



Submission to the Royal Commission into Victoria's Mental Health System

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5th July 2019

Ms P Armytage
Chair of the Royal Commission into Victoria's Mental Health System
PO Box 12079
A'Beckett Street, VIC 8006

Dear Ms Armytage,

We appreciate this opportunity to present our submission to the Royal Commission into Victoria's Mental Health System. Our submission is a reflection of our experiences as an advocacy organisation representing people with lived experience of Borderline Personality Disorder (BPD), their families/friends/carers and clinicians

The BPD Foundation is a volunteer led not-for-profit organisation. 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.

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.

Even today, in 2019, some people are denied access, or treated differently, due to their diagnosis. Many people diagnosed with personality disorders say that they are ignored and blamed for their illness¹ which further adds to their levels of mental distress and stress.

The BPD Foundation Board and its Victorian members are committed to advocating for people living with Borderline Personality Disorder (BPD) to have access to mental health treatment from a workforce that is appropriately trained and feels valued so they can give the care people require. People with BPD have a human right to live a meaningful and contributing life.

We have heard an analogy used of the mental health system as being like a car with its wheels having fallen off. When we consider the treatment and support of people with Borderline Personality Disorder (BPD) we believe that the wheels have never been properly attached to the chassis. This Royal Commission represents an ideal opportunity for reconceptualising what it is we think we need in the first place, rather than bolting on a band-aid solution. We are ready for a completely different

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model of a car, based on latest research of what constitutes best practice for individuals living with BPD and their families.

The Foundation wishes to acknowledge DHHS for funding the recently launched Personality Disorder Initiative in partnership with Spectrum across six Area Mental Health Services (AMHS). We feel confident that this is a step in the right direction and look forward to the results and similar opportunities being made available to the other AMHS.

Unlike thirty years ago, we now know that BPD is treatable. However, in Victoria even today in 2019 we hear of examples where people who are begging for help from our mental health system are frequently dismissed as 'trouble makers', 'attention seekers'. 'frequent flyers' and receive suboptimal access to treatments resulting in further harm and distress rather than receiving an accurate diagnosis and supportive treatments.

Knowing the huge social, economic and personal costs of the disorder across Victoria (including the huge costs associated with the loss of a person's life through suicide and/or situations where help has not been received in time) the BPD Foundation considers we have a duty of care to translate this new information into practice.

We are acutely aware of shortcomings within the current State mental health system that limit access to effective treatment for people with PD. In terms of community prevalence, PD affects 8-17% of the general population; BPD – the PD which places the heaviest demand on services – affects between 0.43 and 2.31% of the community². This suggests that there are between 27,000 and 147,000 Victorians affected by BPD. Of these, Spectrum the specialist Victorian service treats approximately 200 per year (the most complex and high risk cases). Treatment services for other Victorians in need are variously met by the private and public mental health system and providers. However their availability across different regions is highly variable, with many people missing out on the opportunity to receive appropriate, evidence-based life-changing treatment.

The steady demand for effective treatment for PDs and BPD in particular weighs heavily on the Primary care sector. Acute and urgent care services including paramedicine, emergency departments and law enforcement, are under increasing pressure to manage the fall-out of ongoing and unmet need for effective treatment services. Primary care workers, by their own admission, may lack the knowledge and confidence to manage the needs of patients with BPD; this problem is compounded by the lack of effective referral pathways.

The BPD Foundation believes that the required system change needs a whole of government approach to implement the desperately needed reform across multiple sectors and for the person to be seen as an individual first who requires co-ordinated support across many sectors rather than as a 'problem' to be fixed.

The Foundation believes that the following steps would have far-reaching benefits for people living with BPD, their family, friends, work colleagues, and other circles including the forensic and child-protection systems:

- **Suicide prevention initiatives to include and prioritise people with personality disorders.** 10% of people with BPD die each year by suicide resulting in significant personal, social and economic costs. Allocate 10% of the suicide prevention budget to researching suicide and implementing change for people with BPD

- **Eradication of stigma for people with personality disorders.** Fund awareness campaigns through existing advocacy organisations. By increasing awareness of personality disorders through advocacy activities, awareness campaigns and education (of health professionals and the community) will go a long way to normalise the condition and reduce the associated stigma and discrimination.
- **System wide implementation of the key recommendations of the National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines for the management of Borderline Personality Disorder (2012)**
- **Development of effective and well-defined clinical pathways of care** or support for people with personality disorders to facilitate service planning and resourcing, allowing much greater efficiency in use of existing resources. Currently people seeking treatment for BPD often experience long waiting lists, overuse of medication, inconsistent and frequently fragmented care resulting in further distress and harm.
- **Development of a clear statewide policy outlining the imperative for reallocating funding to treatment of BPD including prevention and early intervention.** Without access to appropriate treatment and support, the impact of personality disorders currently has a significant ripple effect on society, including through family, neighbours and friends; educational institutions; workplaces; community services; and the child protection and criminal justice systems. The economic benefits for individuals and system costs saved would be tremendous.
- **Upskilling the mental health workforce** to ensure that people receive appropriate treatment in a supportive environment that is free of blame, stigma and discrimination.

“The secret of the care of the patient is in caring for the patient³”. In order to care for the patient, the ‘care teams’ need to be present in time and place with the person and not to be pulled by all the pressures experienced by an overstretched, bureaucratic system. The person needs to be seen as a human being who deserves the highest level of care (not just as a diagnosis) and work with them (and their families/carers) to move towards whatever is necessary and possible in terms of greater health wellbeing and care in all situations.

Yours sincerely

Rita Brown (President) Australian BPD Foundation

Your contribution

Should you wish to make a formal submission, please consider the questions below, noting that you do not have to respond to all of the questions, instead you may choose to respond to only some of them.

1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

A 2018 report commissioned by the National mental Health Commission in 2018 concluded that *'The current Australian mental health system is not designed to best meet the needs of people living with BPD which remains highly stigmatised and misunderstood.'*¹

This finding reinforces numerous other studies which show that *'Stigma towards persons with BPD being greater than that towards persons with a mental illness more generally.'*²

Stigma against people with BPD also exists across all facets of health care in Australia. For example, it has been identified as a major barrier from within the mental health system to access treatment and recovery, as well as in the general health system to quality physical care.

The stigma associated with BPD can have an impacts on health providers themselves and negatively mediates their work environment^{3,4,5}

People with BPD often feel blamed and judged for their difficulties and especially those who self-harm or attempt suicide are often perceived as being manipulative and/or attention seeking when they seek help.⁶

Reports to the Foundation indicate people frequently receive punitive rather than appropriate care as evidenced by the following examples:

- 1. My daughter's physical health needs were frequently dismissed due to her having BPD as well. She presented numerous times to ED with chest pains. Her concerns were dismissed as 'attention-seeking' and that she was 'wasting the staff's time – they were there to help 'sick' people and she was unnecessarily using their time and a bed. As a consequence, she was regularly sent home without appropriate tests. After I advocated for her in the strongest terms tests were undertaken, and a legitimate illness was diagnosed*^{mother}
- 2. Doctors have sutured my self-inflicted wounds without anaesthetic because they feel 'I must like pain'*^{Person with lived experience}
- 3. I will sit for hours (covered in blood) at the nurses' desk waiting to be seen and be totally ignored or even worse hear staff make derogatory remarks about me. Others are attended to before I am.*^{Person with lived experience}
- 4. The police will bring me to ED as I am feeling suicidal and the staff tell them to take me home again as they don't treat 'borderlines'*^{Person with lived experience}

These stigmatising and judgemental attitudes only serve to increase the intensity of the person's distress and may increase the severity of self-harm incidents so they will be triaged faster.

Rather than going to ED saying she was feeling suicidal and face having to wait for ages in the waiting room and having her feelings negated my daughter would in fact take an overdose so that she would be taken seriously. At other times she would wait for an hour or so after taking an overdose before calling emergency services so that she would be admitted straight away. Naturally this dramatically increased the potential for long term harm and the level of care she

needed^{Carer}

These attitudes also contribute to people's alienation from health services and reluctance to seek help when needed and can also increase hopelessness about their potential for recovery.

Issues surrounding the prevalence of stigma around BPD (especially in young people) may lead to a reluctance by health professionals to give a diagnosis of personality disorder. This is problematic as it results in the potential for many years of inappropriate treatment/s and/or medication which only delays access to appropriate evidence-based treatment in a timely manner.

Stigma is also experienced by men:⁷

'Continual reference by a variety of services on how 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.'

'Being treated by mental health professionals at times as a pest, a nuisance was disillusioning in seeking treatment for BPD as a male and is easy to see why men with BPD would not want to seek treatment and, a lack of treatment may correlate to an increase of suicide in men.' Male With lived experience

Stigma towards people with BPD is largely perpetuated through poor health literacy about BPD health and mental health professionals. Addressing this stigma requires multiple strategies that include more targeted education, advocacy and leadership, along with greater inclusion of the voice of patients with BPD in these processes.⁸

Recommendations:

- Develop and implement a multifaceted and targeted media campaign funded by the State Government with the work undertaken by an existing advocacy organisation such the BPD Foundation or NEA BPD (Aust) eg www.bpdawarenessweek.com.au and a private advertising agency with the correct skills and a proven record. It is recommended that such a campaign 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. The main target audience would be:
 - The general community
 - All Mental Health and Drug Alcohol Services
 - Emergency services including Emergency Departments, Ambulance and Police
 - Crisis call services such as 000, Lifeline and other information support services
 - Forensic, Corrections, Child protection Services
 - Maternal and Child Health
 - Tertiary services such as homeless and housing, psychosocial rehabilitation
 - Employers across public, private and non-government sectors
 - Tertiary Training Institutions including Medicine, Nursing, Psychology, Occupational Therapy, Social Work, Dietetics.

- Schools both primary and secondary / universities and colleges
- Sporting and other recreational clubs.
- ❑ General Practitioners and all Mental Health Clinicians require basic training in core competencies to detect, diagnose and offer psychotherapeutic clinical interactions to enable them to relate to people with BPD in a way that does not result in further iatrogenic harm and perpetuate the stigma and discrimination.
- ❑ Develop and implement systematised education for emergency services staff such as police and ambulance and Emergency Department (ED) staff to increase their understanding of issues related to personality disorders and ways to therapeutically engage with someone with BPD. Adequate support and debriefing to minimise non-therapeutic responses.
- ❑ Increase resourcing of Emergency Departments with mental health staff to provide prompt assessment and intervention for personality disorder and to promote effective therapeutic responses and referrals for follow-up. Minimise wait times in line with accepted triage guidelines.
- ❑ Employers need correct and unbiased education to demystify BPD so that obtaining and maintaining gainful employment is not hindered by having a diagnosis.
“I spoke in the public arena as an advocate about my (BPD) mental health issues. This was seen by my employer who decided they did not want to be associated with me anymore.”
Person with lived experience
- Health and mental health professionals and service providers to use language of hope and respect eg say ‘Trying hard to get their met’ instead of ‘manipulative’, ‘drama queen’, ‘melodramatic’ ‘Choosing not to’ instead of ‘non-compliant/uncooperative’; feeling vulnerable and insecure’ rather than ‘needy/dependent/attention seeking’.
- ❑ Well known and respected personalities championing the cause without fear of repercussions

2. What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

Things that are working well include school interventions, specialist services like Headspace, Reachout and Batyr (although these need to be significantly better resourced), awareness campaigns encouraging people to seek help, and awareness about mental illness across the lifespan.

BPD is often under-recognised due to its presentation with common psychiatric comorbidities including substance abuse, eating disorders, depression, anxiety, bipolar affective disorder² often resulting in years of inappropriate treatments and associated distress and impact on families.

“A survey with 19 Australian family carers of people with BPD asked what they noticed during the person’s infancy, childhood and adolescence, and their experiences of seeking help during that time. Sensitivity was most noticeable during infancy; difficulty making friends, school refusal/truancy and being bullied were prominent concerns once the child was at school; and concerns about anger, moodiness and impulsivity were the strongest prompts to seek help during adolescence, though doctor or teacher recommendation to do so was uncommon.

*BPD family carers' experiences suggest that improved focus on addressing bullying and communication is needed."*⁹

Young carers (aged less than 25) face additional burdens and need to be able to access age appropriate supports

"My mother had BPD and our home life was chaotic. Dad worked 4 jobs to try to make ends meet. I and my siblings became the adults and looked after our youngest brother and also frequently our mother. I needed to leave school early so I could pick my brother up from kindergarten. I left school in Year 9 and started work – I could not deal with teachers hassling me and all the stresses at home. We were regularly home alone for extended periods whilst mum was in hospital. She seemed to be always absent for special celebrations like birthdays and Christmas. We received no support. When I became a mum myself I struggled as I had never been mothered and I suffer from my own mental health issues" Adult child of mother with BPD

Parents frequently attempt to access support for a young child and frequently blamed for 'poor parenting' and offered no support

" My son is 41 years old and has diagnosed BPD. He is often out of control, threatens people, has massive temper tantrums and is abusive. He suffers from high anxiety, takes risks, is inconsiderate, manipulative and irresponsible. Other times he is caring and giving and has a little boy lost side. He is also an alcoholic and threatens to kill himself whenever anything goes wrong in his life. He has little control over his emotions and can't cope but is also a high achiever and has significant business successes. He is intelligent and very knowing. He exhibits a wide range of emotions and seems to ping pong violently from one to another. He is even very charming when he wants to be and can gain from that behaviour. He is also a liar if it will help him get what he wants or keep him out of trouble. Everything he does is to excess. We are currently estranged as he threatened his ex-partner and I supported her when she took out an AVO against him as she is looking after their 3 year old daughter.

He demonstrated this behaviour from an early age. No one could cope with him. At school they tried excluding him from activities and from play with others because he was too much. He began to get depressed and I spoke to the headmistress who said they are at a loss as to what to do with him and feel like they want to suspend him from the ceiling so that he doesn't get into any trouble. (They obviously didn't do this). I separated from my husband when my son was 19 months old, but he had frequent access to him. When he was 9 years old he went to live with my ex-husband as he had remarried and had other children and my son asked to go. He was there for 3 months when I was told that I had to take him back as they couldn't cope. At that stage I'd had a nervous breakdown as I have no other family support here in Australia, had to work full time to support us and I couldn't cope with him. Eventually he was placed at in a prestigious school where he was sexually abused over a number of years by a teacher at the school.

In trying to work out what to do to help him and calm him down I took him to the Royal Children's Hospital for assessment when he was around 7 or 8 years old, they told me there was nothing wrong with him...he was just 'wilful'. That's all very well but what does that mean? How was I to cope with him? They didn't give me any assistance or ask if I wasn't coping or discussed my family

situation. He has gone on to worse and worse behaviour, if the best that the RCH could do when I had him assessed was say he was 'wilful' no wonder more and more children move onto criminal behaviour, serious drug taking and alcoholism. This happened to me over 35 years ago but it seems that not much has changed. My neighbour, a single mother whose eldest boy exhibits the same behaviour as my son when he was young, recently had him assessed and was told the same thing and that her parenting was at fault. How is that helping her? She is at her wits end and has two other children. He is soon going to live with her ex-partner and I can see him being returned promptly when they discover the behaviour patterns that are extreme. The people who assessed him said he didn't display behaviour that required intervention!!! What is going to happen to this boy? Why aren't they listening to his mother?

When is the government going to look at these children and provide real and proper support for parents to deal with them? Not wait until the child kills someone, burns down or smashes up a house or acts out other extreme behaviours. Listen to the parents and give serious consideration to what they are saying. These kids need help now.

My granddaughter, my son's daughter, also exhibited 'wilful' behaviour. To help her I had to go online and search the web to find someone who could assist us in dealing with her behaviour so that she doesn't end up like her father. Luckily I found one and it has given me and her mother a new direction in dealing with her. (It is www.themilitarywifeandmom.com) It is successful and works. Workshops like this should be offered to parents who have trouble coping with children like this.

As to why the behaviour manifests itself is difficult for a layperson to understand. It could be a result of the 'still faced mother syndrome' when the child was young, or the amount of adrenaline in the mother's body when she was pregnant. I know that it occurs in families where parents are professional psychologists, in families of regular people and also highly intelligent people. It may occur in one out of 5 children in a family. I have it, my brother has it but my other 3 siblings don't. My sister's eldest son has it but his 2 sisters don't. I know people who say that if the child who exhibits this behaviour was their first they wouldn't have any more children.

They say that BPD doesn't occur until a child is older, but why isn't anyone looking at children who display this extreme behaviour when they are young so perhaps they won't end up with BPD, in prison or dead." Mother

Personality disorders and many other mental health disorders have their origins in these early life experiences, as well as in genetic or biological factors. eg any difficulties in relation to childhood attachment and trauma can impact on the development of identity and of self-regulation and relationship skills. These impacts are directly linked to subsequent mental health outcomes, including for personality disorder. When the cause of personality disorder for an individual seems to be biological rather than attachment or trauma reasons, early relationships are still important in mediating the outcome of the biological factors and in providing a secure sense of self and resilience.

It follows that fundamental to prevention and early treatment of personality disorders are human relationships that are protective and that foster resilience and security in the presence of stresses or adversity. This applies both to early childhood caregiver attachments and school age

relationships, as well as to treatment relationships when a person engages with health services

Recommendations include:

- ❑ Establish a whole of Government approach to develop and 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 mental health. (stepped care models are already available to guide this development) see response to Q9
- ❑ Re-orient maternal and child services to develop ways of identifying families at risk of psycho-social stresses identify and address issues of concern in early life. Increasing the range and availability of maternal and child health services and so improving family health and social supports.
- Government should develop and implement a “no wrong door” approach with clinicians and services at any point of initial contact equipped with systematised, easily accessible, coordinated referral pathways
- ❑ Government to organise the development of these referral pathways and ensure education for all staff at all levels regarding their use and to set expectations regarding provision and duration of treatment within the stepped care framework
- ❑ Education of child-care providers, teachers, social welfare providers to recognise BPD and offer referral to appropriate services.
- Resource the early childhood education sector to identify at-risk families, or children / families of concern, and implement referral pathways for appropriate support and intervention targeted at increasing caregiver’s resilience and parenting / coping skills and strengthening families
- Extend and further strengthen school ‘wellbeing units’, resilience and anti-bullying programs across all primary and secondary schools to identify at-risk families, or children / families of concern, and implement referral pathways for appropriate support and intervention targeted at increasing the child’s as well as the family’s resilience.
- ❑ Education of primary health care and mental health care providers aiming to build understanding and empathy to improve attitudes and behaviours toward people with BPD. For recovery, it is vital that a person with BPD experience respectful communication and that they are seen as a human in distress and not dismissed as a number of diagnoses/illnesses.
- ❑ Developing a peer workforce, then training and embedding them in AMH Services to assist in psychoeducation and peer support for people living with BPD and their carers and families. This workforce needs to be appropriately trained, resourced and supervised.
- ❑ Develop support services for parents / caregivers / families that are flexible, responsive and available after hours

3. What is already working well and what can be done better to prevent suicide?

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 and 99% of these had had contact with a mental health service within one year prior and 88% within 6 weeks prior to their death.¹⁰

In the 6 weeks prior to death	In the 12 months prior to death
37% had contact with a GP	63% had contact with a GP
50% had contact with a psychiatrist	77% had contact with a psychiatrist
43% had contact with allied health	64% had contact with allied health
25% had presented to an Emergency Department	43% had presented to an Emergency Department

This client group are reaching out for help and not receiving appropriate evidence-based and/or affordable care

Only a fraction of the suicide prevention research is allocated to researching suicidality of people with BPD.

Recommendations

- Allocate 10% of all money for suicide prevention to focus on people living with BPD in line with the evidence showing that 10% of all suicides related to BPD. Generic suicide prevention strategies that are applied for general mental illnesses are not likely to be effective for Personality Disorders given the understanding that treatment principles of chronic suicidality (eg for PD's) are entirely different to acute suicidality¹¹
- Develop a 24/7 Victorian specialist telephone and online helpline for people with BPD, their carers and clinicians staffed by skilled clinicians able to offer the specific assistance needed by people with BPD who are feeling suicidal. An alternative would be to upskill current telephone helpline staff and volunteers. For example, it is not clear that Lifeline currently has the appropriate skills to support this group of people.
- Upskill front-line service staff, including Police, Ambulance and Emergency Department staff, to identify and appropriately respond to people with BPD with clear referral pathways to achieve skilled mental health treatment with no/minimal wait periods.
- Follow up people who have presented to ED with suicidal ideation or actions or who are at risk of suicide.
- Minimise admissions to instances where the person is at high risk to themselves or others as there is a lack of evidence to support hospitalisations as being helpful for the person.¹²
- Establish non-clinical alternatives to Emergency Departments for mental health consumers and people seeking support for their well-being outside of normal service operating hours eg The Safe Haven being trialled at St Vincent's Hospital.
- Although there are no medications that are indicated or patented for Personality Disorders, clinicians in Victoria prescribe excessive amounts of medications for people with BPD in order to provide "some treatment". We believe clinicians often justify prescribing medications believing that they are treating the co-occurring conditions and not BPD. This is against the available evidence that treatment of co-occurring disorders alone is not beneficial.^{13,14}

Medicines should not be used as primary therapy for BPD as they only have modest and

inconsistent effects and do not change the nature and course of the disorder. In addition, since people living with BPD are at elevated risk of attempted suicide by using prescription medication, only minimal amounts of medications should be provided¹⁵ and when deemed to be absolutely necessary.

- Support families of people who present with personality disorder and suicidal patterns.
- A range of school interventions including:
 - More recognition of at risk young people in schools
 - More education in schools about suicide risk factors and equipping young people about how to support or seek help for their peers who are at risk
- A range of interventions for young people and adults including:
 - Timely diagnosis and response
 - Appropriate referral pathways and treatment options
 - Access to adequate periods of evidence based treatment at the earliest opportunity, given current high rates of inadequate or ineffective episodes of therapy which can lead to a false impression that treatment does not work for the individual
 - More availability of evidence based treatment as well as training to all clinicians in the key recommendations of the NHMRC Clinical Practice Guideline for the Management of BPD (2012) so that any interaction with the person can be supportive rather than causing increased distress and harm.
 - Follow up for people who have presented to ED with suicidal ideation or actions, or suicide risk factors, including linking them to treatment services. This requires a greater mental health resource in EDs
 - Support for families of people who present to ED with suicidal patterns

4. What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

What makes it hard?

- Socio-economic factors
- Intergenerational trauma
- Social isolation and loneliness with break down / loss of supportive family and social systems
- Fragmentation and lack of integration of services

Fundamental to mental wellbeing throughout life are experiences in childhood of secure, available and supportive relationships. The importance of being connected and engaged in supportive relationships and social systems continues throughout life. Today's society is characterised by break downs in family and social systems, and intergenerational patterns of violence, abuse, drug use, criminal behaviour, which strip away the foundations of mental wellbeing.

Unless these early and ongoing social and environmental determinants of wellbeing are targeted, we will continue to have generations of people with mental health problems that are difficult to treat because of complexity and prevalence. Preventions targeted at these early and ongoing social determinants will arguably be the most effective intervention we can do.

This is a whole of society problem and requires a whole of government approach.

Recommendations for Improvement

1. Social / Community Level

Fundamental to improving mental health for people across the spectrum of mental ill health is to have the opportunity to be connected and engaged in social communities, within which they experience supportive relationships.

This requires a whole of government approach to mobilise and invest in initiatives that foster community programs, groups, and activities that provide connection and engagement for people.

Recovery to be seen as a whole of life approach.

2. Mental Health Service Level

- Coordination and integration of services within stepped care frameworks and with coordinated referral pathways
- Client centred systems of treatment and support
- Education to all 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.
- Caseloads of AMHS case managers and frequency of contacts / meetings with people with personality disorder to be managed to support therapeutic ways of working rather than bureaucratically driven processes

5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

Drivers behind poor mental health outcomes:

- Issues for rural and remote communities
- Intergenerational trauma
- Indigenous health issues
- Refugee communities with histories of trauma
- LGTBIQA+
- Social isolation / loneliness

These social factors and cultural communities are linked to higher rates of personality disorder and complex trauma, as well as to mood, anxiety and psychotic illnesses.

At the same time, there are multiple issues of accessibility to, and cultural appropriateness of, mental health services for these communities.

Recommendations:

As already recommended for other questions:

- ☐ A whole of government response to identify and address socio-economic-cultural issues is important
- ☐ A stepped model of care to address issues from mild, through moderate, to severe presentations of BPD
- ☐ Referral pathways that are clear, adequately defined and funded

6. What are the needs of family members and carers and what can be done better to support them?

On being a carer:

“I feel our role (as a carer) is best described as a de facto mental health system. Nowhere is this more so than in the case of BPD, where so often our family member is excluded from treatment in the Emergency Department and the mental health system. Frequently my son is sent home whilst still acutely suicidal and we are left to struggle on our own” carer

“We are experts by experience. We play a unique role. We know the person best, probably knew them before they became unwell and we’re usually available 24/7” carer

“We need for clinicians to see us for who we are – concerned and often struggling parents who are not abusers. We’re doing the best we can with what we knew While our parenting may not have been right for our child it was not abuse or done with any malice.” carer

- Relentless, chaotic, confusing, exhausting
“I worry, worry every minute. I live life on tiptoes. I never know what the next phone call will bring, and be assured, there are many phone calls, both day and night. Yet I am too afraid to turn off my phones in case there is an emergency. I live with this anxiety day and night, and yet I keep on going.” carer
- Unable to plan with any certainty
- Isolating – loss of family and community networks
- Often blamed and judged. Stigma
- Lack of recognition of their role as well as the diversity and extent of their role
- Family breakdown / dysfunctional families. Frequently experience violence or live in fear of their family member. Other siblings frequently leave home early to escape the chaos and when their parent has a mental illness children also frequently leave home earlier than the

required.

- Isolation and Exclusion e.g. from planning. May be asked to take a family member home on day leave from a private hospital and is expected to take responsibility for the person without any information as to what is actually happening or what to do if the person experiences a crisis
- Exhaustion – physically, emotionally (bewildering, frightening, filled with fear and uncertainty) and financially (eg frequently need professional counselling themselves subsidising the person who is ill with daily costs of living, accommodation etc)

“I gave up work so that I could look after my daughter and I took out a second mortgage on my home to help pay for her therapy. As she was deemed ineligible for a disability pension (and has been unable to work) I have supported her financially as well. Now I am only a few years away from retirement and we are both facing an uncertain future.” carer

“As my daughter was homeless I allowed her to return home. She became pregnant and the child’s father moved in as well. He is abusive and I cannot live with him. I cannot evict her because of the young child. I now have a choice of living in fear in my own home or becoming homeless myself.” carer

“My son (17) applied for a disability pension which was refused – he was deemed to be ‘well’ yet due to his BPD he was unable to go school or to obtain employment and could not pass the ‘independence clause’ required to apply for the Youth allowance. This meant that I (a single parent) needed to fully financially support him at a time when he really wanted to have nothing to do with me. The stresses impacted upon my own health and I was unable to work as well.” carer

- Grief

“Grief is often invisible, experienced, and not named. It’s not publicly acknowledged, and it is poorly understood. It’s often dismissed. And, it has to put into abeyance while there are crises to be dealt with. It has no beginning, no end, comes in waves, and is always present. As a carer, you have no framework for these feelings, and you are offered no resolution. It’s complicated by the fact the lost person being grieved for, is present and in pain. Around mental health professionals, your grief must be hidden, otherwise, you risk being labelled and your grief used to discount your standing. Your grief never goes away, it just continues to rise” carer

“The pain of seeing someone we love struggle to get the treatment they need, (or be denied treatment or be treated as ‘time wasters’ trouble makers or to be treated like they have done something wrong and punished by being secluded or restrained or worse still, losing their life is immeasurable and forever” Bereaved carer

“We have the added grief in many cases of being marginalised from the rest of our family. I know of many siblings who can no longer cope with their sibling with BPD and not only move out of home, but some leave the State. We have now lost not only the hopes and dreams we had for our child with BPD and have lost the warmth of a normal relationship with our other

children.

Our family celebrations are more often than not, either fraught with tension, or disjointed as one member or the other refuses to attend the celebrations because of the angst of being with the person with BPD. The grief we live with is unimaginable for most people. We keep it to ourselves, both because we don't want to burden others, and also because they don't understand." carer

- Young carers (aged up to 25) – loss of childhood impacting upon their development, their own future well-being, education and future employment prospects

"My mother had BPD and our home life was chaotic. Dad worked 4 jobs to try to make ends meet. I and my siblings became the adults and looked after our youngest brother. I needed to leave school early so I could pick him up from kindergarten. I left school in Year 9 and started work – I could not deal with teachers hassling me and all the stresses at home. We were regularly home alone for extended periods whilst mum was in hospital. She seemed to be always absent for special celebrations like birthdays and Christmas. We received no support. When I became a mum myself I struggled as I had never been mothered and I suffer from my own mental health issues" Adult child of mother with BPD

- Vicarious trauma – carers often develop their own trauma disorders due to the challenging situations they need to manage with little/or no support
- Caring is harder without a diagnosis – reluctance of clinicians to use BPD as a diagnosis because of stigma can cause its own set of problems

"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 get the right treatment. At this stage we feel some hope that things will improve." carer

- Carers need to know their family member is safe especially as they themselves age and may now longer be able to maintain the level of care they once provided.

"Given the chaos and turmoil that BPD can causes within families, good, independent accommodation is a must. Most children leave the family home and live independently by the age of say 30. For someone with BPD, often unable to work the accommodation options, are on the whole, abysmal.

My son has been fortunate to access 'a nice unit' in public housing however he lives in fear and is too scared to venture outside due to the gangs that roam the corridors. I feel unsafe to visit him. The police will no longer attend the units. He receives no support for his BPD." carer

Recommendations:

- The Victorian Chief Psychiatrists Guideline for the Inclusion of Families should be implemented.
- Mental health professionals / 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 and validated.
- This means legitimising and validating carers' experiences, emotions, thoughts, beliefs – even when there may be a discrepancy between the carer's viewpoint and the person with BPD. Carers need to be acknowledged as doing the best they can at that particular moment – if they were able to they would be doing something different. They also need to be regarded with an attitude of realistic hope and respect – for both themselves and the person with BPD. No blame. No shame. No judgements.
- *“Where an adolescent has BPD, involving family members embedded into the treatment package is even more important....Early intervention is likely to be more effective before problematical patterns get locked in.”*¹⁶
- Family and carers need to be engaged in all stages of care and planning. They need to be provided with accurate information about BPD, including diagnosis, about the treatment to be provided including roles of therapy, medications, basic coping skills such as validation, empathy, acceptance, listening and what to do if the person with BPD self-harms or has urges of suicide and whom to communicate with, ways to manage risk, crisis services and hospitalisations.
- Carers need to feel safe. They need support for instances of domestic violence when the perpetrator is their child. Family and carers need support to 'debrief' in a safe and caring space.

“A family friend lives with her son who is frequently violent and abusive. She lives in constant fear and locks herself in her bedroom at night. When the mother told staff at the hospital, (where she was told her son would be detained but he was subsequently discharged a few hours later), that she was afraid to have him home, they suggested she take out a restraining order against him. She felt she could not do this as then he would be on the street homeless. She questions ‘Why?’ when he was initially deemed to be sick enough to be detained?” Family friend

- Effective case management is needed to identify concrete options, and not just a list of recommendations which may or may not be acted upon. Mental Health workers need to be proactive in coming together with consumers and carers to develop and review ongoing plans that are cohesive and meaningful.
- Family and carers need a 24/7 service/response team (or upskill current helplines) for times of crisis to:

- Provide information about services
 - Advise on rights of carers e.g. to information, confidentiality
 - Provide advocacy for e.g. inclusion of carers in discharge plans
- Funding should be provided for group psychoeducation¹⁷ and support to equip family and carers supporting people living with BPD to respond in way that is supportive of the person with BPD as well as their own well-being and enhance their capacity to maintain the relationship. These programs need to recognise the real risk of harm (and potential 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.

“It does not make sense to treat the person with BPD in isolation, with them just returning back to the same unchanged environment where their behaviour developed and/or continues.”¹⁸

- ☐ Family members and carers need to know they can be linked with other people in a position similar to their own, so they need no longer feel so isolated.

“In a research project currently being undertaken at Spectrum Personality Disorder Service investigating the outcomes of a Day Psychoeducation Program for Families and Friends Supporting a person with BPD one of the commonest responses received is “great to know we’re not alone’ So reassuring to meet others facing challenges like we are”^{Researcher}

- ☐ The system needs to affirm the legitimacy of family and carers looking after themselves, so they can continue to care for their loved ones and trying to keep their own lives going.
- ☐ Provide appropriate accommodation eg cluster housing where people can have their own small unit, space and be supported by staff with a good knowledge of BPD. This should include provision for people living with dual disability (ie mental illness and an intellectual disability).
- Expansion on the BPD carer peer workforce – this workforce needs to be appropriately recognised, skilled and supported

7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?

Issues affecting the workforce include:

- Stressful workloads
- Mental health professionals find this work very challenging and feel they have not been adequately trained.^{19, 20}
- Complexity of clinical problems especially in the context of early trauma, family violence, substance abuse, refugees etc

- High turnover of staff, with associated loss of experience
- Undergraduate education that does not prepare the workforce to understand and work with personality disorder and complex trauma
- Lack of flexible ways of respecting and retaining mature, experienced clinicians, eg, flexible workloads and work hours

Recommendations:

- A whole range of training interventions at under-graduate and graduate levels to better prepare the workforce to understand and work with the range of mental health conditions
- More provision of mentoring and group and individual supervision for staff
- Better management of clinician workloads
- Focus on clinical leadership as opposed to bureaucratic management
- Accessibility of training in evidence based models and common factors treatments to increase confidence and job satisfaction
- Resources to develop peer workforce models that are appropriate for different contexts and diagnostic groups. Appropriate recognition of the peer workforce. Flexibility within working conditions for the peer workforce to accommodate their own mental health needs and/or their caring responsibilities
- Adequate models for providing treatment and support to clients. When these are in place and with good clinical leadership, staff generally feel more positive about the work they are doing, and gain satisfaction from seeing positive outcomes for their clients.

8. What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

Recommendations:

- Provide expectations and incentives for employers to employ people with disability and people who struggle to find and sustain work related to their mental health difficulties
- A whole of government approach to address multiple psycho-socio-economic-cultural determinants of poor mental health

9. Thinking about what Victoria’s mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

1. People with BPD should have access to the type of service best suited to their needs. Care is most likely to be effective when tailored to the individual’s needs and guided by a well-documented management plan. Effective and safe treatment for BPD can be given in a

variety of service settings, including primary care (general practice, Aboriginal medical services, community health), public community mental health services (including child and adolescent mental health services, adult mental health services and aged mental health services), public and private hospital outpatient psychiatry departments, inpatient psychiatric facilities, private office-based psychiatry practices, specialised BPD programs and services, accident and emergency services, and combinations of services (e.g. through structured private/public collaborations).

2. Consumers have expressed a demand for a choice of services for BPD treatment that is flexible and supports their desire to live as contributing a life as possible.

The four main priority areas for people with BPD are:

- * improved self-identity (self-confidence, self-acceptance, sense of direction in life)
- * improved relationships (especially with close family and partners, greater trust and more secure attachments)
- * greater well-being (paid work, reductions in medications, better health)
- * symptomatic improvement (reduction in emotional dysregulation, impulsivity, anxiety and suicidal ideas)²¹

3. System wide implementation of the key recommendations of the National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines for the management of Borderline Personality Disorder (2012)²²

The Guidelines emphasise:

- * The importance of avoiding inpatient mental health admissions
- * When an admission is clinically indicated due to acute risk to self or others, length of admissions should be brief

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 EUPD (also known as BPD). Results from the study suggest the enhanced Clinical Pathway to be a feasible, clinical and cost effective model of acute inpatient care for patients with EUPD

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, 95% CI [\$926,685, \$6.7M].^{23, 24}

4. A research project in 2017 by Project Air Strategy in NSW found the provision of evidence-based psychological treatment to patients with BPD results in a reduction in costs associated with both the use of mental health services and related community costs, The mean cost saving for treating evidence-based psychotherapy was USD\$2,987.82 per patient per year (AUD\$4000/yr). A further mean weighted reduction of USD\$1,551.37 per year per patient was found compared to Treatment As Usual that significantly exceeds the cost of no treatment or treatment as usual.²⁵

Priorities for Change:

5. System wide implementation of the key recommendations of the NHMRC Clinical Practice Guidelines for the management of BPD (2012)²⁶
6. Develop a “no wrong door” approach with well-developed and accessible referral pathways

for mental health and community and social service providers to utilise

7. Resource maternal and education sectors to identify at-risk families, or children / families at risk of psychosocial stress, and implement referral pathways for appropriate support and intervention targeted at increasing the caregiver's resilience and parenting / coping skills and strengthening families

8. Develop a whole of school intervention for personality disorder and self-harm in youth

*"Schools are important locations for addressing student wellbeing, because of the reach and familiarity to students and families, the opportunities they afford for mental health promotion and prevention as well as the link between wellbeing and learning outcomes. Teachers have established relationships with students and are ideally placed to notice changes in students' behaviour that may indicate a mental health concern. We report that providing teachers with appropriate knowledge and skills improved their confidence in supporting and working collaboratively with school counsellors to achieve better outcomes for young people with personality disorder."*²⁷

9. Improve education to all health professionals, targeting under-graduate and graduate programs, to improve understanding of personality disorders, complex trauma and other mental illnesses, and to inform of treatment approaches and referral pathways

10. Develop and implement a stepped model of care^{28,29} coordinated across all health services from primary care to public mental health with easy two-way referral pathways as appropriate for the person's needs including:

Mild: Provision of readily accessible (private and public) evidence-based psychotherapy early in the initial onset of mental illness and as required

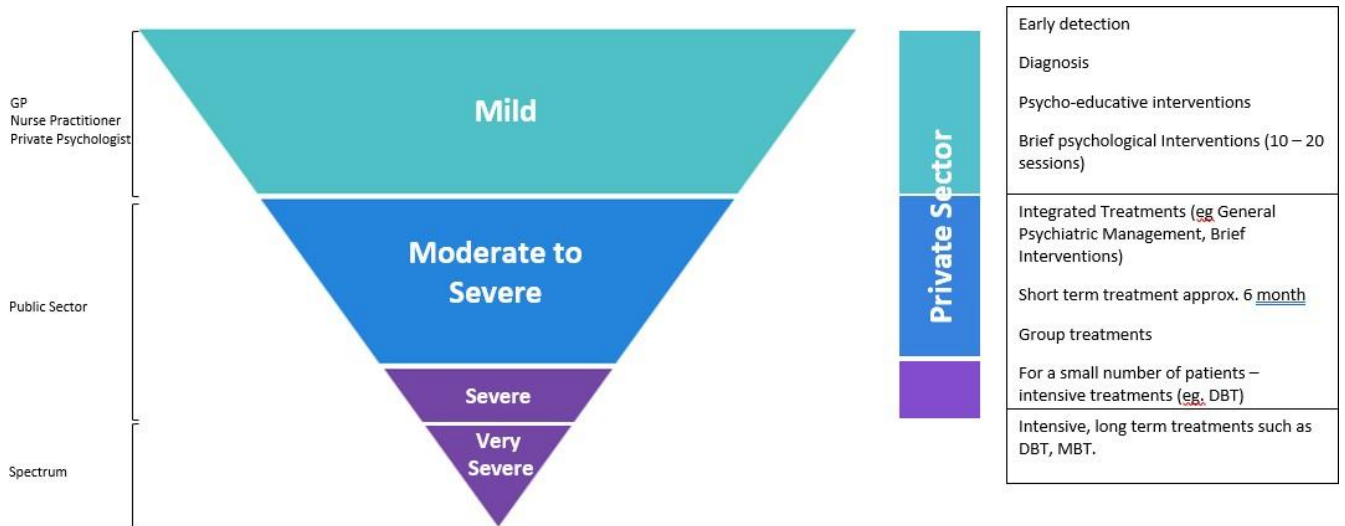
The moderate to severe cohort to receive treatments within the private and public sectors and receive integrated therapies such as Good Psychiatric Management, Brief Interventions and/or short term interventions

Complex and severely unwell: Following a step up model everyone with a complex and severe BPD should be referred to a specialist PD service (such as Spectrum). The current eligibility criteria for entry to Spectrum's services needs to be revised to enable equitable access – case management should not be a requirement. From our estimate there needs to be at least a five-fold increase in access to Spectrum's services.

We suggest referral to a specialist service for people who are treated in the Primary, Public or Private sector who have:

1. Presented 5 or more times to an emergency department in the preceding 1 year
2. Made 3 or more suicide attempts in the preceding year
3. Had involvement with Child Protection Services
4. Are homeless
5. Had unsuccessful treatment for a year
6. Needed multiple medications, or two or more courses of Electro

Convulsive Therapy (ECT) or Transcranial Magnetic Stimulation (TMS) (even if it is for treatment of co-occurring disorders such as depression, bipolar disorder or psychosis – this is due to the available evidence that when depression, bipolar disorder or psychosis co-occur with BPD, treating only the co-occurring disorder and ignoring BPD treatment leads to poor outcome for both the disorders. Treatment with specific psychotherapy for BPD, however, leads to remission of both BPD and the co-occurring disorders.



11. Treatment of people with complex Personality Disorders

More than half of people with a diagnosis of BPD have substance use disorders. Also, more than half of people who abuse substances have a personality disorders. People with these co-morbidities experience further stigma and are frequently refused services. Mental health services (including Spectrum) refuse services for this cohort of patients until the consumers have stopped abusing substances. However, we believe both conditions should be treated simultaneously. Specialist services eg Turning Point and Spectrum should develop joint clinics and provide simultaneous services.

12. People with BPD in Forensic and Criminal Justice systems

There is extremely limited access for evidence based psychological interventions for people with PD in these settings. Absence of such treatments seems to result in aggression towards staff, self-harm behaviours and suicide. This lack of access equips them poorly to reintegrate back into the community post incarceration/discharge. We don't believe forensic services, justice systems and specialist services eg Spectrum work adequately together to improve outcomes for people with BPD, given the high prevalence rates (estimated at 20%) in these settings.

13. Treatment of PD in private settings

It is commendable that most Private Psychiatric Hospitals in Victoria provide psychological treatments for people with Personality Disorders through their day programs. However, it is of concern to note that we believe excessive (and we believe often inappropriate) amounts of hospital admissions, ECT and TMS that is provided for people with personality disorders in Private settings.

14. Developing research priorities and appropriately funding applicable research into a number of areas such as: -

* Models of care – suitable for the Australian Health sector

- o Emergency Department / Psychiatric Assessment and Planning Units (PAPU) and for crisis treatment
- o In patient care / Prevention and Recovery Care (PARC) for structured crisis and brief treatment
- o CATT
- o Community- for more general treatment
- o Suicide prevention specific for personality disorders (see response to Q3)

*Brief interventions

*Consumer Peer Workforce

*Family Education programs

*BPD and Substance use disorders- concurrent management

* Stepped care

* Emergency Departments – for crisis treatment

* In patient care for structured crisis and brief treatment

* Community- for more general treatment

* BPD in old age and children/youth aged 0 -18

* Late manifestation BPD

Men with BPD

* Chronic pain and BPD

The prevalence of BPD in pain clinics is 25%. Also, one third of patients with BPD have Chronic Pain disorders. This co-morbidity is poorly recognised. People with chronic pain who have BPD often do not get an appropriate diagnosis or treatment. This seems to result in chronicity of pain and administration of poly-pharmacy.

* Increasing the number of available psychologist sessions to 40 either through the Medicare Funded Better Access, through the NDIS or Primary Health Networks - the current 10 sessions is not adequate

15. Tele-Health service

24/7 telephone access needs to be established for consumers with PD, their families and carers, and the clinicians treating them. This would specifically enable clinicians working with people with PD in rural and remote areas to better support their patients. People with BPD who are in crisis, especially suicide crisis can get specialised and appropriate telephone support.

Families and carers who are often desperate to assist their family member can get timely help. This 24/7 telephone support needs to be delivered by professionals who have specialised training and skills in dealing with chronic suicidal behaviours, chronic self-harm behaviours (non-suicidal self-injury). Generic mental health helplines and suicide helplines are often less helpful because the principles of management of chronic suicidal behaviours is entirely different to the principles of management of acute suicidal behaviours³⁰

16. Tele-health therapies

To enable evidence based and effective psychological treatments for people with PD in rural and remote areas tele-health therapy options should be explored from specialist services (such as Spectrum Personality Disorder Service).

17. Child protection Services

It has been reported that one third of parents whose children are under the custody of child protection services have BPD. This condition is again poorly recognised and parents with personality disorders in this setting often do not get evidence based psychological treatments or parenting skills training. This has the potential to result in traumatising children and increasing the incidence of BPD across generations.

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

The State Government of Victoria should commission the development of a clear clinical pathway for People with Personality Disorders in Victoria across all health services.

Building a new Mental Health system that would improve outcomes for people with Personality Disorders

- Victoria has recently rolled out a Personality Disorder Clinical Specialist Initiative. This is being currently piloted in 6 AMHS. After a period of 6-12 months of trial this initiative could be rolled out to all the MHS in Victoria and triple the funding to ensure there are at least 3 clinicians in each of the AMHS who hold a PD Specialist portfolio, and take up treatment of people with Personality Disorders within the context of AMHS.
- All Mental Health clinicians should have foundation training in early detection, early intervention, suicide risk detection and prevention and treatment principles. Achievement of competencies in these areas should be measured, documented and monitored.

In our opinion, unfortunately the various colleges (eg College of Psychiatrists (RANZCP) College of Psychologists (APA) or the colleges of Nursing) have provided inadequate leadership to improve the level of training that is required of clinicians for effective management of people with Personality Disorders. The colleges and bodies need to be asked to step up and provide leadership.

- Equitable access for everyone who needs to access treatments/supports. Currently people with Personality Disorders are often declined services in AMHS stating that these patients “do not have case management requirements” Case management requirements should not be an

entry criteria for eligibility of services for PD consumers.

11. Is there anything else you would like to share with the Royal Commission?

Thank you for this opportunity to contribute.

Privacy
acknowledgement

I understand that the Royal Commission works with the assistance of its advisers and service providers. I agree that personal information about me and provided by me will be handled as described on the Privacy Page.

Yes No

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