times higher than the same KPI for NSW, and so this should be open to immediate review. Further, a number of Victorian services appear to exceed the seclusion rate KPI (15 seclusions/1000 occupied bed days) without any apparent consequences, which opens opportunities to tighten sector accountability and interrogate the effectiveness of safeguards and oversight mechanisms. Meanwhile, mechanical and physical restraint data needs to be

made public on a per service basis. Neither chemical nor psychological restraint are measured or publicly reported in Victoria, despite them both quite clearly being common practice on inpatient units. These practices must be measurable and measured, before they can be eliminated. For far too long, DHHS and Chief Psychiatrists have avoided measuring chemical restraint by delaying an agreed national definition: yet chemical restraint is clearly and consistently defined internationally, and in the Australian disability sector. I am hopeful that the Royal Commission can move this along after years of avoidance by the sector and government. This is another obvious area for rapid reform.

- 67 More challenging, but just as needed, is a commitment to reduce and eventually eliminate compulsory detention and treatment. Currently, there is no motivation to reduce compulsory treatment, and DHHS annual reports suggest more than half of all inpatients are still detained and compulsorily treated. Until this occurs, the sector could benefit from KPIs on the maximum proportion of compulsory treatment orders, with an expectation that there will be a statewide annual decrease in the rate. Tightening oversight at the Mental Health Tribunal end, and putting more investment into supported decision making at the service delivery end, will help move along this kind of change. It may also be beneficial to consider policies which pull back from risk assessments, given the weak evidence base for their predictive value. I recommend discussing the concerns about risk assessments with the Chief Psychiatrist, who hosted a forum on this topic in 2018.
- 68 I would be delighted to see an immediate end to compulsory treatment, however I recognise this is highly unlikely to occur in the immediate future. So instead, I suggest a gradual reduction in compulsory detention and treatment could be supported through many staged reform strategies, such as:
- (a) **Tightening criteria (risk of harm):** the current, nondescript criterion of 'risk of harm' could be tightened to 'risk of imminent, fatal harm'. At the moment, this loose description allows people to be placed on orders for such minor and highly subjective reasons as 'risk of financial harm' or 'risk of reputational harm'. Regardless of the type of risk, the fact remains that risk assessments have little predictive value – and so the foundational justification for compulsory treatment is flawed, as well as being traumatic and of questionable benefit to anyone.
  - (b) **Tightening criteria (least restrictive):** The criterion of least restrictive practice could be expanded to specifically include access to peer support and talking therapies, including trauma specialist therapies, and the option of people just having more time to sit with their experience. Sometimes, distress passes on its own.

- (c) **Greater rights protections:** Advocates should be given a statutory role with powers of entry to services. Advocates and legal representation should be provided (and funded) on an opt-out basis rather than an opt-in basis. Irrespective of the trauma and recovery impacts, this should be a fundamental human rights safeguard, to balance the extreme rights restrictions imposed by the *Mental Health Act 2014* (Vic).
- (d) **Add physical health safeguards:** Require that compulsory treatment cannot exceed maximum recommended therapeutic doses, and cannot employ polypharmacy (prescribing multiple types of the same class of drug). Both of these practices are well-evidenced to be ineffective and put people at high risk for serious adverse effects. It is problematic enough if people consent to risky treatment with poor evidence – but it should not be possible for the state to sanction forced treatment that is unproven and risky. This could be supported by offering consumers/survivors regular physical health reviews reported to the MHT, and the cessation of compulsory treatment orders if adverse effects impede physical health or quality of life. This will have the effect of reducing compulsory treatment, but it will also help to address the inequitable and inexcusable life expectancy gaps for consumers/survivors.
- (e) **Add trauma safeguards:** Given that compulsory treatment is inherently contraindicated for trauma survivors, the *Mental Health Act 2014* (Vic) could be amended to ensure that all people are screened for trauma by appropriately skilled workers, and that trauma therapy and specialist support should be offered to all survivors, prior to even considering compulsory treatment. If compulsory treatment occurs, the impacts on psychological wellbeing should be regularly reassessed.
- (f) **Diversify and balance the Mental Health Tribunal:** The membership of tribunal panels could be made more balanced by introducing a fourth member who must have lived experience as a consumer/survivor and opening up the psychiatry positions to any clinician, with a focus on recruiting members with trauma expertise. This could provide a more procedurally fair process.

69 Further strategies in legislative reform, which could move the sector closer to trauma informed practice, include:

- (a) changing the current requirement for an 'authorised psychiatrist' to an 'authorised mental health worker of the person's choice', creating space for people to choose a trauma specialist; and
- (b) replacing advance statements with advance directives to protect consumers/survivors right to equality before the law, and build trustworthy and collaborative services. I can think of no reasonable justification whatsoever as

to why mental health consumers/survivors should not have equal rights to decide for or against treatments in advance;

- (c) strengthening the provisions for supported decision making. If authorised psychiatrists are retained, then consider how we ensure that the people in these roles understand their responsibilities under the Act. I would propose that people in these roles should have to attend training, and pass an assessment, to ensure they have appropriate knowledge about trauma, consumer/survivor perspective and human rights; and
- (d) I recommend the Royal Commission examine the compliance of the sector with the Act, and consider ways to improve sector compliance. While consumers/survivors are quite literally forced to comply with the wishes of their psychiatrist, not all services are compliant with legislation. Leave is often denied to voluntary patients, and mobile phones are frequently confiscated as a matter of course, and in contravention of the Act – both of which can cut people off from access to their community, advocacy, legal advice and the requirements of daily living.

- 70 Trauma informed practice is a change of a very large magnitude. It is notable the most similar reform, recovery-oriented practice, was introduced in Victoria's Framework for Recovery Oriented Practice in 2011, and yet recovery-oriented practice has still not been authentically implemented. Trauma informed practice and recovery-oriented practice have significant overlaps and dependencies. However, trauma informed practice is arguably even more complex and challenging to implement than recovery. A part of any reform in this area must consider the scale of change and plan for change in a way which is achievable rather than tokenistic. This should include analysis of why many previous reforms like recovery-oriented practice, and reducing restrictive practices, have largely failed.

### ***Supporting the mental health workforce to deliver trauma-informed care***

- 71 **Qualifications:** Existing qualifications for the mental health workforce need to incorporate reasonable knowledge about trauma, recovery, human rights and consumer/survivor perspective. Further, qualifications need to incorporate greater skill development in talking therapies and counselling – or incentives need to be provided for workers to gain additional relevant postgraduate qualifications. I recommend that the Royal Commission compare the curricula and skill sets on trauma between trauma specialists, and typical staff at a mental health service – the gaps will be significant.
- 72 **Shifting the dominant psychiatric paradigm:** Both recovery-oriented practice and trauma informed practice run contrary to the dominant paradigm of biogenetic approaches in psychiatric services. The sector paradigm is grounded in the idea that

emotional distress, trauma and mental health challenges are biological and genetic in origin and are best characterised as illness or disease. The natural consequence of this perspective is that treatments are almost entirely biomedical, such as medications and electroconvulsive therapy. It is not like psychiatric units in the movies—very few people receive talking therapy at all in the current inpatient system, and it is likely that no-one ever receives talking therapy or peer support to the exclusion of biomedical interventions. The biogenetic approach is ingrained in psychiatric training and practice, and this perspective flows through to other disciplines like nursing, psychology and allied health. It is difficult to see how trauma informed and recovery-oriented practice can be embedded into mental health services unless the overarching and powerful dominant paradigm, largely controlled by the psychiatric discipline, is changed. It is almost as difficult to see a pathway to engage the psychiatric profession in a large change of this nature and magnitude.

- 73 **A reconceptualised workforce, bringing in outside expertise:** An alternative or parallel strategy towards trauma informed (or specialist) practice is to reconceptualise what makes up a trauma informed mental health workforce. The existing predominant mental health disciplines mostly do not have expertise in trauma recovery or trauma informed practice. However, there is a workforce outside of mental health, in trauma specialist services for sexual violence, family violence and refugee trauma, who have substantial expertise. These workers are largely trained in social work, psychology or counselling, with additional postgraduate qualifications and specialist training. In the broader sector of private practice there are also nurses, occupational therapists and consumer workers who have specialist counselling training and skills. The question arises about whether it makes sense to try and skill up people who are not experts in trauma— or to bring in people who already have the expertise. A commitment to a substantial and growing proportion of trauma counsellors and therapists into inpatient and community mental health services is a pragmatic strategy for beginning to change culture and practice around trauma. It would also help reduce the perceived impact of workforce shortages in psychiatry and nursing, by changing the overall workforce balance.
- 74 **Be wary of tokenism:** Typical strategies for introducing practice change, including the department releasing guidelines and framework documents, and short training courses, may help to build basic knowledge and skills amongst the current workforce, but this is unlikely to be sufficient to bring about the changes needed for trauma informed practice, and certainly not trauma specialist practice. A document and a short course will never succeed in introducing trauma informed practice.

- 75     **Supervision is essential:** In a trauma informed service, staff should all receive practice supervision, and have access to consumer perspective supervision. Supervisors should have expertise in trauma along with other required knowledge and skills.
- 76     **Placements & swaps:** A more creative strategy to build knowledge and skills could involve placements of mental health staff within trauma specialist services and/or bringing external trauma specialists into services on placements to model best practice and provide practice reflection.
- 77     **Lived experience leadership:** Consumers/survivors with expertise in trauma and recovery should have leadership roles in the introduction of trauma informed or specialist practice. This kind of reform requires a big conceptual shift, and this may be aided by being able to see and hear from people who have relevant lived experience.

***Settings for the delivery of trauma-informed care, treatment and support beyond mental health services***

- 78     **New types of trauma specialist service:** Victoria has a lack of trauma services specialising in multiple types of trauma, particularly with presentations that don't align with classical PTSD or mood disorders. Instead, trauma services tend to be funded around particular types of trauma events, like sexual or family violence. Many mental health consumers/survivors have experienced multiple types of different trauma. If a woman was abused as a child, bullied at school and then experienced family violence, and these are related to her experience of hearing distressing voices, which type of trauma service should she go to? I propose that we need specialist trauma services which are not tied to a particular type of trauma, and are skilled in working with complex and multiple trauma, across a wide range of possible presentations.
- 79     **Consumer/survivor roles in trauma services:** In the area of trauma specialist services there is currently expert knowledge about PTSD and complex-PTSD trauma responses, but there is likely to be lack of understanding about how trauma plays out for people who hear voices or have unusual beliefs, and for people with 'BPD' labels. In this area, there could be substantial benefit in introducing peer support into existing trauma services and developing consumer/survivor-led training for trauma counsellors. Funding placements or positions for peers embedded in trauma services could be an important innovation, and worthy of a trial.
- 80     **Group programs:** Increased opportunities for peer support outside of clinical, residential or crisis settings should also be considered. In particular, there is opportunity for group programs which are trauma informed and recovery oriented. Prior to the NDIS rollout, for example, there were close to 30 peer support hearing voices support groups across Victoria. These groups provided a safe space for people to explore their

experience of hearing voices and unusual experiences, to talk about trauma and how the voices make sense in that context and to connect with fellow peers. Similarly, a US peer-run service, Western Mass, operate peer support groups called 'Alternatives to Suicide'. These groups provide a much needed safe space to talk about how to live with suicidal feelings, without the risk that the police or CAT team will be called (this issue is a barrier for many consumers to seek help in a crisis, for fear of being readmitted to hospital). This type of peer support can be highly supportive and is far more cost effective than many clinical service models. Peer workers and groups could be based at community support services, community health services or even out of neighbourhood houses. A central hub could provide support, supervision, promotion and coordination. This type of program would be substantially different to the 'lived experience delivered' program proposed in the Royal Commission interim report. It would be grounded in peer work, in consumer perspective, and should be run by consumers themselves.

- 81 **Recovery camps:** Another opportunity is to fund recovery camps and trauma recovery camps. This approach may be peer led, or multidisciplinary, or both, and provides a non-clinical, residential program for people to immerse themselves in an intensive recovery and healing process. Similar camps are run elsewhere in Australia and overseas (particularly in the UK).

## **Families, carers and personal support networks**

### ***The role of families, carers and broader personal support networks in recovery***

- 82 The role of families and carers is often stereotyped and oversimplified in the mental health space, and as a consequence, both consumers/survivors and carers/families, can have worse outcomes.
- 83 For many consumers/survivors, family can be the most helpful and supportive part of their recovery. In these instances, family/carers respect the person's will and preferences and act accordingly. There are healthy boundaries, and at least some elements of mutuality, so that people don't feel that their original roles (e.g. mother and daughter) are lost and replaced by mental health system roles (e.g. consumer and carer). From a recovery oriented perspective, families, carers and broader support networks are what give us our sense of connectedness and belonging, and may also be an important part of our identity and meaning. Families/carers can be great advocates for our rights, will and preferences, and assist in supported decision making. Families/carers can also offer many very practical supportive resources.
- 84 However, not all consumers/survivors have carers/families, and when we do, they are not always supportive. There is a clear tension between trauma informed practice, and family inclusive practice, that has not been considered in policy and practice: what

happens when the family is the source of trauma? An uncomfortable part of the high prevalence of trauma amongst consumers/survivors is that sometimes the people who hurt us are family members. Perpetrators of child physical and emotional abuse, and neglect, are most commonly a primary caregiver.<sup>29</sup> Child sexual abuse is commonly perpetrated by a wider group of people, including a parent, family member, close family friend or others known to the child (e.g. sports coach, teacher, priest).<sup>30</sup> By the time someone becomes a mental health consumer/survivor, family perpetrators may no longer be in our lives – but sometimes they are, and I have known consumers/survivors where this is the case. Sometimes a carer/family member is not the perpetrator, but they may not believe disclosures of past abuse and this can be particularly damaging for trauma recovery. I have seen a great many examples of this amongst consumers/survivors that I've worked with, and the impacts can be devastating. It is important that mental health services recognise and respond to these issues, rather than automatically assume that all family/carers are benevolent and want the best for the person, or that the consumer/survivor is the person with the problem, and the family/carers has no issues. That will very often be true, and sometimes it won't be. Stereotypes are just as unhelpful and inaccurate for carers as they are for consumers.

- 85 Another area of tension, and potential opportunity, is the role of carers/family in decision making for the consumer/survivor. Best practice for recovery oriented and trauma informed practice is for people to be fully informed and then be supported to make their own decisions about treatment and care. Carers/family can play a very supportive role in this process when there is respect for the person's rights and an understanding that making empowered choices is part of recovery and healing. In these instances, a consumer/survivor may choose to make a carer/family member their nominated person. However, conflicts and tensions can arise where there are conflicting opinions between a person and their carer/family, and the person's voice is silenced. This can be damaging for recovery and for the larger family relationship. These different views, or being estranged from family/carers, are both good reasons why consumers/survivors often do not choose a carer/family member to be their nominated person. In some instances of abuse within families, consumers/survivors have spoken about wanting to be able to name 'excluded persons' to the service, as well as nominated persons. This would require a legislative amendment to the *Mental Health Act 2014* (Vic), but would provide a sensible protection for consumers/survivors experiencing family violence, or with perpetrators of abuse within families. Mental health services can support families/carers by encouraging them to find out and seek to uphold the person's will and

<sup>29</sup> Australian Bureau of Statistics, "Personal Safety Survey Australia (Cat No. 4906.0)," 2005, cited in Australian Institute of Family Studies, "Who abuses children? CFCA Resource Sheet," September 2014, <https://aifs.gov.au/cfca/publications/who-abuses-children>

<sup>30</sup> Australian Institute of Family Studies, "What is child abuse and neglect?: CFCA Resource Sheet," September 2018, <https://aifs.gov.au/cfca/publications/what-child-abuse-and-neglect>



preferences, and respecting the person's preferences about who to involve, when and where—and who to avoid.

- 86 For context, it is important to note that consumers/survivors and carers/family in the systemic advocacy space sometimes have conflicting views about reforms. In a general way, some carers/family tend to advocate for safety above all else, which comes into direct conflict with the most common consumer/survivor priority for human rights above all else. Issues related to trauma in families can also be a source of great tension between the two lived experience groups. This is a trend I have noticed in my advocacy work in a multitude of different contexts, for example, when carers want to be able to have someone admitted or placed on a community order, and consumers want to retain their right to equality before the law. It becomes an issue when policy makers put the views of carers/family above those of consumers/survivors, driving compulsory, risk-averse, paternalistic practice, rather than rights-based, recovery-oriented, trauma-informed practice. Carer/family views matter, of course, but their expertise lies in their own needs, not in the needs of consumers/survivors.

***Information and support needs of families and carers with young people affected by trauma experiences***

- 87 Families and carers need to understand the prevalence and impact of trauma on young people, as well as the many different types of trauma, and how trauma can be related to any type of mental health challenge, regardless of diagnosis. Families also need information that balances the dominance of biogenetic messages about mental health challenges. Many people are still being told, for example, that 'mental illness' is a result of 'a chemical imbalance in the brain'. This is an outdated theory which was never backed up by research, yet it is still in circulation, and is, frankly, dishonest. It would be helpful for families to understand that, for many people, mental health challenges can be seen as a normal and meaningful reaction to trauma. I suggest that instead of this much needed information, families and carers are instead too often provided biomedical explanations for the young person's distress.
- 88 Perhaps the most important message we can give families and carers about trauma is how critically important it is that they believe disclosures of trauma by young people. Not being believed can have a devastating impact on trauma survivors. After this, important messages for families about trauma would align with trauma informed principles, such as the importance of being trustworthy, creating safety and supporting the young person's voice and choices.
- 89 Many types of trauma occur outside families, however child abuse is most likely to be perpetrated by a family member. Disclosures, even suspicions, of child abuse, can tear families apart. Families need support and information about signs of child abuse, what

steps to take, and where to go for more support. Other family members besides the consumer/survivor may also need intensive trauma support services.

### **Lived experience and peer support workforce**

#### ***Providing lived experience and peer workforces with training, development, capabilities and skills to enable roles designing, delivering and providing oversight of mental health services***

- 90 It is critical that all practice related training and development for consumer/survivor workers is provided by experienced consumer/survivor educators.
- 91 There is a growing demand for consumer/survivor roles as consultants and advisors, due to an increase in coproduced projects and research. Investment needs to be made in training and development, by experienced consumer/survivor workers, for these roles, as well as in the peer work space.
- 92 Training opportunities could benefit from greater depth and breadth for peer workers, and other lived experience roles. Currently the Certificate IV in peer work, and the short course in Intentional Peer Support (IPS) are the two primary development opportunities. In terms of depth, there would be significant value in developing more training that addresses a deeper knowledge of the consumer movement and our history of debates and conclusions on many different issues in mental health. This kind of training would be useful for all lived experience workers, and particular valuable to consumers moving into policy, leadership and oversight roles.
- 93 Breadth training could add significant value in areas such as critical thinking, influence and negotiation, coproduction, practice supervision, leadership, research, governance, policy and management skills, depending on career interest. Potential learning streams in these and other breadth topics could be targeted towards different career pathways.
- 94 Lived experience workers require access to consumer/survivor perspective supervision (or co-reflection) as both a development and support opportunity. Access to co-reflection groups of other consumer/survivor workers would also assist development.

#### ***Priorities for strengthening the skills, training and development of lived experience and peer support workforces and better supporting lived experience workers***

- 95 Dedicated learning spaces should exist for consumers/survivors and carers/family to learn in separate spaces, as well as some joint spaces. While both groups draw on lived experience, there are some fundamental differences in philosophy and focus between the two workforces, and peer work in each group is driven by different types of

experiences. Consumer/survivor peer work is grounded in human rights, trauma and welcoming of diversity—and actively avoids stepping into ‘helping’ roles. Carer/family peer work is grounded in helping and supporting and providing information. There are certainly some overlaps, such as the use of lived experience, but the differences are significant.

- 96 The demand for consumer/survivor workers is growing very rapidly for a small workforce. An important opportunity to support this demand growth may be to provide funded internships for newly trained peer workers, in order to develop skills, and identifying career progression pathways into more senior lived experience roles.
- 97 Currently most peer worker roles are in clinical services, which is the most complex and traumatic part of the mental health system. It's also the environment where peer work practice is most likely to be co-opted by biogenetic and other clinical paradigms. For these reasons, inpatient settings are not the best place for a newly trained peer worker to begin their practise. Instead, funded opportunities for more peer workers in the community sector, or in outpatient clinical settings, or in an increasing number of peer-run services, will provide a better environment to skill up new workers in more supportive environments.
- 98 Depth training could also develop knowledge and skill in consumer/survivor peer specialities, like the hearing voices approach, trauma, alternatives to suicide, Emotional CPR, peer respite and crisis work, human rights and advocacy, co-reflection and group facilitation.
- 99 Another priority that will assist lived experience workers is training for non-lived-experience workers. Many consumer/survivor workers experience trauma, tokenism, discrimination and other barriers to a healthy and welcoming workplace<sup>31</sup>, in fact I have experienced all of these issues myself during 15 years of working in the sector. In part this can be due to co-workers not understanding lived experience roles and growing knowledge amongst the broader workforce would be valuable.
- 100 Issues of tokenism, bullying, harassment, discrimination and co-option need to be taken seriously by the sector, and addressed. It may be that HR departments need to be better briefed to understand these issues, and create more supportive workplace cultures.

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<sup>31</sup> WA Peer Supporters' Network. *"The Peer Workforce Report: Mental Health and Alcohol and Other Drug Services."* 2018. <http://www.comhwa.org.au/wapsn>

***Contribution of people with lived experience to the development of policy, practice and research***

- 101 Throughout my career, I have noticed myself, and other consumer/survivor workers, open up fresh perspectives on old issues for the mental health sector. When we read documents, hear about issues or reflect on opportunities, our lens is often different to the status quo. Having been in services, and having a lived experience of distress and recovery, means that we are constantly finding ways to shift mental health services to better meet the will and preferences of the people using services.
- 102 For example, a clinician once told me he was organising for nurses who seclude consumers to provide a debriefing to the person afterwards. He thought I would think it was a positive improvement, but what I noticed is that this approach could recreate the dynamics of child abuse for a trauma survivor, where the person who hurts you is also the person who helps you. Instead, I suggested that an independent, or wholly new person provided debriefing (and that the best strategy, of course, was to stop secluding people altogether).
- 103 Another example comes from a training course to nurses, who were speaking about how they believed that 'aggressive patients' were generally angry. Yet I knew, from my own experience, and years of talking and working with fellow consumers/survivors, that this is more often going to be a fight reaction that comes from fear, rather than striking out in anger (although of course, sometimes there are good reasons to feel angry in a psychiatric inpatient unit). This was a new idea to many of the nurses, and it changed the way they thought about responding to people. The conversation shifted from wanting to control people, to wanting to help people to feel safe.
- 104 Any good service, no matter the industry, will improve by listening to the people that it serves. But mental health services have a very particular obligation to elevate and privilege consumer/survivor voices – precisely because of the many rights restrictions and breaches we experience in services. Mental health services are still a long way from being rights-based, respectful services. For too many consumers/survivors, they can feel more like prisons than healthcare. Ensuring that consumers/survivors can speak about every issue that affects our lives is a critical part of driving change.

***Ensuring that people with lived experience have a meaningful and enduring voice in decision-making at all levels of system design, policy planning and setting and service delivery and legislation***

- 105 There are many reasons why consumer/survivors don't always have a meaningful and enduring voice in decision making at all levels.

- 106 Most commonly, we're not involved in decisions because we are not invited into decision making roles or spaces – but rather we are brought in as advisors, or participants, or a consultation group. Or we are employed after all the major decisions have been made. Or we're invited onto projects where decisions are made outside the team meetings. Or we're invited to join a research project, after the funding and ethics (and therefore major decisions) have all been made.
- 107 There are not yet enough consumer/survivor roles in all the places where decisions are made. And the roles we have are often not senior enough to make decisions.
- 108 Too often, just a single consumer/survivor advisor is employed into teams, and at one of the lowest pay grades, and is tasked with the expectation of creating culture change and being an advocate for change. This does not set people up for success.
- 109 There is a lack of formalised training for consumer/survivor advisors, consultants, advocates and policy experts. Instead, we tend to learn on the job, through co-reflection and mentoring with more experienced consumer/survivor workers, and through reading consumer-perspective literature.
- 110 The often intolerably painful nature of this work can cause us to leave. Bullying, discrimination and tokenism take a toll on lived experience workers, but perhaps one of the biggest issues is being exposed to past traumas, over and over again. I know that I willingly go into these spaces because I am passionate about influencing change, but nevertheless, most roles I've had come with an expiry date, after which the emotional impact becomes too great. For example, I have often sat in meetings where clinicians laugh and joke about practice that for me, and others, has been deeply traumatic. I once had a colleague grin and tell me 'you're lucky we don't lock you all up.'
- 111 At DHHS, I once spent three solid weeks sitting on a review panel that examined the deaths of 12 individual people in inpatient units. Every day for three weeks, I intentionally tried to seek out the person's voice in the various notes and reports, to find their story of why they died, and help give it voice. As a consumer/survivor, it is not my place to seek 'clinical objectivity', but to seek out the person and connect. I know that I made important contributions in this space, highlighting issues that the clinical reviewers missed. And yet, it was excruciatingly traumatic. In different work roles, I have sobbed in my office, hyperventilated in the toilets, and have always needed supervision and therapy. The point I am making here is *not* that consumer/survivor workers shouldn't go into these spaces because it's not safe – but rather that we need to make these spaces safe. I think most workplaces, for consumer/survivor workers, are not unlike what many male-dominated workplaces felt like for women joining the workforce in the 1960s. The sector and DHHS need to do better.

112 Change in this area requires:

- (a) Making workplaces safe for consumer/survivor workers. This is a complex area, and would benefit from greater focus, and possibly learning from what has worked for other marginalised groups in the workplace, and/or what has worked to create safety in carceral work environments. While the sector uses the language of 'compulsion' and 'restriction', from a lived experience perspective these are violent systems that frequently use threats and actual force – and this influences workplace cultures.
- (b) A professional development pathway for consumer/survivor advisors, consultants, advocates and policy experts to move into more senior lived experience roles.
- (c) Funding more positions, and with pathways to more senior roles, with equal pay.
- (d) Protecting lived experience roles by making them 'designated roles'.
- (e) Creating incentives to employ more consumers/survivors in governance and executive roles.
- (f) Possible establishment of more formalised mentoring arrangements for experienced lived experience workers to support newer workers.

113 A commitment to moving up the ladder of participation towards increasingly more coproduction and consumer/survivor led projects is a fundamental plank for improvement. Most work in the sector still excludes consumers/survivors, and the next biggest group of work tends to use tokenistic consultation: where a big group can offer small feedback on something that is already mostly planned. We have no say in whether or not our advice is taken and often we never find out what happened with our advice. Often these opportunities are unpaid or at very low levels of remuneration. Moving up the participation ladder can be improved by:

- (a) Widespread training on coproduction, codesign and consumer/survivor-led practices.
- (b) Establishing a dedicated funding stream, with flexible timeframes, for innovative coproduced and codesigned project work – this can give people practice in new ways of working, build confidence, and provide opportunities for lived experience workers to develop broader skill sets.
- (c) Commitment (and incentives) to a growing proportion of work being codesigned, coproduced, and consumer/survivor-led.

***Mechanisms to enable service provider organisations that are governed and delivered by people with lived experience***

- 114 While it was encouraging to see a recommendation for a lived experience delivered service in the Royal Commission's interim report, this is, of course, still a big step away from consumer/survivor-run organisations. I urge the Royal Commission to include recommendations in its final report which move us closer to this goal, because these are the spaces where the workforce can most flourish, and where innovative practice can be best nurtured.
- 115 Recognise that a lived experience run, service delivery organisation needs to be run by people with the type of lived experience that its participants have. So if it provides service delivery to consumers/survivors, it needs to be a consumer/survivor run organisation. The reverse is true for a carer support organisation, It is unhelpful to try and include everyone in a single model, and can instead lead to compromised scope of practice, and conflicts of interest.
- 116 The following mechanisms could be implemented to enable the emergence of service provider organisations that are governed and delivered by consumers/survivors:
- (a) establish a thinktank for consumer/survivor led services with 70-80% consumer/survivor leaders and 20-30% mentors with expertise in innovation, governance and service design (from within mental health, and also from the disability sector, where there is greater experience);
  - (b) survey the existing consumer/survivor workforce for interest, ideas, and relevant skills and experience;
  - (c) fund a staged approach that can grow over time. For example, fund small peer-run initiatives that allow skill development through experience. This could include funding small groups of consumers to run smaller scale peer support projects, like regular group programs at a neighbourhood house, or short-stay recovery camps, or even social enterprises. Funding could include access to lived experience mentoring, and/or other relevant mentoring or skills training;
  - (d) incentivise services to put more consumers/survivors into management and governance roles, building expertise for future peer-run initiatives.

**Lived experience of trauma and recovery**

- 117 The remainder of this statement includes my personal lived experience of trauma, distress, the mental health system, recovery and healing. I have written this because it gives another lens on most of the issues raised elsewhere in my statement and may help readers to understand. I have also written it because, while this is my truth, it is not

only mine. I know that thousands of other consumers and survivors have similar stories – and not always with the good ending that I was lucky to find, or with the opportunity to be heard that I have in this process. This is not a pleasant story to read. But I hope it is useful.

- 118 My history of trauma is complex. As a young child, I experienced the effects of intergenerational trauma. My mother had been a pregnant teenager in the 1960s, and like many young women back then, she was put in a 'charitable institution' in NSW during her pregnancy, then forced to give up her baby for adoption. I never knew about my Mum's own trauma until years later, when she was dying and began to talk about her lost baby, and her lifelong shame. But like me, no-one ever supported my Mum for her trauma. She had at least two psychiatric admissions that I know of, and also like me, she did not want psychiatric medication and did not stay on it for long.
- 119 My parents split up when I was in primary school, and for periods of time, there was no other adult to see my Mum when she would lose control. Sometimes she was neglectful, disappearing for periods of time, and I would need to feed and look after my little brother and sister. Sometimes she was extremely violent, beating me up and down with hairbrushes and wooden spoons, screaming at me in fury. However, it was not all abusive by any means. My Mum was also loving, often fun, fiercely protective, and helped instil in me a belief that I was smart and strong. This kind of parental experience can have very particular traumatic impacts, as the person who I looked to for protection and love, was sometimes also the person I was most afraid of.
- 120 My second experience of trauma involved antisemitic bullying. I had grown up Jewish, on my father's side. When I told the local kids, who I used to play with behind our block of flats, they pushed me away. Suddenly, if I wanted to ride my bicycle to the milk-bar, my old friends would yell out religious slurs, and throw rocks. Twice I was beaten up by other children. I became afraid to go outside, or to tell others about our faith. I changed schools, twice, to get away from the bullying.
- 121 The combination of these traumas made life very scary, and contributed to my decision, aged thirteen, to run away from home. On the first day, an adult man approached me and encouraged me to go with him to a regional town, so the police wouldn't find me. I stayed with this man for two weeks, in an abandoned, derelict farmhouse. He told me that we had to hide, because the police would be after me, and because his older father was part of a cult that would hurt me. So even though I could have left, I was too scared to try. He brought me small amounts of food, whiskey, and said he was planning to bring me heroin and I would love it. During those two weeks he behaved in ways which, looking back, are best described as grooming. And during that time, he raped me.



- 122 After a fortnight, the police found us at this farmhouse, and my abuser and I were put together in the back of a paddy wagon. He urged me not to tell the police about the sex, because they would lock him away. I agreed, and when the police questioned me, I refused to speak. My mother came to take me back home. On that first night she said to me 'I don't want to know what happened while you were away. You're not to speak about it, ever.'
- 123 The next day I was taken into a Melbourne police station and was interviewed by an officer. First I was taken to a small room and the officer told me that I was in big trouble, and would probably be going to a girl's home. Then she left me alone for what felt like an hour or more. I was very frightened. When she came back I was grilled about what happened when I ran away. But both the man, and my Mum, had told me not to speak, and so I didn't. Eventually, I was sent home.
- 124 This last trauma can best be described as abduction and child sexual abuse, although for most of my adult life I didn't call it that. Inside my head, it was 'that thing that happened when I was thirteen.' This experience was never formally reported as a crime, and so I never saw justice. I never received counselling or support because I had to keep it secret. And I was punished, by the police and my mother, for running away. I had to make sense of it on my own, and so the conclusion I reached was that it was all my own fault, that I was bad and disgusting. I kept the secret of this trauma for a great many years. I had not spoken of it to anyone when I entered the mental health system.
- 125 In my twenties, prior to entering the mental health system, I was a successful young executive, earning a very good salary and with a bright future. I was slender and attractive, had lots of friends and most people would have considered me successful. Most people didn't know about my childhood, or that I lived with suicidal urges, and bouts of despair. I coped by being a high achiever, and keeping constantly busy. But as time passed, it was harder and harder to hold it together.
- 126 By the age of thirty I had been diagnosed with 'depression' by a private psychologist. I briefly saw a private psychiatrist who prescribed antidepressant medication.
- 127 Within months, after attempting suicide, I was in a public psychiatric hospital, my voice screaming at me, diagnosed with 'schizophrenia' and was told that I had a serious brain disease, I would need psychiatric medications for the rest of my life, and that I would probably never work again. I thought my life was over.
- 128 For nine years, off and on, I was a patient of the public acute system, with about 10 hospitalisations and more Emergency Department visits than I can remember. I used other services too, including the psychiatric outpatient clinic, community support services and often the police or ambulances would bring me to hospital. I went onto a

Disability Support Pension, and I attended a disability employment program. In between, I attended art school but that became hard to maintain. For a time, workers encouraged me to enter supported housing, but I resisted this.

- 129 My prescribed psychiatric medication expanded over time. Neuroleptic medication (so-called 'antipsychotics') were added, then mood stabilisers, then benzodiazepines. The dosages kept increasing too. At one time, I was on three times the maximum recommended amount for my 'antidepressant'. Initially, I believed that the medication would work. I believed it when the doctors told me I had a 'chemical imbalance in my brain' and that 'the pills would correct it'. I didn't know that the idea of chemical imbalances as a cause of 'mental illness' was just an unproven theory. But over time, I stopped believing this, because all the pills were not helping. The best thing I can say is that I was so drugged up, that sometimes I was less distressed. But I felt like a zombie.
- 130 As my faith in the medication and the psychiatrists decreased, I would try to take less of the medications. Sometimes I would stop them. This led to more of my admissions being compulsory, where I had no choice but to take the pills. One time, before discharge, my psychiatrist told me that I needed to agree to get depot injections of my 'antipsychotic' or he would put me on a Community Treatment Order. I didn't know my rights, or that this was unethical, so I agreed. That period of time is blurry in my memory because I was massively sedated. I used to sleep for 12-16 hours a day and I gained a massive amount of weight, becoming morbidly obese.
- 131 My diagnosis changed over time. Before I entered the hospital system I was diagnosed with depression, and then depression with psychotic features. The hospital said it was schizophrenia, and then schizoaffective disorder. Over time, as nothing was helping and I became more despairing, I began to self-harm and make suicide attempts. I could see no reason to keep living, and I increasingly believed the voice I heard, which told me I was evil. I didn't want to live, and I didn't think I deserved to live.
- 132 I remember one time when I attempted suicide while I was an inpatient. I often used to believe that I was a bad person, and that I should protect the world by killing myself. The attempt failed. When the staff found me, I was forcibly walked straight to a seclusion room and locked in by myself. This was a terrifying and deeply shaming experience. There was nothing whatsoever to distract me from the overwhelming emotions, and I concluded that I must indeed be a terrible person, because they were punishing me. I remember hitting myself in the head, over and over. Looking back, I think this was absolutely cruel and inhuman treatment, and a very serious rights violation. I wish that those staff had instead been able to sit with me in a quiet room, show some compassion and empathy, and just asked me what had led me to feel this way.

- 133 Another time, I was given a course of 12 Electroconvulsive Therapy ('ECT') treatments. Apparently, I consented to this treatment, although I cannot remember why, or whether the consent process was adequate, because I have permanently lost memories around that time. I have had to rely on journal entries to reconstruct some of these memories. The ECT had a short-lasting positive effect in that my mood lifted and I was discharged from hospital. But within about three months, these positive effects wore off, although some memories never came back. There have been times when friends and family have been shocked that I don't remember past significant conversations or moments. I have grieved over these lost memories, and particularly worry about what parts of me might be lost forever because no-one else knows about them. A part of myself was stolen by ECT, a part that should be inviolate. On reflection, I wish I had never consented to ECT. It had a most serious and violating impact, and no lasting benefit at all. I often wonder if the brief positive effects came about simply because I temporarily forgot why I was so despairing and ashamed.
- 134 As my self-injury increased, the diagnosis of 'Borderline Personality Disorder' ('BPD') was added to my file, and that had a new kind of negative impact on my experience of mental health services. Suddenly I was treated very differently. Instead of getting more 'help' than I wanted, I couldn't get any help at all. Staff told me I was 'attention seeking', I was turned away from services. One time I went to an ED because of a particularly deep injury and a clinician stitched me up without a local anaesthetic. She said to me 'you obviously like pain so I won't waste any anaesthetic on you.' This made me feel like I was less than human. It reinforced all my beliefs about deserving to die.
- 135 Another time, my psychologist called the police to do a welfare check on me at home. I had been self-injuring and was not fully clothed when the police came into my home. I was huddled in the corner of my lounge room, under a table, as the police yelled at me to 'drop the knife', which I did. They grabbed me and took me to hospital by force, without stopping to let me get a top to cover up my breasts. I was put in an open cubicle in the Emergency Department and still no-one brought me a hospital gown or anything else to cover myself with. It is difficult to estimate how long I was in that cubicle, exposed, and without any basic dignity or humanity, but it would have been at least an hour, if not several hours.
- 136 Not once during my experience of mental health services, which must have comprised of thousands of hours and a great many people, did a single person ever ask me about trauma or my childhood. In the early days it was on my mind, but I was too ashamed to ever bring it up. I thought, if what had happened to me was important, that surely one of these specialist people would ask me about it. But they told me I had a disease, an illness. There seemed to be no space for the idea that my distress was a meaningful response to terrible things that had happened to me.

- 137 The first stage of my personal recovery came in two parts. A community support worker (an art therapist by occupation) supported me to find hope again, and to connect with a creative consumer/survivor community of fellow artists. This belief that my life could change, that my future could hold something positive, was a critical beginning, and aligns with the hope and connectedness elements of recovery-oriented practice. In fact, it was at this service, a few years later, that I got my first job in mental health, and my previous support worker became my team leader instead.
- 138 The second part of stage one came from learning coping skills, after I was referred to a Dialectical Behaviour Therapy ('DBT') program at the hospital outpatient clinic. DBT had both positives and negatives for me. The positive impact came from learning new coping skills, which meant I was able to wean myself off psychiatric medication (although I had serious and protracted withdrawal effects, for which it was difficult to get support), stop self-injury and manage my distress independently.
- 139 However, there were some negative aspects of DBT. Again, my past trauma was never acknowledged or discussed. Instead of being told that I had an illness, now I was told that my personality was 'disordered' and that I was 'wilful'. These aspects of DBT actually worsened my shame about past trauma. Also, my DBT therapist required me to commit to stop self-injury, and that if I did it, I couldn't see her for 24 hours. This was very dangerous for me, because self-injury helped me to cope, and without it, I often felt like suicide was the only option left to me. DBT enabled me to get free from mental health services, it increased my independence and sense of self-efficacy, however it also deepened my beliefs that I was an inherently bad person. From a recovery-oriented perspective, DBT contributed to being able to live a more meaningful life (with coping skills and no drugs, I could work again) and a feeling of empowerment (I could manage without medication and hospital admission). However, from that same perspective of being recovery-oriented, DBT damaged my identity. Further, my self-injury returned a few years later. I believe this was because the fundamental reasons for me using self-injury (i.e. the trauma) had never been addressed in DBT.
- 140 Several years later, still coping on my own, but secretly hating myself and my life, I came across other consumer/survivor leaders, including Ron Coleman (Scotland), Jacqui Dillon, Pete Bullimore, Eleanor Longden and Rachel Waddingham (England). As I listened to their stories of recovery and emancipation, I realised that they had something more than me. I had 'a life I could cope with'. But they had rich lives that they loved. I noticed a similar thread through all of their stories. Their recovery had not been about coping, it had been about making sense of their experience. At the heart of this, was understanding their emotional distress and mental health challenges as a meaningful response to trauma. All of these people had been diagnosed with 'psychotic'

conditions like me, and yet all of them had also experienced significant trauma, also like me.

- 141 I began to see a private clinical CBT psychologist, with the aim of exploring my own childhood trauma, and finding my own kind of healing. For the very first time, in 27 years, I told another human being about 'that thing that happened when I was thirteen'. It was frightening and intense. This therapy didn't go well. Rather than beginning by ensuring I was safe, we moved very quickly into me disclosing the full story. My voice increased in intensity and terror, and I began dissociating and self-injuring again. Then I began making attempts on my life because I was overwhelmed with the belief that I was an evil person.
- 142 This led to my last three psychiatric admissions around 2009. I have particularly painful memories of one admission. At the time I was reliving memories of the childhood sexual abuse, feeling trapped, vulnerable, and like I was dirty. The hospital sent police into my home and they took me to hospital. I was taken into the High Dependency Unit and made to strip off all my clothes to be searched. Then I was drugged up with medication. This admission process felt like a recreation of my abuse: being taken away, locked up, stripped naked, drugged. As I look back on that admission process, it is the very furthest thing from trauma-informed practice that I can imagine. It is no wonder that I tried to escape ('abscond') many times.
- 143 In those last admissions, I was finally able to tell the psychiatrists about my past trauma. They did not offer any therapy, but instead put me back on all the medication again, and worse, they contacted my psychologist and told him not to speak to me again about my childhood. This felt like an absolute betrayal. The psychiatrist told me that I just had to forget what happened in the past and let it go. I remember her saying that she wished she could diagnose me with Complex PTSD, but it wasn't recognised yet, so she couldn't. In that meeting, I resolved to kill myself, because that clinician had just taken away my last hope of healing.
- 144 Thankfully, within a day, I was visited by Dr Rufus May, who was out in Australia from the UK. Dr May is an NHS psychologist who specialises in hearing voices. In just one extended therapy session with me, on the inpatient unit, he helped me find a way out of my dilemma, find a way to reduce the terror of my voice, and showed me a way to begin to have compassion for myself. My hope returned, but I knew the hospital would never help me to heal, and could easily get in the way.
- 145 I lied to my psychiatrist in order to get discharged and not be put onto a Community Treatment Order. I knew that if I was forced to take the medication for too long, I wouldn't have the cognitive ability to do therapy. I pretended that I liked the medication, I wrote some goals for my recovery, I promised to see a CAT team member for the first

few days after discharge. It worked, and I was discharged without any ongoing force from the service.

- 146 Once I was discharged, and the CAT team stopped visiting, I got rid of all the medication, and I contacted the Centre Against Sexual Assault ('CASA'). I was able to see a sexual assault counsellor, who supported me to process the past trauma in a safe and very healing way. My counsellor used creative therapies and feminist counselling. She gave me the words 'abduction' and 'rape' and 'child abuse'. She told me I could still lay charges. That I could access victims of crime compensation. In counselling, I learned about grooming and Stockholm syndrome, which explained away so much of the shame that had been tormenting me for most of my life. In parallel with this counselling, I used strategies from the Hearing Voices Approach, and informal peer support, to begin working with my voice, as part of my healing. In just a year or so, my shame was dramatically reduced, and my voice, while still present for some time, no longer terrified me. I finally reached that outcome where I wasn't just coping, I felt like a worthy human being.
- 147 This part of my recovery was also aligned with recovery oriented practice: the counselling about shame and abuse helped me to build a new identity, where I was no longer a 'psychotic, hopeless, evil person', but instead I was a 'victim of trauma, who had done her best to survive'. It was recovery oriented because it gave meaning to my experience: I came to see that my distress was not an illness, it was a normal response to extremely abnormal experiences. It was empowering because I had choices and rights, and I was an active agent in my healing, rather than someone who just had to take her pills.
- 148 My recovery, like most, has not been about 'cure'. I do not believe there is any such thing for these experiences. But it has been about creating a life worth living, that I value. And it has been about making sense of my past, so that when I become distressed these days, it is mostly something I can understand and find ways to address.
- 149 It is about 18 years since I was secluded and had ECT. It is 10 years since I was last admitted to hospital against my will, or forced to take psychiatric medication. Yet even now, sometimes I still have nightmares about these experiences. At times when I am emotionally distressed, I have a terror of seeking help from any health practitioner, for fear I may end up subjected to these practices again. I don't feel able to share my honest feelings, not even with a GP. For me, mental health services did enormous, long-lasting harm. I think it is a tragic irony that the place that should have helped me heal from trauma, instead created even more trauma for me.

- 150 The mental health system failed to help me, and it often caused greater distress and disability. It failed utterly to understand or respond to trauma because every service and practitioner viewed my experiences through a 'disease' lens, rather than a 'trauma' and recovery-oriented lens.
- 151 The many restrictions and breaches of my fundamental human rights, by mental health services, are difficult for me to reconcile. I would not support such severe human rights restrictions, even if psychiatric treatment was reliably helpful and supportive. But given the fairly weak efficacy of most psychiatric treatments, the failure to offer anything except pills and ECT, the complete ignoring of the wide prevalence of trauma – I believe that human rights restrictions in mental health services are entirely unreasonable. In particular, I point out that many of my experiences in psychiatric services demonstrate a breach of the absolute right to freedom from torture, cruel, inhuman and degrading treatment. There are no excuses for breaching absolute rights, and it is astonishing to me that this continues to happen in our contemporary society, let alone in health services.
- 152 And finally, I point out that all those years of expensive, intensive treatments and rights restrictions and breaches were to no avail. In the end, without any rights restrictions or medications or psychiatrists, in about a year, and at very low expense, a counsellor and some peer workers supported me to do life changing healing. I have never been back to a mental health service again.



sign here ► \_\_\_\_\_

print name Indigo Daya

date 12 May 2020



**Royal Commission** into  
Victoria's Mental Health System

## ATTACHMENT ID-1

This is the attachment marked 'ID-1' referred to in the witness statement of Indigo Daya dated 12 May 2020.



## Curriculum Vitae: Indigo Daya

I have worked in consumer perspective roles in mental health for more than a decade, including service delivery, advocacy, policy and, most recently, academia. My interests lie in strategic work that elevates the voices of the people who are subjected to coercive mental health systems, advancing human rights and in reconceptualising 'mental illness' as a meaningful response to adversity, diversity and trauma.

### Qualifications

Bachelor of Business (Communication)  
Queensland University of Technology, 1990.

Diploma of Management  
Monash University / Australian Institute of Management, 1995.

Certificate IV in Training and Assessment  
Wodonga TAFE, 2010

### Publications

Daya, I., Maylea, C., Raven, M., Hamilton, B., and Jureidini, J. (2020). Defensive rhetoric in psychiatry: an obstacle to health and human rights. *The Lancet*, 7(3), p.231.  
[https://doi.org/10.1016/S2215-0366\(19\)30534-6](https://doi.org/10.1016/S2215-0366(19)30534-6)

Daya, I., Hamilton, B. and Roper, C. (2020). Authentic Engagement: A conceptual model for welcoming diverse and challenging consumer and survivor views in mental health research, policy and practice. *International Journal of Mental Health Nursing*, 29, 299-311.  
<https://doi.org/10.1111/inm.12653>

Daya, I. (2009). I am the person of whom you speak. *Psychosis*, 7(4), 359-365.  
<https://doi.org/10.1080/17522439.2015.1105283>

### Sessional Teaching

- 2020. School of Nursing, University of Melbourne
- 2018 – 2019. School of Social Work, University of Melbourne
- 2019—2020. School of Social Work, Latrobe University
- 2019. School of Global, Urban and Social Studies, RMIT
- 2016 – 2020. School of Occupational Therapy, Australian Catholic University
- 2015. School of Psychology, Swinburne University of Technology

### Fellowships

2018—Present. Honorary Fellow,  
Melbourne Social Equity Institute,  
Faculty of Law, University of Melbourne.

2014—2016. Adjunct Research Fellow,  
Swinburne University of Technology.

### Research Grants

2018. Melbourne Social Equity Institute.  
Interdisciplinary Seed Funding.  
(\$46,520)

## Recent employment history

Ordinary Member	2020—Present Committee of Management, VMIAC
Consumer/Survivor Perspective Consultant	2019—Present Self-employed
Consumer Academic	2019—Present Centre for Psychiatric Nursing, University of Melbourne
Consumer Academic	2019—Present School of Global, Urban and Social Studies, RMIT
Strategic Projects Manager	2018—2019
Policy & Communications Manager	VMIAC (Victorian Mental Illness Awareness Council)
Human Rights Advisor	
Senior Consumer Advisor	2017—2018 Office of the Chief Psychiatrist, Department of Health & Human Services
Senior Policy Advisor	2016—2017 Consumer Portfolio, Mental Health Branch, Department of Health & Human Services
Board Director	2014—2016 Uniting Prahlan Mission
General Manager	2014—2015 Consumer and Carer Advocacy, MI Fellowship (now Wellways)
Program Manager	2009—2014 Voices Vic, Uniting Prahlan Mission
Independent Consultant	2011—2014 Self-employed
Support Worker	2005—2009
Arts Program Coordinator	Second Story, Uniting Prahlan Mission

## Conferences

26 conference papers since 2016.

Recent papers include:

Daya, I. and Edan, V. (2019). A Declaration of Dreams: Victorian consumers launch a collective vision. *Psychiatry, Psychology and Law: Collaboration and Challenges Across the Global South*, ANZAPPL, Singapore.

Daya, I. (2019). Family Involvement: Over-rated or Underdone? Keynote speaker, *Bouverie Mini Conference*, Melbourne.

Daya, I. (2019). Welcoming diverse and challenging consumer/survivor views and voices. *Victorian Collaborative Mental Health Nursing Conference*, Melbourne.

Maylea, C. and Daya, I. (2019). Physical health: A human rights issue. Keynote speaker, *Equally Well National Forum*, Melbourne.

Daya, I. (2019). A Clarion call: Stop hurting us, start helping us. Keynote speaker, *Reawaken Conference*, Adelaide.

Daya, I. (2019). Human rights and citizenship in community mental health. Keynote speaker, *TheMHS Summer Forum*, Sydney.

Daya, I. (2018). The Mad Agent Emerges: Reflections on human rights after two years on the inside of government. Keynote speaker, *World Hearing Voices Congress*, The Netherlands.