Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF RITA BROWN

I, Rita Brown, President of the Australian BPD Foundation, of PO Box 942, Bayswater VIC 3153, say as follows:

Background

1 I am the President of the Australian BPD Foundation. I am presenting this witness statement in my role as President of the Australian BPD Foundation, and am authorised to do so. This statement is also informed by my role as a carer and working within a mental health service. This statement is not made on behalf of Eastern Health or Spectrum Personality Disorder Service.

2 The Australian BPD Foundation (**the Foundation**) is a volunteer led charity advocating for and representing people with lived experience of Borderline Personality Disorder (**BPD**) and their families, friends, carers and clinicians. Our vision is that people with BPD are acknowledged as having a legitimate mental illness and require access to appropriate treatment and support for themselves and their families/carers.

3 The mission of the Foundation is to promote a positive culture to support the recovery journey of people with BPD and their families/carers. The Foundation also supports clinicians, health care personnel and researchers working in this field and acknowledges everyone who works towards a better recognition of BPD.

4 I became the President and Chair of the Foundation nearly two years ago. My role as Chair and President is to further the objectives of the Foundation as outlined in our Constitution:

> *"…to promote the prevention of… …"Borderline Personality Disorder" (BPD) by promoting access to appropriate treatment and adequate service provision for people with BPD and their families/carers."*

5 Key ways the Foundation carries out its objectives are by encouraging open, stigma free dialogue and involving consumers and carers with lived experience of BPD in everything the Foundation does. In my role as President some of what I do is informed by my lived experience, though I aim to 'hold' multiple perspectives and advocate for everyone impacted by BPD. I especially advocate for the lived experience voice (consumer and carer) to be included in the development of policies and programs and

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

feel very strongly that people who are being consulted for their lived experience should be remunerated.

6 I am employed by Eastern Health as a carer consultant with Spectrum Personality Disorder Service. My role is to represent the views and opinions of carers and advocate for their needs within the service and statewide. I support and facilitate workshops for carers and inform clinicians of the views and needs of carers. As the consumer role is currently vacant, I also try to represent the consumer voice as heard in my role at the Foundation.

7 I am a volunteer co-facilitator of the BPD Carer Support Group run monthly by Mind Australia. Attached to this statement and marked 'RB-1' is a copy of my curriculum vitae.

Definition of carer

8 I use the term carer or families to describe those who, on a voluntary basis, are actively involved in caring for, or about, a person with a diagnosis of BPD. This may include a family member, a partner or spouse, a friend or other person. It may also include a young child supporting a parent or sibling. They may or may not live with the person they care for (or about) and they may not identify readily as 'a carer' – instead they may see themselves doing what a caring person does to support someone in distress.

9 Caring 'for' is often taken to be physical actions. However, being a carer can include caring 'about' someone in a very distressed emotional state. I wish to acknowledge the emotional and/or physical abuse that may have happened within families and acknowledge the impact that such abuse has had on their wellbeing. However, over the years I have had contact with many families where trauma or abuse has not been a factor in their child's life. Sometimes, especially when the person with BPD is unwell the family may be 'blamed' by the person as the cause of all the person's difficulties rupturing the family. In situations like this, the person with BPD may wish to disconnect from their partner/family of origin though that family is still caring and concerned about the person. Often, they may still be supporting the person financially or even still living under the one roof.

10 A note regarding the use of the term 'consumer': I wish to acknowledge that many people with lived experience of mental illness prefer not to use the term consumer. Whilst it is far from perfect, I feel it's the best word we have available at the present time and I have used it through much of my statement.

Changes needed to create a mental health system where the needs of people living with mental illness are fully met, and their families and carers are supported

11 There are several changes to the mental health system that are necessary to ensure the needs of people living with mental illness and their families/carers are fully met. People will be able to access support, care and treatments early in the development of their mental illness, in particular BPD, and early in any crisis or worsening of mental health. They will not just be told that it is 'adolescent behaviour'.

12 'Care teams' need to be present in time and place with the person and not pulled by all the pressures experienced by an overstretched and bureaucratic system. The person needs to be seen as a human being who deserves the highest level of care, not just as a diagnosis. The care teams need to work with the person and their families/carers to move towards whatever is necessary and possible in terms of greater health, wellbeing and care in all situations.

13 Treatment will be person centred, with the ability to step-up and step down as needed. The system is offering a service and should adapt to the needs of the person, not expect the person to adapt to what a service (often designed by clinicians with no lived experience) can offer. *"Failure by a person to engage or respond to treatment efforts should prompt the service to respond creatively and with a greater emphasis on developing a milieu which supports engagement."*[1] That is, responsibility should be put back on the service rather than patients being blamed.

14 Support services for people experiencing BPD, parents, caregivers and families will be flexible and responsive. The services will cater to the individual person's needs, and balance the needs of their family, and be more accessible, including being available after hours. Services will be culturally sensitive. Services will support a person's desire to live as contributing a life as possible. The person must be seen as living within a network of people who need education and support themselves to be able to support the person experiencing BPD.

15 Clinicians on the coal face such as those in Emergency Departments (**ED**), police and Crisis Assessment Teams need a clear pathway of support, treatment and referral options for people coming to them in serious distress. Police being told to *'just take the person home'* when they take someone to ED is a serious problem and the 'rejection' felt by the person further adds to their distress, feelings of shame and worthlessness. This is a challenging and distressing situation for all involved.

---

[1] Royal College of Psychiatrists (UK) Position Statement, *Services for people diagnosable with personality disorder*, January 2020, p 20 available at https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/position-statements/ps01_20.pdf?sfvrsn=85af7fbc_2.

16 GPs are often a first point of contact for carers and people with BPD. They also need appropriate training to identify BPD, to know how to best support people with BPD and provide clear pathways for ongoing support and treatment.

17 Although it is a federal issue, it is vitally important that the number of mental health sessions available on Medicare is increased. The BPD Foundation is advocating for an increase in the number of sessions available for BPD and complex mental illnesses to 40, which is in line with best practice. The National Health and Medical Research Council (**NHMRC**), Clinical Practice Guidelines for the management of Borderline Personality Disorder (**NHMRC Guidelines**) provide:

> *"When planning structured psychological therapies for BPD, the therapist should adapt the frequency of sessions to the person's needs and circumstances, and should generally consider providing at least one session per week."*[2]

18 This is generally averaged out to equate to 40 sessions/year and would be aligned to the changes to the Better Access Scheme announced for people with an eating disorder. Both Dialectical Behaviour Therapy (**DBT**) and Mentalization Based Therapy (**MBT**), the two treatments with the greatest evidence base for successfully managing BPD, recommend a minimum one hour per week of treatment for at least one year (group and individual).

19 Mental health professionals and clinicians need to be educated to acknowledge the important role family members can play as an integral ally to the clinical team. It is imperative for carers to feel welcome, included, valued and validated. Families are experts by experience and hold much more knowledge of the person than the clinician can hope to. They often knew the person before they became unwell and have an understanding of the person's risks and supports. Their way of being in relationship with the person may not appear to be the most helpful however, invariably they are doing the best they can, often in difficult circumstances and juggling a number of conflicting commitments. They are usually available 24/7. As a result, they are much better placed than clinicians to help mimimise emotional dysregulation, risks and potentially self-harm. Unfortunately, some clinicians still hold the outdated views of refusing to involve families in psychotherapy. I recommend that the default option for all services is family inclusion rather than exclusion. I also feel that it's important to phrase this in a way that encourages a discussion and exploration of why consent may be declined – not just a 'tick the box option', which I discuss below at paragraphs 76-82.

---

[2] National Mental Health and Research Council, *Clinical practice guideline for the management of Borderline Personality Disorder*, 2012, Recommendation 9, pp 10, 58 available at https://www.nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality-disorder.

20 Project Air (NSW) has recently published a paper[3] that explores the topic *'How could organisations improve how they provide services for people with personality disorder'* via roundtable discussions held between consumers, carers and clinicians. The discussions highlighted four overarching themes: (i) increasing consumer, carer and peer worker involvement in care; (ii) re-orienting approaches to service provision; (iii) improving access and availability of treatment services; and (iv) building capacity of services. The paper highlights:

> *"...the value of using formulation-based rather than diagnosis-based approaches, offering non-verbal therapies, addressing stigma, recognizing that some interventions do not work for everyone and providing choice to consumers regarding their treatment. These findings point to the importance of a holistic, integrative whole-of-service approach that emphasizes that treatment is not to be a one-size-fits-all approach but an individualized approach that considers the consumers experiences and preferences."*

Ways in which people should be able to access information about their mental health

21 People should access information about their mental health at the time of diagnosis and in discussion with their treating clinician, so they have the opportunity to ask any questions and express concerns if something regarding their diagnosis doesn't resonate with them.

22 There is a lot of discussion within lived experience circles about stigmatisation of the name BPD and whether BPD is an illness or a disorder, or whether it is the result of the body experiencing enormous amounts of stress, distress or trauma. In that sense, telling someone that they have BPD without discussing the diagnosis with them when "having an illness" may not resonate for them is potentially harmful. Everyone has their own way of understanding their experiences and to have their understanding dismissed can be very negating and invalidating for them and may encourage them to seek alternative sources of information, for example Google or social media, where much negative misguided misinformation exists. I believe a 'dark web' of information about BPD exists fuelled by hate and open displays of self-harm. As a result, I feel it is essential that clinicians have a conversation with the person about their symptoms, what the experiences means to them and the best way for them to understand what is happening with the goal of moving towards 'a meaningful life.'

23 The sharing of connection with peers and a shared experience is also valuable.

---

[3] Ng, F., Townsend, M. L., Jewell, M., Marceau, E. M., & Grenyer, B.F.S. (2020). Priorities for service improvement in personality disorder in Australia: Perspectives of consumers, carers and clinicians. Personality and Mental Health. https://doi.org/10.1002/pmh.1485.

How mental health services would ideally be delivered

24 Ideally, mental health services will be delivered in a way that is peer and trauma informed, within the community and within a person's support network.

25 There are challenges in attracting BPD peer workers as often people with lived experience of BPD prefer to no longer identify with the diagnosis after they have 'recovered'. Peer work can be challenging work. You are working based on your own lived experience (and potential vulnerabilities) and often challenging the viewpoints of the so called 'experts' (clinicians). To have your lived experience dismissed by the 'experts' is extremely negating. Attitudes of services (including individual staff) are often quite biased. Peers frequently work in isolation and often do not receive peer specific supervision and support.

26 Some of these challenges may be overcome with appropriate education of clinicians and the recognition of a peer workforce as a valuable discipline, similar to the role of social workers or occupational therapists. This includes appropriate remuneration, education, workloads, training and supervision. I believe the sector is working towards that stage, but there is still a long way to go, partially because there is not yet the opportunity for many peer workers (and those being consulted for the lived experience) to get appropriately remunerated.

27 Unfortunately, stigma and discrimination still exists, which can increase a person's concerns about disclosing their lived experience. A big part of creating opportunities is overcoming stigma and discrimination. I am aware of a couple of advocates who have advocated quite openly and then have experienced discrimination in their workplace and have ceased advocating as a result.

28 For consumers, there would be a much greater emphasis on early intervention and community based treatments; this is particularly important for groups who are high risk. Maternal and child services would be re-oriented to develop ways of identifying families at risk of psycho-social stresses and to identify and address issues of concern in early life. For example, in the Netherlands they have put in place a system of offering support to at risk children as young as 5 (both children and families) and families within the child protection and criminal justice systems are offered treatment based on DBT Principles.[4] It appears to be having a long-term benefit and has lowered the amount of people who end up in the forensic system.

---

[4] Australian BPD Foundation National Conference 2014 – A/Prof Sathya Rao https://youtu.be/Ie8lbaolKF8 - 4m27s to 7m10s.

29 The Royal College of Psychiatrists (UK) Position Statement[5] recommends at 4.7.2:

> *"Local [Child and Adolescent Mental Health Services] should ensure there is support available. This will be for parents and carers of those with personality disorder as well as offering consultation to adult services who are working with people with personality disorders who have children".*

30 There should be a 'no wrong door' approach so that people with BPD can seek help anywhere in the mental health system and be appropriately assessed, diagnosed and referred regardless of age or diversity. Without appropriate identification and treatment, there is an extra burden on the health system – often only co-morbidities are identified and are treated without consideration of the underlying condition of BPD, meaning treatment approach is often short-term and inadequate. This often results in years of distress for the person and their families, which could potentially have been avoided. In addition, people with BPD are extremely vulnerable to feelings of rejection shame. To feel excluded from services or not listened to further compounds their distress and feelings of self-loathing.

31 As outlined in the Foundation's original submission, a whole of Government approach needs to be developed to implement a coordinated stepped care approach to treatment and support for personality disorder across Victoria so that people are able to access treatment and support early in the development of mental illness and early in any crisis or worsening of their mental health. Such a framework would include clearly defined referral pathways and an integration of services.

32 We need to educate primary health care and mental health care providers with the aim of building understanding and empathy to improve attitudes and behaviours towards people with BPD. For recovery, it is vital that a person with BPD experiences respectful communication and that they are seen as a human in distress and not dismissed as a number of diagnoses or illnesses. The education should be provided to health professionals at graduate levels, with staged training progressing from foundational level for non-mental health clinicians to higher levels of training for those directly involved in working with personality disorder.

33 I would also like to offer a word of caution about the widely held belief that everyone with BPD needs to receive DBT. It is a very specialised, resource intensive, structured long-term therapy that takes 18 months to two years. It is an extremely helpful treatment for people with severe BPD, though potentially unnecessary for everyone who has BPD. Many people will benefit from shorter, less intensive therapies. The NHMRC Guidelines investigated the common factors of the main evidence based therapies and made

---

[5] Royal College of Psychiatrists (UK) Position Statement, *Services for people diagnosable with personality disorder*, January 2020, p 24.

recommendations on the characteristic of a generalist treatment. Spectrum has trialled a brief intervention day program (80 hours) based on the Common Factors for therapy for BPD with promising results. The paper is currently being prepared for publication.[6] They also have limited data on small group 10 and 20 week interventions, which also seem to be showing positive results.

34 Currently, the BPD Foundation is rolling out a national training strategy aimed at mental health clinicians from all disciplines. It is a four stage strategy:

(a) Stage 1 was a series of six webinars which are available online through our website.

(b) Stage 2 is an e-learning tool developed by Project Air in New South Wales which is also available free of charge on our website.

(c) Stage 3 is a series of intensive two day workshops around Australia which were due to start at the end of March but they have been put on hold as a result of COVID-19. This stage also includes a Train the Trainer component and the establishment of a register of BPD Foundation endorsed trainers.

(d) Stage 4 is post training mentoring and supervision which is designed to enhance the integration of new skills learnt into everyday clinical practice. This support will be available for all participants for the life of the project.

35 The Foundation has partnered with Spectrum to develop a brand new curriculum which is guided by the NHMRC Guidelines and informed by current research and clinical experience. The content has been reviewed by a multidisciplinary team including a psychiatrist, a mental health nurse, a social worker and people with lived experience. The training will be led by Spectrum clinicians. This is the first curriculum I know of that is putting a multidisciplinary focus on the training. We may run the workshops online in light of COVID-19, though we are reluctant to do so as we think that a highly important aspect of supporting someone with BPD is building a relationship which can be modelled and practised more effectively in face-to-face training.

The role of schools, employers and communities in the delivery of mental health services

36 Schools play an important role in stigma reduction and supporting people to seek help. They need to raise awareness that mental illness in general and BPD in particular is not a scary or an untreatable condition. I also believe that tackling bullying (in all forms) and equipping children with some skills to help regulate emotions (especially those children 'at risk') is essential.

---

[6] Lavin, D., Broadbear, J. & Rao, S. 2018. Brief Intensive Group Intervention for BPD: Making the case for more accessible and affordable psychotherapy. *World Psychiatry Conference.* Melbourne.

37 Employers will provide their staff with greater flexibility. It is important to note that understanding from employers assumes that consumers and carers feel comfortable to disclose what they are experiencing – and often they do not feel supported to do that.

38 There are currently a number of employment difficulties carers can face. These arise from employers' lack of understanding of, and stigma towards, mental illness. Similar issues are also experienced by consumers.

(a) **Inability to secure flexible work arrangements** – carers often need to be absent from work for longer periods with little or no notice when their loved one is experiencing a prolonged mental health episode. It is often difficult for carers to secure flexible working arrangements during or post a loved one's experience of mental health episode. A carer's need for flexibility can also lead to strained team dynamics, where colleagues resent the carer's inability to perform tasks at the pace of their colleagues.

(b) **Insufficient leave** – carers have carers' leave (10 days) and annual leave (20 days) to fulfil their caring role, which is usually insufficient. Further, carers experience difficulty accessing the leave they do have to fulfil their caring responsibilities.

(c) **Career interruption and delayed career progression** – as a result of reducing working hours, or exiting employment, to fulfil caring responsibilities, carers often step down into lower level responsibilities, compared to someone with similar experience and qualifications. This results in lower remuneration and delayed career progression.

(d) **Precarious employment opportunities** – in order to have the kind of flexibility that is required to accommodate their caring responsibilities, carers often need to obtain work that is lower paid and less secure, for example casual employment or 'gig economy' opportunities.

(e) **Discrimination** – carers are potentially discriminated against while job-seeking due to appearing unreliable based on their need for flexibility, and a work history that reflects their caring responsibilities.

(f) **Stigma and privacy** – carers are often concerned about disclosing the nature of their caring role, for fear of it impacting on their employment, or simply wanting to maintain their privacy, or their family member's privacy.

(g) **Mental health issues** – carers often develop their own mental health issues from the stress of balancing caring and employment responsibilities, which can affect the carer's capability to work, their work performance and their wellbeing.

39 Within communities I feel there is a lot of ignorance around mental illness in general and BPD specifically. Certainly, some of the behaviours associated with BPD seem extremely challenging and difficult for the community to understand. For example, seeing people self-harming in car parks and shopping centres. People don't see the distress; they see people self-harming and can't understand why. I discuss this further below at paragraphs 57-64 regarding stigma.

Suicide prevention

Effectiveness of existing mental health services, including those delivered in emergency departments, in responding to people who are at risk of suicide and their families and carers

40 I personally don't like the term 'suicide prevention'. I see suicide as a breakdown in societal structures. To me, suicide prevention is like putting a band aid on a leg to prevent it from breaking before jumping from a great height. People with BPD frequently feel suicidal 100% of the time – it is a coping strategy to help them to stay alive. Focusing on whether the person feels suicidal is unhelpful; the focus should be on why the person needs that coping mechanism to help them to stay alive. I am not aware of any research in that area.

41 Generic suicide prevention strategies that are applicable for general mental illnesses are not likely to be effective for personality disorders. This is because the treatment principles of chronic suicidality (e.g. for personality disorders) are entirely different to acute suicidality.[7] A recent qualitative analysis undertaken by Spectrum[8] shows that the majority of Victorian mental health services' risk assessment tool (or protocol or procedure) listed one or none of the NHMRC Guideline specific risk factors for BPD. In addition, AMHS protocols consistently recommend completion of clinical risk assessment at only three of the seven time points indicated by the NHMRC Guidelines.

42 In a recent study undertaken by Spectrum Personality Disorder Service and the Victorian Coroners Court using the Victorian Suicide Registry (2009-2013), there were a total of 253 deaths where there was a diagnosis of, or symptoms consistent with, a diagnosis of BPD. This is 10% of all suicides in Victoria; 99% of these had contact with a mental health service within one year prior and 88% within 6 weeks prior to their death.[9] This cohort is reaching out for help and not receiving appropriate evidence-based and/or affordable care. No suicide prevention research funding is specifically

---

[7] Paris, J (2007). Half in Love with Death – Managing the Chronically Suicidal Patient. Routledge Publications.

[8] Wheeler J, Mildred H, Broadbear JH, Mellor D, Rao S. How is suicide risk assessed in Australian Public Mental Health? A qualitative analysis of risk protocols in the context of Borderline Personality Disorder. Revising for submission to Psychiatric Services, May 2020.

[9] Spectrum Personality Disorder Service (unpublished research). Coroners' investigations of suicide in Australia: The hidden toll of Borderline Personality Disorder Jillian H. Broadbear, Jeremy Dwyer, Lyndal Bugeja and Sathya Rao (under review by the Journal of Psychiatric Research).

allocated for researching suicidality in people with personality disorders despite the Royal College of Psychiatrists (UK) stating:

> *"Among people who die by suicide, more than half are likely to have suffered from a diagnosed personality disorder (Cheng et al, 2000) and in prisons approximately 60–70% are estimated to satisfy the diagnostic criteria for personality disorder (Singleton et al, 1998)."*[10]

43 In line with the Victorian evidence showing that 10% of all suicides relate to BPD, the BPD Foundation recommends that 10% of all money for suicide prevention should focus on people living with BPD.

Key aspects that prevents mental health services from better responding to the needs of people

44 A key aspect is stigma. There is evidence that people presenting at ED with suicide/self-harm behaviours experience stigma. These are frequent symptoms of BPD so we need to make the ED environment as safe and supportive as possible. I feel that some of this stigma is related to a lack of in depth understanding about the needs of people with BPD, in addition to compassion fatigue. Compassionate experienced staff are often not supported by management to fully engage and support people with BPD, for example *'get that BPD person out of my ward'* is a statement I have frequently heard by frustrated staff.

45 There is also a lack of alternative options to ED. EDs are not the most appropriate places for people with mental distress. The rest of the mental health system is overburdened with long waiting lists and often suicidal crises happen 'after hours' when ED is the only option available. It would be helpful to up-skill families in deescalating crises or have a teleweb support line available 24/7, which I discuss below at paragraph 49.

46 For many clinicians the fear of the Coroner's Court and potential litigation makes then reluctant to manage high levels of risk. Other issues include fractured services (i.e. the availability of services is often dependent on where you live) and a lack of clearly defined referral pathways.

47 Another key aspect, I believe, is related to the amount of education and training delivered in the various graduate courses for mental health clinicians. The Foundation is planning to make available the curriculum developed for its National Training Strategy (mentioned above at paragraph 34) to the various colleges and universities with the offer for them to incorporate it into their own curricula.

---

[10] Royal College of Psychiatrists (UK) Position Statement, *Services for people diagnosable with personality disorder*, January 2020, p 24.

Ways in which mental health crisis services, emergency services and emergency departments could help prevent people who present in crisis from attempting suicide

48 For someone who is suicidal, they often crave a personal connection with somebody in the time of crisis. It is important they can speak to someone about what might be helpful for them. If a person receives empathetic and compassionate treatment throughout their contact with the health services, it seems likely that the need to feel suicidal as a coping strategy and consequently the frequency of potential fatal outcomes as the result of non-suicidal self-injury (**NSSI**) and the number of suicide attempts would decrease. I have heard anecdotally from experienced clinicians that sometimes connecting with 'someone' e.g. phoning Lifeline is more effective than using the online chat function, as it allows the person a more personal connection.

49 The BPD Foundation recommends developing a 24/7 Victorian BPD specialist teleweb help service. The service would be staffed by skilled clinicians 24/7 and lived experience consumer and carer workers would be available to offer support to consumers and carers during business hours. The peer workers would be able to offer the specific assistance needed by people with BPD who are feeling suicidal and their families/carers. In the Foundation's experience, it is quite rare that a crisis just happens out of nowhere. There is usually a series of events, which for the inexperienced person may seem insignificant, but for the person experiencing those events they are huge. Implementing strategies and skills early would considerably decrease the distress experienced and potentially the need for more intensive interventions.

50 I do not believe at this stage merely upskilling the current helplines would meet the need. Feedback received by consumers and carers contacting the Foundation indicates that the current helplines do not have the skillset to differentiate between acute and chronic suicidality – the management of which is quite different. We hear that helplines tend to err on the side of caution and call emergency services if in any doubt about the person's level of risk – an appropriately skilled clinician would have the skillset to assist the person to deescalate to the point of not requiring ambulance and police attendance. Rather than having their autonomy taken away this approach helps to promote confidence for the person in being able to manage their distress themselves. This is a difficult balance for clinicians and services: the balance between allowing autonomy and risk management.

51 Because the level of risk is much higher the helpline staff require regular mentoring and supervision from appropriately skilled staff to avoid burnout and experiencing vicarious trauma themselves. This level of support cannot be readily achieved with clinicians working in isolation. It can if the service is run alongside a specialist service. With time,

in a decade or two, as the overall skillset clinicians and of helpline staff increases and they become more comfortable working with the high level of risk a separate service may no longer be needed.

52 Having a specialist teleweb service would be quite cost effective when you consider the current costs of police and ambulance attendances and of beds in EDs. The BPD Foundation estimates that the program would cost approximately $1 million per year staffed 24/7 by clinicians and a 1.5 EFT carer and 1.5 EFT lived experience worker (both Monday-Friday business hours) if carried out by Spectrum Personality Disorder Service. The venue and infrastructure (telephone and online systems, supports, 24/7 rostering service and so forth) are already available at Turning Point and would only require an increase in capacity as Turning Point is housed in the same building as Spectrum and teleweb staff will be able to readily obtain support and advice from their colleagues. Due to COVID-19 and the implementation of telehealth, clinicians have already been upskilled in offering online support. The line would not be publicised; we envisage that it would be offered as a referral point for crisis/helplines such as Lifeline, GPs, psychiatrists and psychologists for times when they need some guidance themselves or feel the person requires a more specialist service.

53 Due to time pressures and limited resources, EDs have the potential to become a counterproductive environment, exacerbating destructive or maladaptive behaviours. ED can be quite a triggering environment for people. We therefore also recommend establishing non-clinical alternatives to EDs for people with BPD seeking support for their wellbeing outside of normal service operating hours. For example, the Safe Haven Café which is being trialled at St Vincent's Hospital.

54 Mental health crisis services should minimise physical restraints wherever possible.

55 There is also a need for connectedness between systems. A 12 month audit of three Melbourne metropolitan hospitals showed that of a total of 157,360 ED presentations, 1,123 (or 3 patients/day across the 3 hospitals) were related to BPD. 583 of the BPD presentations represented unique individuals (many attended ED more than once over this period) and 15% of BPD patients accounted for 53% of 1,123 ED visits.[11] This reinforces the need to connect patients with readily accessible community support services to alleviate their reliance on emergency services. An alternative option called Open Borders is currently operating in WA which I discuss below at paragraph 88.

56 The Royal Perth Hospital undertook an initiative to bridge the gap between evidence and practice by designing a clinical pathway for the acute inpatient care of patients with Emotionally Unstable Personality Disorder (also known as BPD). Results from the study

---

[11] Emergency Department utilisation by patients with a diagnosis of Borderline Personality Disorder – what can we learn? Jillian H Broadbear, Joe A Rotella, Sathya Rao (unpublished paper).

suggest that the enhanced clinical pathway is a feasible, clinical and cost effective model of acute inpatient care for patients with BPD. The study found a total of 2,395 WA mental health bed days were saved, facilitating greater throughput of 154 more admissions and the treatment of 90 more consumers in a 12-month period, or a total cost-saving of $3.4m.[12]

Stigma and discrimination experienced by people with mental illness, and their families and carers

57 People with BPD (and their families) experience stigma from clinicians working within mental health services, and this is well researched.[13] Stigma towards people with BPD is largely perpetuated through poor health literacy about BPD from health and mental health professionals.[14]

58 In the Foundation's experience, there is often reluctance by health professionals to diagnose people with BPD. We postulate that arguments about the name BPD are unhelpful in decreasing stigma and may in fact be promoting it. I wish to acknowledge that the term 'borderline personality disorder' is not the most appealing for this patient group and may on its own be perceived as stigmatising. However, I believe, just changing the name will not change the stigma. Changing the name will need to happen at a global level. Currently I see the focus on changing the name diluting interest, funding and research away from focusing on better treatments and outcomes for people with BPD.

59 The NHMRC Guidelines recommend that clinicians should explain the diagnosis to the person in a non-stigmatizing way and instilling hope. There is a desire among some clinicians to not mention the name BPD or use the old-fashioned terminology 'Cluster B

---

[12] The Enhance Study: Effectiveness of a Clinical Pathway for the Acute Inpatient Care of Patients with Emotionally Unstable Personality Disorder (thesis) Alicia Wilson Child and Adolescent Mental Health Service Available from https://www.researchgate.net/publication/322819568_The_Enhance_Study_Effectiveness_of_a_Clinical_Pathway_for_the_Acute_Inpatient_Care_of_Patients_with_Emotionally_Unstable_Personality_Disorder/related (last accessed 5/7/2019); The Enhance Study: Clinical and Cost Effectiveness of an NHMRC Guideline informed Clinical Pathway for the Acute Inpatient Care of Patients with Emotionally Unstable Personality Disorder (EUPD) November 2016 Conference: 5th Annual National Health and Medical Research Council Symposium on Research Translation 2016 at Melbourne, Victoria, Australia. Available at https://www.researchgate.net/publication/322819307_The_Enhance_Study_Clinical_and_Cost_Effectiveness_of_an_NHMRC_Guideline_informed_Clinical_Pathway_for_the_Acute_Inpatient_Care_of_Patients_with_Emotionally_Unstable_Personality_Disorder_EUPD (last accessed 5/7/2019).

[13] Lawn, S., McMahon, J., Zabeen, S. (2017). FOUNDATIONS FOR CHANGE: PART2- Consumers: Experiences of Consumers with the Diagnosis of Borderline Personality Disorder (BPD) 2017 Update. Private Mental Health Consumer Carer Network (Australia) Ltd: Marden, South Australia, Australia.

[14] Clinician attitudes towards borderline personality disorder: A 15-year comparison. Personality and Mental Health 12: 309–320 (2018-11). Nicholas J.S. Day Annalise Hunt Louise Cortis-Jones Brin F.S. Grenyer (2018) https://doi.org/10.1002/pmh.1429; Daniel Ring & Sharon Lawn (2019): Stigma perpetuation at the interface of mental health care: a review to compare patient and clinician perspectives of stigma and borderline personality disorder, Journal of Mental Health, DOI:10.1080/09638237.2019.1581337; Black, Donald & Pfohl, Bruce & Blum, Nancee & Mccormick, Brett & Allen, Jeff & North, Carol & Phillips, Katharine & Robins, Clive & Siever, Larry & Silk, Kenneth & Williams, Janet & Zimmerman, Mark. (2011). Attitudes Toward Borderline Personality Disorder: A Survey of 706 Mental Health Clinicians. CNS spectrums. 16. 10.1017/S109285291200020X; Weight, Emma & Kendal, Sarah. (2013). Staff attitudes towards inpatients with borderline personality disorder. Mental Health Practice. 17. 34-38. 10.7748/mhp2013.11.17.3.34.e827.

disorder', however this can leave the person feeling totally confused about their diagnosis.

60 The Foundation has heard anecdotal evidence from Western Australia, where the term Emotional Unstable Personality Disorder (**EUPD**) is the preferred term used, of people being discharged into the care of a service where the staff have no knowledge about how to support someone with EUPD. This leaves people and services very vulnerable. Difficulties have also arisen where people have moved interstate.

61 Current BPD treatments tend to be focussed on the needs of females. Until recently it was misunderstood that the prevalence of BPD was highest in women. Consequently the majority of people treated for BPD by services were women, which has meant that the majority of the published literature is on treating women.[15] It is only in recent years that the impact of BPD in men has been appreciated and research is now happening. The community prevalence of BPD in men is approximately equal to that in females, however there are usually less men within most treatment settings.[16] In the BPD Foundation submission to the Royal Commission we provided the following quote from a man with lived experience of BPD:

> *'Continual reference by a variety of services on how the majority of individuals diagnosed with BPD are women creates an inadvertent feeling of inadequacy for a male suffering from BPD and presents as an additional barrier to seeking treatment as a male with BPD may question their masculinity.'*

Addressing experiences of stigma and discrimination

62 Addressing stigma and discrimination requires multiple strategies including a multifaceted and targeted media campaign, more targeted education, advocacy and leadership, along with greater inclusion of the voice of people of lived experience of BPD in planning and implementation.[17]

63 It would be helpful to develop and implement a multifaceted and targeted media campaign funded by the State government, with the work undertaken by existing advocacy organisations such as the BPD Foundation or the National Education Alliance for Borderline Personality Disorder, and a private advertising agency which has shown an understanding of working with stigma and discrimination especially in the context of

---

[15] See, for example the following study which quotes 10 RCTs using DBT where only female participants were included all but three of the studies: Effectiveness of dialectic behavioral therapy in routine outpatient care: the Berlin Borderline Study. Stiglmayr, C et al. Borderline Personal Disord Emot Dysregul. 2014; 1: 20. doi: 10.1186/2051-6673-1-20

[16] TOMKO, R. L., TRULL, T. J., WOOD, P. K. & SHER, K. J. 2014. Characteristics of borderline personality disorder in a community sample: comorbidity, treatment utilization, and general functioning. Journal of personality disorders, 28, 734; GRANT, B.F., CHOU, S.P., GOLDSTEIN, R.B., HUANG, B., STINSON, F.S., SAHA, T.D., et al., 2008. Prevalence, correlates, disability, and comorbidity of DSM-IV borderline personality disorder: results from the Wave 2 National Epidemiologic Survey on Alcohol and Related Conditions. J. Clin. Psychiatry 69 (4), 533–545.

[17] Daniel Ring & Sharon Lawn (2019) Stigma perpetuation at the interface of mental health care: a review to compare patient and clinician perspectives of stigma and borderline personality disorder, *Journal of Mental Health*, DOI: 10.1080/09638237.2019.1581337.

trauma and mental illness. The organisations involved in the campaign need to be prepared and able to work with people with lived experience. It is essential that the campaign is informed by people directly affected by the stigma and discrimination and they need to be involved in all facets of the planning, delivery and evaluation of the campaign. Such a campaign could be modelled on the very successful Beyond Blue awareness raising campaign for depression, or the current award-winning ‘Stop it at the start’ campaign to reduce domestic violence.

64 There needs to be adequate support, training and supervision for frontline staff, ED staff, police and paramedics. I acknowledge that it must be challenging for doctors to maintain empathy to re-stitch the wounds that they stitched the night before. That is why it is important that clinicians are given appropriate support, as this will go a long way to helping them to provide compassionate care.

Families and carers and innovative practices

The impacts on people caring for someone experiencing poor mental health

65 Caring for someone with BPD can be bewildering, relentless, chaotic, confusing and physically and emotionally exhausting. Life can be filled with fear, uncertainty and sometimes grief – and difficult to plan. It can also be an isolating experience involving the loss of family and community networks. Carers experience stigma and can often feel blamed or judged.

66 Carers often experience family breakdown and dysfunction and frequently experience violence or live in fear of the family member with BPD. The chaos can impact upon other family relationships; for example, other siblings may leave home earlier than they otherwise would to be able to look after their own mental health.

67 There is a lack of recognition among health care workers of the role of carers, in particularly the diversity and extent of the role. Carers frequently take on multiple roles depending on the needs of the person at the time. These range from being an advocate and helping the person navigate the mental health system (and sometimes legal and other systems), taking the person to multiple appointments, supporting everyday living costs as well as costs associated with therapy and medication, ensuring the person eats and showers, as well as cleaning up after periods of self-harm. For partners where there are young children in the family they may be both the primary caregiver and the sole wage earner. For grandparents they often take on the primary care-giving role for grandchildren when their child is unable to care for them.

68 The young person being supported may not be well enough to go to school or work, and also unable to access Centrelink benefits because they do not meet the ‘independent’ status. This means they become totally dependent upon their family for financial

support; this can increase disputes within the home. The Foundation is conscious that this is outside the Commission's brief, but Centrelink should consider the 'independence' requirement for young people with mental illness accessing youth allowance.

69 The experience of being a young carer caring for a parent or sibling is especially difficult. It often involves a loss of childhood, which impacts upon a person's development, future wellbeing, education and employment prospects.

70 Carers often experience vicarious trauma and develop their own trauma disorders due to the challenging situations they need to manage with little or no support and require professional counselling themselves.

71 Caring for someone for BPD can be especially hard without a diagnosis. I quote a carer from the BPD submission to the Royal Commission:

> *'It was such a relief to get a diagnosis and know that there is a medical reason that our family member is behaving as they are and that they are not simply "behaving badly" as we were so often told. We have a better idea of what we need to cope with and can support our family member to get the right treatment. At this stage we feel some hope that things will improve.'*

Ways in which the impacts on carers vary

72 The impacts on people caring for someone experiencing poor mental health certainly vary a lot and are dependent on the carer's own physical and mental health, resilience and levels of life stressors. The impacts also depend on the behaviours of the person with BPD. People with BPD can direct their anger internally or externally

73 Many carers live in fear of the person, eg domestic violence (both against male and female partners, parents and other family members). Parents may feel obligated to provide a roof for their child yet live in fear locking their bedroom door at night to offer a sense of safety. Parents have become 'homeless' because they are unable to evict their child yet unable to live under the same roof as their child.

74 Living with someone who is directing their anger internally and is withdrawn and angry has its own set of challenges. Other family members are still aware of their internal distress.

75 Sometimes living apart can be as stressful as living under the one roof – you don't know whether the next call will be the hospital telling you that your child has been admitted and you didn't know they had taken an overdose – or the police at your front door

ringing you at work saying they had been contacted by an online helpline concerned about your child's welfare and seeking your consent to break into the house.

Ways in which the mental health system can approach and engage consumers in the context of their existing family and social relationships

76 Currently the involvement of family by mental health services is an opt-in rather than an opt-out requirement. This should be changed to be opt-out so that the assumption is that family will be involved from day one.

77 If a person with BPD denies consent for their family to be involved in their treatment and care, it is important not to immediately accept that as the status quo. It might be necessary to explore why that consent has been denied, for example:

(a) Does the person consider themselves an adult who does not need to be 'cared for'?

(b) Does the person want to 'protect' their family from how distressed they really feel?

(c) Does the person understand the potential role their family can play to actively support their recovery journey, and the potential benefits of having their family involved?

(d) Has the person constantly felt invalidated or unsupported by their family and as a consequence is no longer willing to share their inner most thoughts?

(e) Does the person blame their family for their state of mental health?

(f) Are there other aspects of the person's life they do not wish to disclose to their family, for example information of abuse by other family members?

(g) Does the person feel intense shame and consequently that they are 'unloveable' and they don't deserve their family's support?

(h) Does the person have an understanding of what information the clinician will actually share?

(i) Does the person trust clinicians not to divulge information they wish to keep private?

(j) Is the person involved in legal disputes such as custody of shared children and are not in a position to be inclusive?

(k) Does the person have an entrenched paranoia about some family members?

78 Clinicians have told the Foundation that it tends to be much easier to involve the client's family when family involvement is an expectation of the service and is conveyed in the initial meeting with the client.

79 It is important for the clinician and patient together to identify a primary carer (including name and contact details) and this information should be documented in the treatment plan. This documentation is best done when the person is experiencing a level of emotional stability.

80 It is well recognised that people with BPD can experience emotional crisis and due to real or perceived rejection/abandonment they may refuse to have the primary carer involved at certain times. The clinician should treat this as a temporary rupture and revisit as soon as the crisis is over and not to perceive it as a permanent rupture.

81 Identifying carers also means they can be offered appropriate information and support.

82 I emphasise that clinicians need to be appropriately trained and supported to involve families.

Access to respite services

83 My belief is that respite in its current format is mainly used for people with psychosis and disability and is in general unlikely to be helpful for people with BPD.

84 I would reframe the concept of respite to consider that a person with BPD is potentially looking for some respite from themselves. If they convey that they feel unsafe, a night in a dedicated short term unit may help them, particularly if they have full understanding that they will be discharged in the next 24-48 hours. It may give them permission to let go of having to manage some of the distress themselves and help them feel safe and heard. One option trialled in WA is the Open Borders Program which I discuss below at paragraph 88.

85 Respite ('time out') could also be used as a useful strategy to manage emotional storms which can happen frequently. At these times it is incredibly challenging for both the person with BPD and the carer to manage the high emotional intensity. A period of temporary separation would be helpful (for both) to help calm the storm. Therefore, either the person or their carer accessing respite may help to break this cycle. Ideally the decision needs to be mutual because if the carer tells the person *'I need some time out'* I suspect it would be perceived as abandonment/rejection or perceived by the person as blaming them for being *'too difficult.'* The respite needs to be flexible, available at short notice, for short periods and anyone can access it.

86 Ideally the respite workers need to have appropriate training and skills to support people with BPD. The Foundation has heard of a number of instances where untrained NDIS workers have gone to the home of someone with BPD and the experience has been negative for both the person and the worker.

87 It is helpful that currently some hospitals have Psychiatric Assessment and Planning Unit (**PAPU**) units attached for a short stay of 24-48 hours to help the person to de-escalate from a crisis with appropriate supports. It is important to have dedicated beds for people with BPD so they can receive the unique support that they require, i.e. psychological support rather than the current default option which is medication – primarily sedation. I am aware of situations where people have been in involuntary care for years because they are feeling suicidal and who are only treated with medication. Offering appropriate psychotherapy treatment and support through a dedicated bed may help people regain some semblance of a ‘life’.

88 There is also a service in WA which has been running for 6 years now called “Open Borders”[18] which offers a residential recovery-oriented programme that provides brief admission, respite, and phone coaching for people with BPD who are heavy users of the public mental health system. Enhanced client outcomes include a reduction in self-harming and hospitalization and an increase in self-efficacy and an improvement in their quality of life.

Alternative services or practices to respite services that provide respite relief to carers

89 Funding should be provided for group psychoeducation[19] and support to equip family and carers supporting people living with BPD to respond in a way that is supportive of the person with BPD, as well as their own wellbeing, and enhance their capacity to maintain the relationship. These programs need to recognise the real risk of harm (and potential risk of death) that participants frequently live with. These groups need to be available at readily accessible times and places to accommodate the other commitments carers have and minimise impacts as much as possible on their (and their families’) rights to lead a ‘normal’ life.

90 Another option are Peer Carer Support groups that have an understanding of the challenges of supporting someone with BPD especially around the issues of balancing risk and autonomy. Because of the level of need of participants, I feel these groups are

---

[18] Staff and client perspectives of the Open Borders programme for people with borderline personality disorder. Sheila Mortimer-Jones RN, PhD Paul Morrison RN, CPsychol, PhD Ahmed Munib MBBS, Mphil (Psychiatry) PhD Francesco Paolucci PhD Sonia Neale B.Arts (Psych/Counselling).

[19] A Randomized Controlled Trial of Group Psychoeducation for Carers of Persons With Borderline Personality Disorder. March 2018 · Journal of Personality Disorders 33(2):1-15 DOI: · 10.1521/pedi_2018_32_340.

best facilitated by a peer and a mental health clinician with a deep understanding of BPD. These groups provide:

(a) an opportunity for connecting with other carers and to realise that you are not alone;

(b) an understanding about why people are behaving the way they do;

(c) opportunity to learn more helpful ways of relating to someone with BPD;

(d) reassurance to try new ways of supporting the person with BPD;

(e) encourage a balance between support and self-care; and

(f) empowerment.

Ways in which governments could better support families and carers and incentivise development and implementation of new and innovative service models, particularly family and carer inclusive practices

91 It is important that teams and ward staff are responsible for ensuring carers are recognised, listened to and supported, and that this is a directive from government. Further support for a defined carer/peer worker career pathway will provide a vital direction for carer support across services.

92 I feel that really listening to and engaging people in the initial stages of mental distress would overcome the cynicism and mistrust of services and will assist in engagement with services and treatment and ‘recovery.’

93 The role of clinicians in supporting the wider family should be acknowledged and supported by management. The default position of services should be carer inclusion, highlighting for the consumer the potential value of family inclusion, what families can expect from the service/clinicians and the information that clinicians can or will share. In order to do this services and clinicians need to be given the confidence and skills to work assertively and creatively to engage families. Having read and consulted widely I conclude that clinicians who are proactive and gently persistent have considerable success in engaging some of the most reluctant or hesitant families.[20]

94 Families who for any reason are unable to or unwilling to engage should never be categorised as indifferent and should be able to access support when they are ready.

95 One way to incentivise services to engage educate and support carers is to include, as a standard KPI item a report on family engagement to be discussed in clinical review

---

[20] See for example, Igor Galynker, Talking to Families about Mental Illness: What Clinicians Need to Know, available at https://books.google.com.au/books?id=4Zg9gHpGdRYC&pg=PA19&lpg=PA19&dq=clinicians+engage+with+reluctant+carers&source=bl&ots=YDAdlAcMyV&sig=ACfU3U35Eg3OF_N1SMGF_e9_YzQ4sy9YeA&hl=en&sa=X&ved=2ahUKEwjl5ZPg3uLpAhX66XMBHYEBAhYQ6AEwCHoECAoQAQ#v=onepage&q&f=false. At pages 19-22 Galynker refers to engaging carers effectively.

meetings AND if not – why not? As a minimum this contact would include an introduction of the care team, provision of information about carer resources and support.

96 Numerous innovative service models have been developed and have not generally been implemented. The Foundation recommends system wide implementation of the key recommendations of the NHMRC Guidelines. Although they have existed since 2012, they are still relevant – the issue is that they have never been implemented.

97 The NHMRC Guidelines include 63 recommendations covering diagnosis, management, treatment and information for supporting carers and families. The Guidelines emphasise that the majority of a person's treatment for BPD should be provided by community based mental health services (public and private) and that admissions to hospitals or other inpatient facilities should not be used as a standard treatment for BPD and should generally only be used as short-term stays to deal with a crisis when someone with BPD is at risk of suicide or serious self-harm. Hospital stays should be short, and aim to achieve specific goals that the person and their doctors have agreed on.

98 There have been over 40 randomised control trials researching family inclusion (mainly relevant to psychosis) that show a decreased relapse rate of 20%, decreased acute admissions, increased adherence to medication and decreased psychosis symptoms.[21] Comparative research for BPD is lacking. A quantitative study from SA demonstrates that carer inclusion can minimise healthcare burden, reduce hospital time and carers can assist in making accurate and timely management plans if they are consulted and work in partnership.[22]

99 A large incentive to encourage clinicians to work with families is that they tend to report increased satisfaction from their work when they appropriately engage with families. The families become collaborators rather than enemies, and the fear of an antagonistic relationship or any potential litigation decreases.

100 Finally, one of the main arguments for family inclusion is that it does not make sense to treat a person with BPD in isolation if they just return to the same unchanged environment where their behaviour developed and/or continues. The symptoms of BPD tend to be most evident in close relationships and, in fact, may potentially be maintained

---

[21] The 40 studies I referred to are referenced in the following reviews: Cuijpers P (1999) The effects of family interventions on relatives' burden: a meta-analysis. Journal of Mental Health 8(3) 275-85; Pharoah F, Mari J, Rathbone J, Wong W, (2006) Family intervention for schizophrenia. Cochrane Database of Systemic Reviews 4 and Pitschel-Walz G et al (2001) The effect of family interventions on relapse and rehospitalisation in schizophrenia. Schizophrenia Bulletin – a meta-analysis. 27(1) 73-92.

[22] Acres,K: Loughhead, M; and Procter, N. Please talk to me. Please include me. I want nurses to understand: A report on carer perspectives on emergency department nursing practices for a person with borderline personality disorder. Available online https://www.unisa.edu.au/contentassets/65b73cb620f64e6ba564256a70f72c99/bpd-carers-views-report.pdf.

by that relationship. As the emotional intensity increases in people with BPD, those that are trying to support them find it harder to engage in effective problem-solving, emotional validation, and emotional tolerance. As a result, they may become less supportive, more judgmental, critical, attacking, and withholding of affection. A vicious circle ensues, which further increases the person with BPD's distress and as a result, dysfunctional behaviours within the relationship.

101 Supporting the family to learn new skills and more helpful ways of being in relationship helps to break this spiral. They are also able to instil hope when the person may be struggling and support the person on their recovery journey.

Best practice models for family and carer inclusive practice.

102 As mentioned above at paragraph 98, the research and evidence base for best practice models is predominantly for families with a family member with psychosis, anxiety, or depression. Several papers highlight the impact on caring of someone with BPD[23] and also comment on the paucity of research in the area.[24]

103 Best practice models for family and carer inclusive practice will involve state-wide accessibility for family and carers informed by, and preferably developed and facilitated by, a carer peer workforce and include a range of contemporary, evidence-based therapeutic and psychoeducation models including: single session family consultation, family-specific education groups and carer peer support groups:

104 The NHMRC Guidelines devote a chapter to '*Supporting families, partners and carers*' and make six key recommendations. The recommendations highlight the need for health professionals to refer families, partners and carers of people with BPD to support services and/or psychoeducation programs on BPD, where available, and to provide families, partners and carers of people with BPD with information about BPD or direct them to sources of reliable information.[25]

105 Overall research to develop an effective model is lacking and implementation of the NHMRC Guideline recommendations for supporting carers has been poor. There are some examples:

---

[23] Bailey, R. C. & Grenyer, B. F. S. (2013). Burden and support needs of carers of persons with borderline personality disorder: a systematic review. Harvard Review of Psychiatry, 21 (5), 248-258.

[24] Guillén, Verónica & Díaz-García, Amanda & Mira, Adriana & García-Palacios, Azucena & Escrivá Martínez, Tamara & Baños, Rosa & Botella, Cristina. (2020). Interventions for Family Members and Carers of Patients with Borderline Personality Disorder: A Systematic Review. Family Process. 10.1111/famp.12537.

[25] National Mental Health and Research Council, *Clinical practice guideline for the management of Borderline Personality Disorder*, 2012, Recommendation 52, p 112.

(a) Project Air (NSW) has trialled and researched a program *"Staying Connected when Emotions run High"* which is clinician led.[26]

(b) Spectrum Personality Disorder Service has been running a one-day workshop and evening information session *"Learning More About BPD: A workshop for family/friends supporting someone with BPD"*. The program has been written and is facilitated by a carer who is supported by a clinician. Research has been undertaken over the last 2 years and the report is currently being written. Early results are promising. The value of the peer facilitation has been commented on by many participants. It is planned to manualise the program so that it can be run in other areas.

(c) National Education Alliance for BPD[27] ('NEA-BPD Australia') introduced to Australia a 12 week psychoeducation program based on DBT for carers, *"Family Connections"*, which has been running in the USA for approximately 20 years. In Australia, the workshops are predominantly led by both volunteer carers and clinicians. The workshops are run around Australia, however the demand is huge and they have a long waitlist.

(d) MBT-FACTS (UK)[28] is an intervention for families of a person with BPD based on MBT and led by trained family members.

(e) Fostering Realistic Hope is a support group with a therapeutic focus for carer families supporting a family member with BPD that is held over 2 days at the Bouverie Centre in Brunswick once a year.[29]

Other recommendations

106 BPD needs to be given specific funding. Without specific allocation, services may regard people with personality disorders and BPD as too difficult and treatment resistant and they will continue to receive a lower level of care or, as currently happens, denied care. There needs to be a specific plan in place to make sure that people with BPD aren't continually refused treatment.

107 There also needs to be specific funding for carers supporting someone with BPD. The experience is different as are the experiences of those supporting a person with a physical disability compared to those supporting someone with a mental illness. Currently, there is a move to group all carer supports together i.e. physical and

---

[26] A Randomized Controlled Trial of Group Psychoeducation for Carers of Persons With Borderline Personality Disorder. Journal Of Personality Disorders, 33 (2), 214-228. Grenyer, B. F. S., Bailey, R. C., Lewis, K. L., Matthias, M., Garretty, T. & Bickerton, A. (2019).

[27] Family Connections versus optimised treatment-as-usual for family members of individuals with borderline personality disorder: non-randomised controlled study. Flynn et al. Borderline Personality Disorder and Emotion Dysregulation (2017) 4:18 DOI 10.1186/s40479-017-0069-1

[28] A randomized controlled trial of a mentalization-based intervention (MBT-FACTS) for families of people with borderline personality disorder. Anthony Bateman & Peter Fonagy. (2019). Personality Disorders: Theory, Research, and Treatment, 10(1), 70–79. https://doi.org/10.1037/per0000298.

[29] https://www.bouverie.org.au/help-for-families/fostering-realistic-hope.

psychosocial. I am concerned if this occurs carers supporting someone with BPD will be unable to access supports that are appropriate and relevant to their needs and taking into account the level of risk carers need to live with and the episodic nature of mental illness. At the moment there is some uncertainty whether the Mind Australia Family & Carers Support Services will continue to run with the roll over of funding from state services to the NDIS.

108 We recommend increased funding for the Carer Support Fund administered by Tandem on behalf of DHHS that provides immediate financial assistance to families and friends in crisis. The funding level has remained static for a decade, while the number of consumers has increased by over 50%. An increase of $1 million to the Carer Support Fund from $1.6 million to $2.6 million would make an invaluable difference to the experience of carers.

109 We also recommend that psychotherapy be offered within forensic settings. Approximately 20% of the forensic population have a potential diagnosis of BPD and are largely being treated inappropriately with medications, contrary to recommendations in the NHMRC Guidelines.

110 We recommend increased funding support for the Victorian Branch of the Australian BPD Foundation to allow us to further our advocacy work. As a volunteer run and led charity, we are struggling to survive without a secure funding stream.

111 In conclusion, the Foundation's five key priority areas are:

(a) **Integrate clinical treatment pathways for people with personality disorders with existing resources.** There are no organised, effective and well-defined clinical pathways of care or support for people with personality disorders. What is available often has a long waiting list and does not offer continuity of care.

(b) **Implement the NHMRC Guidelines.** Implementation of the NHMRC Guidelines would go a long way to redressing the insufficient treatment and support for personality disorders within the mental health sector.

(c) **Address gaps in funding and services for people with personality disorders.** Without access to appropriate treatment and support, the impact of personality disorders can have a significant ripple effect on society, including through family, neighbours and friends; educational institutions; workplaces; community services; and the criminal justice system. Taking a preventative approach to recognising and treating people with personality disorders will reduce the personal, social and economic impact of this treatable condition.

(d) **Suicide prevention initiatives to include and prioritise people with personality disorders.** Death by suicide has significant personal, social and economic costs. Provision of appropriate recognition and early diagnosis and treatment for people with personality disorders will prevent the condition from developing into this devastating crisis point.

(e) **Eradicate stigma for people with personality disorders.**

sign here ►

print name Rita Brown

date 24 June 2020

Royal Commission into
Victoria's Mental Health System

ATTACHMENT RB-1

This is the attachment marked 'RB-1' referred to in the witness statement of Rita Brown dated 24 June 2020.

CURRUCULUM VITAE

1977 BPharm awarded by the Victorian College of Pharmacy. Member of the Pharmaceutical Society of Australia

1977 – 2012: Retail pharmacist

2005 – present: Volunteer peer cofaciliator of a BPD Carers support group run by Mind Australia

2012- 2015: Research assistant with the Faculty of Pharmacy and Pharmaceutical Sciences (Monash Uni)

2013: Founding Board Member Australian BPD Foundation

2016 – Present: Carer Consultant Spectrum Personality Disorder Service

2018 – Present: President Australian BPD Foundation

Presentations:

2016:
Eastern Health Statewide Services (Turning Point/Spectrum) Access forum '*Carer inclusion'*

2017:
Peer Perspectives: How to make your lived experience count! *Carers and Borderline Personality Disorder*

Eastern Health Consumer and Carer Forum *Where do consumer and carer's fit in? – examples from Continuing Care, Mental Health and Statewide Services Programs*

RANZCP: Leadership and Management Module for SIMGs *'Consumer and Carer Engagement'*

Australian BPD Foundation National Conference 2017; Keynote speaker *'From Stigma to Strength- A Carer Perspective'*

2018:
Project Air Strategy (NSW) 12th International Conference Consumer and Carer Day *'Opening presentation: Importance of Lived Experience'*

2019:
Mental Health Professionals Network Meeting: *BPD: a lived experience carer perspective*

PaNDA workshop: 'Complex Trauma Disorder and Borderline Personality Disorder in the Perinatal period' *BPD: a lived experience carer perspective*

2020:

NEA BPD Conference Panel: "Bringing families into the picture"