SUBMISSION

TO THE

ROYAL COMMISSION INTO VICTORIA'S MENTAL HEALTH SYSTEM

BPD Community humbly submits to the Royal Commission into Mental Health in Victoria that:

Borderline Personality Disorder (BPD) requires a response specific to the needs of those with lived experience:

- A focus on addressing the stigma and discrimination specific to BPD;
- A focus on recovery;
- Active inclusion of families as people with lived experience;
- A response to meet the needs of all with BPD, not just the most severely affected in crisis.

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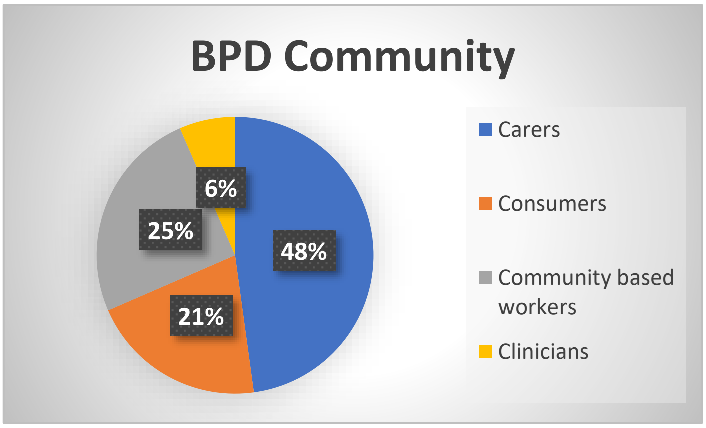
Introduction

Borderline Personality Disorder (BPD) is a serious mental illness, a quiet epidemic. People with lived experience, both those with BPD and their families, are generally excluded from the mental health system. *"People with BPD have so far been overlooked, or perhaps it is more appropriate to say deliberately excluded, from mental health services and mental health reforms."* (Senate Standing Committee on Community Affairs, 2008). Although this was written in 2008, while the goodwill towards those affected by BPD has improved, there has been no significant change in how the system responds to BPD.

Who is BPD Community?

It was in response to the lack of effective action on BPD here in Victoria that BPD Community was formed in mid-2015. BPD Community is a peer-led, grassroots and independent not-for-profit organisation. It has a community of 380+ members.



What BPD Community does and what BPD Community wants to do:

Our mission is to replace stigma and discrimination with hope and optimism and to create a community to support recovery. Our core values are Collaboration, Acceptance, Respect, and Empathy and this informs all the work of BPD Community. We are proud of the sound foundation upon which all our work is based. We build social capital; we have created a community of interest.

Our Strategic Plan is based on three domains: People, Information and Sustainability.

People Programs

NOW: Our People Programs are limited to what we can offer with no resources and no budget. Our Family and Friend's Group has been operating every month since October 2015. It has reached about 70 individuals, and attendances number over 400. The experience of operating this program has allowed us to develop a theory of practice and we have created a model that works. Our Manual to support the program means that the model can be easily adapted to other locations.

FUTURE: Our future programs are based on our experience working directly with people with lived experience, since 2015. We will create Community Hubs, both virtual and geographic-based, for people with BPD and their families and friends. The programs for these two groups will be complementary and are designed to meet their differing needs.

For people with BPD, they are designed to support recovery and to work collaboratively with existing services in the area. They involve identifying gaps and where possible, filling the gaps. The concept is centred on the employment of 'life coaches' (e.g. occupational therapists, social workers, etc.) who will work individually with people to support their recovery and who will develop peer-led monthly support groups.

For families, the focus is on support and psychoeducation designed to develop supportive relationships with their loved ones. Individual support will be available, but the focus is on the monthly Family & Friend's Group. These geographic specific supports will be supported centrally through the website and the other virtual supports.

Information Service

NOW: Our Information Service is based on our website, monthly email updates, quarterly Info Nights, quarterly newsletters, and Facebook and Twitter. We have held 15 Info Nights since 2015, attracting an average of 24 participants, and this October we will hold our 5th Celebration Night in BPD Awareness Week. We have distributed over 600 copies of the National Guidelines for the Clinical Management of the Treatment of BPD. Our website has an annotated, subject-defined collection of research papers on BPD, especially for those who work in the field.

FUTURE: We will operate a BPD phone line with a view to support and refer. We will develop an interactive facility on the website, building on the existing facilities (Sane Forums). We will use closed Facebook groups where appropriate. We will develop podcasts and video content to develop support and psychoeducation. The current site will be reviewed to improve accessibility. The quarterly newsletter will be reviewed and updated. A public relations and marketing campaign will spread the reach the BPD Community and up-to-date, accurate, accessible information will reach more and more people. We will develop hard copy to distribute to GPs, service organisations and treatment centres.

Sustainability

NOW: Our focus has been on developing a sound organisational structure that encourages peer participation. We are developing a theory of practice that complements existing treatments and service supports. We have developed training programs for workers in the community sector. We are currently running an Ambassador Training program for our people with lived experience, to enable them to learn how to tell their stories publicly.

FUTURE: We will develop a variety of training programs to meet the needs that exist. As an independent organisation, we are not held to specific theories or philosophies that can restrict other organisations; we can be more flexible, innovative and creative. Nonetheless, we are committed to up to date, research-based information, and strive to ensure our work is always complementary to existing organisations.

Training needs specific to the circumstances of GPs, nursing staff, community sector workers and the general public is planned, complemented with the production of hard copy material to support the needs of these groups.

A quality assurance program to assess whether a service is BPD friendly is a core element of our sustainability program.

BPD COMMUNITY

THEORY OF CHANGE

How BPD Community achieves its goals

Currently BPD Community has an income of less than $10,000 a year. It has achieved much in a short time. This is a result of volunteer and pro bono support. There are no staff, no facilities, no office, no resources. This is unsustainable.

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

Stigma is a mark of disgrace associated with a particular circumstance, quality or person. Stigma sets people apart. Discrimination is the unjust or prejudicial treatment of different categories of people. Discrimination is the effect of stigma. Research indicates that Borderline Personality Disorder (BPD) is among the most stigmatised of all personality disorders (Sheehan, Nieweglowski, & Corrigan, 2016). Our response to this question covers the primary causes and effects of stigma and discrimination in relation to BPD, which emanates from the mental health professions and the mental health system.

Stigma and discrimination in the mental health system

The stigma and discrimination in relation to BPD emanates from the mental health professions and the mental health system, even when intentions are best. There is a considerable amount of evidence for this in the research literature, as well as in our direct experience as an organisation that connects with people with BPD and carers. We are proud of the difference we make to this.

The Australian Parliamentary Senate Select Committee on Mental Health in 2006 found that "a diagnosis of BPD closes the door to already limited mental health services. It leads to social rejection and isolation. Sufferers are blamed for their illness, regarded as 'attention seekers' and 'trouble makers'" (Senate Select Committee on Mental Health, 2006, p. 90). Indeed, "(BPD) seems to be as much a recipe for marginalisation as it is a diagnosis" (2006, p. 89). Then, in 2008 the report of the Australian Parliament Senate Standing Committee on Mental Health added, "People with BPD have so far been overlooked, or perhaps it is more appropriate to say deliberately excluded, from mental health services and mental health reforms" (Senate Standing Committee on Community Affairs, 2008, p. 168).

The following outlines in more detail the primary ways in which the mental health professions and the mental health system generate stigma and discrimination for people with BPD, and the impacts of this.

Negative attitudes

Increasing research shows that mental health professionals often have negative attitudes towards people with BPD that reveal themselves in lowered empathy, and reduced availability and quality of services (Sheehan et al., 2016). People with BPD are seen as liars, manipulators, drama queens, attention seekers, emotional vampires and more. This is the first-hand experience of people with BPD when they seek help from the 'helping professions'. They are perceived as too difficult to help. Research says that people with BPD reach out more than others, yet they experience judgement, rejection, hostility and worse. A recent survey of the literature conducted in 2015 (Wilding, St Vincent's Hospital) revealed that from 2000 to 2015 there were eighty references to people with BPD that included adjectives such as difficult, untreatable, manipulative, unmanageable, attention seeking, impossible, and hateful, while ninety articles referred to stigma in relation to BPD among mental health clinicians.

It is important to note that people who have chosen to work in the mental health field are caring, well-intentioned people. It is always challenging for someone to face their own stigmatising, prejudiced and discriminating behaviours. This may help to explain the findings from an extensive 2013 literature review that revealed frequent social distancing by clinicians in relation to people with BPD (Sansone & Sansone, 2013). Other clinician responses included defensiveness, being less helpful, expressing less empathy and expressing anger. The authors suggested that these data "simply reflect a very human reaction to the complex and pathological behaviours of these patients" (Sansone & Sansone, 2013). These 'complex and pathological behaviours' are maladaptive, but usually represent desperate means by which the person with BPD endeavours to get help and understanding for their deep emotional pain. Sadly, blaming the patients is a way of avoiding responsibility for the clinicians' own unhelpful responses to them.

A negative attitude or stigma towards BPD in the mind of the clinician can result in a self-fulfilling prophecy. If the therapist believes the patient to be difficult and possibly manipulative, then it is reasonable to expect that this attitude would be unconsciously communicated to the patient. It "can activate the patient's self-critical tendencies and a cycle that involves self-loathing and self-injury, followed in turn by the therapist's confirmation of the stigma and his or her own emotional withdrawal from the patient" (Aviram, Brodsky, & Stanley, 2006). The consequences of this are varied but include increased self-harm and withdrawal from treatment.

Another issue is the misinterpretation of the behaviours of people with BPD. People with BPD may present as intense and challenging which can be interpreted by the mental health professional as a decision by the patient to be personally demanding. "The perception that patients have control over their own behaviour can perpetuate the stigmatisation of Personality Disorders in general and BPD in particular" (Aviram et al., 2006).

People with BPD are also often seen as having self-control: suicide attempts and chronic self-harm are seen as attention seeking. When a diagnosis of BPD is present, "clinicians form pejorative, judgemental and rejecting attitudes" (Lewis & Appleby, 1988). In their study on stigma, Aviram et al. (2006) suggest that stigmatisation could be reduced if it was accepted that BPD is a legitimate illness and not an example of moral failing or lack of willpower.

First-hand account from a BPD patient:

"My most recent experience of stigma and discrimination was during a telephone consultation with North West Mental Health Triage Service earlier this year. During that period I was suffering from severe emotional distress and my partner had contacted the team due to concerns over my safety. When I received a call from the Triage officer I had calmed down significantly (i.e., no longer considering self-injury) but was still vulnerable. I was happy to proceed with protocol and answer the relevant questions regarding my mental state, however I began to feel what can only be described as emotionally abused by the operator. The Triage officer repeatedly stigmatised my disorder and dismissed my distress by communicating that I was to blame for my history of mental ill-health and disengagement with services. I was told that I was "pathologising" my behaviour to avoid responsibility for the chronic nature of my condition, reprimanded until I was full of despair and internalised self-stigma; I couldn't believe it - my partner had utilised this service to seek help in a crisis situation and I was being shamed and mistreated by the person I needed desperately at the time to support me. I felt abandoned, hurt, confused, and left with the resounding idea that I was nothing more than a bad person who had avoided blame for a lifetime of suffering. The call ended with me sobbing and the Triage person grunting an order at me to call back at another time when I wasn't crying.

Thank you."

Female mid-20s, 2015.

Active dislike of patients with BPD and a wish to avoid them is frequently reported by clinicians from all areas of mental health treatment: this will have significant adverse effects on people with BPD who are predisposed to feeling rejected. The above anonymous first-hand account from a Victorian with BPD provides just one of many examples of these attitudes and behaviours, and the impact that they can have on people with BPD. Sensing rejection from treating clinicians can lead to permanent damage to the treatment relationship; acts of self-harm or suicidality; or to premature withdrawal from treatment. Disturbingly, many clinicians simply refuse to treat people with BPD if they suspect the diagnosis.

Diagnostic practices

The NHMRC recommends “informing individuals [diagnosed with BPD] of [their] diagnosis, explaining symptoms and formulation, and emphasising the possibility of effective treatment”, for adults and adolescents (National Health and Medical Research Council, 2012). Despite this recommendation, it is very difficult for people with BPD to get a diagnosis. BPD is often discredited, underdiagnosed, misdiagnosed. An anecdotal report suggests 11 years to get a diagnosis – if you are lucky enough to get one. There may often be good intent for this, as psychiatrists’ hesitancy to diagnose may stem from seeking to patients experiencing labelling and stigma (McMahon & Lawn, 2011; Paris, 2007). However, the damage of misdiagnoses is immense. When a person fails to receive a correct diagnosis and effective treatment, recovery is impaired, inhibited, undermined. Psychiatrists’ preference to treat symptoms without a diagnosis has various implications, especially that families and friends are unable to search out the supports they need and the help to improve their capacity to support their loved ones.

Questions about the legitimacy of the diagnosis and concerns about issues of stigma contribute to misdiagnoses. In particular people with BPD today are often misdiagnosed with bipolar disorder (Ruggero, Zimmerman, Chelminski, & Young D, 2010). Similarly, where there is co-morbidity with other disorders, such as an eating disorder, drug dependency disorder, anxiety or depression, a therapist may solely focus on these conditions and neglect to address the underlying BPD. Confusion as to whether a diagnosis should be BPD with PTSD or Complex PTSD, also confounds (Ford & Courtois, 2014). Currently those who have built their CVs on trauma-based care are keen to rename BPD as complex PTSD, thereby alienating those who do not have a trauma background. Emphasis on trauma translates into abuse, which translates in childhood abuse, which equates to blame the mothers/parents. It is a feature of BPD that some with BPD do believe they have been abused by their parent – while the evidence is to the contrary.

In a recent report by Sane Australia, Carrotte and Blanchard (2018) conducted qualitative research with seven participants with a diagnosis or suspected diagnosis of BPD or BPD traits, three carers, and two who fell into both categories. The authors identified a theme of “identity and discovery” connected to diagnosis (p. 50). The majority of participants with BPD stated that it took a long time to get a diagnosis and identified missed opportunities where they could have been diagnosed and referred to treatment pathways. For some of these participants, misdiagnoses were reported. However, most participants, including carers, described “relief” from finally being offered a diagnosis, as the diagnosis “offered a label that could help facilitate self-discovery and inform treatment”, which in turn led to a sense of hope (p. 50). The authors offered an example of this, where “Abby (aged 36 years, diagnosed with BPD) and her mother shared a bottle of celebratory wine after Abby received her diagnosis in her early 20s” (Carrotte and Blanchard, 2018, p. 50).

Another issue is that many who do get a diagnosis do not receive adequate information about their diagnosis. Two Australian national online surveys were conducted in 2011 by the Private Mental Health Consumer Carer Network, concerning experiences of people with diagnoses of BPD, and those of their family members and carers. It was found that 38% of the people diagnosed with BPD in the study had not had their diagnosis explained by a health professional, and 19% had had it explained but did not understand the diagnosis (McMahon & Lawn, 2011, p. 10). Similarly, 62% of the 93 carers who completed the surveys reported that the diagnosis had not been explained to them by medical professionals (McMahon & Lawn, 2011).

Medication practices

There is a strong emphasis among many psychiatrists on prescribing medications for people with BPD. However, “the most recent systematic review of pharmacotherapy of BPD concludes that ‘evidence of effectiveness of medication for BPD remains very mixed’”(Starcevic & Janca, 2018, p. 70). Starcevic and Janca (2018, p. 70) have noted that “from a patient’s perspective (…) a widespread use of medications reflects clinicians’ generally negative attitude toward BPD and lack of understanding of and knowledge about BPD”, and also results from “an overreliance on medications and the lack of resources for managing BPD adequately”. These authors concluded that “all this suggests a need to rethink the usual practice of automatically ‘medicating’ BPD patients when they present in a crisis” (Starcevic & Janca, 2018, p. 71).

Outdated attitudes and misinformation

In June 2015 the SANE website provided the following advice for those wanting to learn about BPD: *“People with BPD can get better. Contrary to common belief, people with BPD can recover well with appropriate ongoing treatment and support. While there is no cure yet, BPD is a treatable disorder.”*

When we read the information on the SANE website, we were dismayed. This advice effectively told the layperson that BPD is a lifelong sentence and recovery is not possible. We pointed this out to the organisation, offering our help to fix it. We were advised that SANE received their information on BPD from an expert psychiatrist of Victoria and their then BPD consumer consultant from WA. Fortunately, this misinformation was quickly addressed. Since then SANE has worked on its response to BPD and it was just this year that SANE produced an excellent research paper on BPD.

BPD is treatable, and treatment can lead to remission or a full recovery. To say there is no cure, or that BPD is untreatable, or that recovery is not possible, is to add to the stigmatisation of the disorder. Unfortunately, the outdated belief that BPD is untreatable is still held by some clinicians. There is much discussion in the current literature about what constitutes remission, recovery, or cure for BPD. This confusion of terms may add to the stigmatising of BPD, because it could obfuscate the fact that there are now many empirically validated treatments for BPD with good treatment outcomes, including recovery. In fact, successful treatment for people with BPD has been known about since the 1980s when Dialectical Behaviour Treatment (DBT) first began to produce results and to prove that recovery is possible.

The patient is seen as the problem, not the illness

Mental health professionals are described as emotionally retreating from people with BPD under the guise of a 'scientific attitude'. People with BPD are considered "'difficult' because they evoke personal emotional difficulties that challenge the clinical assumptions about professional neutrality" (Hinshelwood, 1999). Hinshelwood wrote this in 1999, when psychoanalytic psychotherapeutic approaches were still widely used for BPD. These approaches advocate 'technical neutrality' on the part of psychotherapists.

However, a neutral, unengaged stance can lead to problems. People with BPD are hypersensitive: in the face of a neutral stance, they feel disliked or rejected. When the person treating them offers the face of professional neutrality as a way of distancing themselves from the patient, this would not be productive for the therapy. Moreover, people with BPD also have difficulties with self-identity; they look to others as a way to define themselves. If they are faced with a professionally neutral response, they are challenged to know where they stand. This can be therapeutically unhelpful. People with BPD also have difficulties with maintaining and keeping relationships. Sound therapeutic relationships are essential to support their treatment. When faced with professional neutrality, this can only serve to undermine the therapeutic relationship.

Current treatment manuals of all the empirically validated treatments for BPD advocate an active, collaborative, validating engagement with these patients –not a neutral stance. It is indeed unfortunate if some clinicians continue to feel conflicted about the strong emotions that can be aroused during work with these patients, because these can be used to understand the patient at a deeper level than would otherwise be the case.

The invisibility of stigma and discrimination

Psychotherapists “may justify and rationalise” why “they turn down referrals or when individuals with BPD terminate therapy prematurely” (Aviram et al., 2006). Such therapists are unlikely to be aware that their decisions are being unconsciously shaped by pre-existing stigma, making these behaviours and prejudice difficult to challenge effectively. Nonetheless, stigma undoubtedly would have an effect upon such decisions.

Stigma outside of clinical settings

If the world of mental health stigmatises and discriminates against people with BPD, then the rest of the world is likely to follow their lead.

A recent critical review that discussed mental illness in the news and information media found that the media had a tendency to stigmatise mental illness in general (Pirkis & Francis, 2012). BPD was not included in this research, although schizophrenia and mood disorders were.

On the internet there is some extremely hurtful stigmatising and discriminatory information. In the general public however, BPD is primarily unknown and given its prevalence in the community this is further evidence of discrimination.

As an example of this lack of community knowledge of BPD, in a recent study, participants were shown a vignette which described someone with BPD (Furnham, Lee, & Kolzeev, 2015). Of these participants, only 2.3% identified BPD, whereas 72.5% recognised depression and 65.6 % recognised schizophrenia (Furnham et al., 2015).

Carrotte and Blanchard’s (2018) qualitative research also highlighted the low levels of awareness of personality disorders, including BPD, in the community, and the scarcity of positive representations, as major issues. For instance, participants identified that personality disorders are effectively invisible in the public sphere, which leads to harmful misinformation and stereotypes.

Recommendations:

In conclusion, it appears that stigma and discrimination by mental health practitioners can have a significantly detrimental impact on the lives of people suffering from BPD and that attempts to find ways of modifying these prejudices and the behaviours described are of paramount importance. The paradigm shift in thinking in the mental health professions and the mental health system that would benefit people with BPD and their families equates to non-judgemental, compassionate behaviour. People who work in the mental health system and related professions express discrimination against people with BPD in a multitude of ways; these attitudes exist because of a lack of accurate up-to-date information on BPD. The solution is therefore accurate and up-to-date information on BPD (Aviram et al., 2006). It is clear that the clinical community needs to receive education that assists the development of empathy and understanding of people with BPD.

The solution to stigma and discrimination which lies within the mental health professions and the mental health system is therefore to:

- Take the focus off treatment and onto recovery
- Increase knowledge about BPD
    - Research into the situation in Australia in relation to BPD needs to be undertaken.
    - Provide education, training and the support needed for GPs to play a better role in the lives of people with BPD and their carers.
    - Provide education, training, and support for all community-based workers who would have contact with those affected by BPD.
    - Educate the teachers and professors in universities and other places of mental health education and learning.
    - Introduce training and education regarding BPD into these places of learning.
    - Include the perspectives of people with lived experience – including family members.
- Include families (and friends) in the treatment process of their loved ones
    - Families are a part of the solution and need to be included along with people with BPD. They are the ones who know best what it is like and what is needed.
    - Provide support and psychoeducation for families (and friends).
- Provide adequate access to treatments
- Provide adequate access to holistic supports for recovery
- Listen to independent grassroots peer-led organisations whose priority is empowerment of the community.
    - Develop a mechanism to encourage a cohesive, collaborative approach amongst the Victorian BPD organisations *(and change the way BPD is a football to fight over)*

Question 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?

The current situation

Based on a prevalence of 5.9% for BPD (Grant et al., 2008), accepted by the national government of USA (SAMHSA, 2011), about 1.1% of people with BPD have access to treatment (based on an assessment by Dr Sathya Rao, Spectrum in 2016); the picture seems bleak. Most people with BPD do not get a diagnosis, and do not get access to treatment.

This situation is complicated when we consider that most people with BPD have other mental health conditions, anxiety and depression of course, but also Drug and Alcohol Disorders, Eating Disorders, PTSD and so on. It is understood that unless the BPD is treated, the other conditions will not be successfully treated. The mental health system does not cope well with co-mordibity.

The situation for mental health organisations in Victoria has been described as involving a Famine Mentality in relation to funding for mental health services. Treatment centres and mental health organisations are focused on their survival.

The concept of a BPD-specific treatment centre, such as Spectrum, works only for those who can gain access.

The community mental health sector has been devastated by recent cuts. It was in these Community Health Centres and related organisations that many people with BPD were supported. Even so, anecdotally, a community based mental health worker said in 2017, that people with schizophrenia made up about 70% of her caseload; based on the prevalence of BPD her caseload would have increased by 300% to be proportionally balanced. However, that job no longer exists as a result of the Victorian Government cuts to the community sector.

Although psychotherapy has been proved effective in treating BPD, the cost of accessing it is challenging. Public programs are known to attract long waiting lists and are not available in every Primary Health Network (PHN). People may receive treatment through a Mental Health Treatment Plan (MHTP) but, this option doesn’t cover all costs related to accessing evidence-based treatments for personality disorders. Moreover, a MHTP only provides 10 sessions per calendar year, which is inadequate for evidence-based treatments for BPD, even more so when there are comorbidities including trauma and/or substance use (Carrotte & Blanchard, 2018, p. 42). Rao and Beatson (2019, p. 370) note that “a sense of abandonment when the 10 session treatment ends can (…) be overwhelming for patients with BPD, and can lead to increased self-harm or suicidal behaviours”.

Recommendations:

- Navigating the existing system is a complex bewildering experience and a BPD-specific response is essential to address this confusion and the subsequent distress it causes.

The solutions for prevention of the development of BPD lie in family supports. Wherever families are stressed, those with a predisposition to BPD will feel it more. Information about emotional regulation and learning the skills to support emotional regulation is critical.

- Improved early childhood parental education and support is essential.
- In primary school years, education and training for parents need to run alongside the education of their children.
- In secondary years, supports for parents, education and training to the end is essential.

Families more vulnerable because of their special needs or due to low socio-economic status will always struggle more until this is addressed.

In the meantime, there are hundreds of thousands of people with BPD becoming parents themselves.

- Parents with BPD need access to BPD-focused support to enable them achieve recovery.
- Support the development of BPD Community Hubs: a combination of both a virtual and physical place where focus is on the development of personal relationships delivering support for individuals to attain recovery. A BPD Community Co-ordinator would work with those with BPD to help co-ordinate the wide range of services and organisations that could help in achieving recovery. Where something does not exist, for example, art therapy, financial counselling etc., BPD community would seek to fill this gap. This is a model able to work with existing services, that can be embedded within existing services wherever appropriate. The model is designed to be adaptable to what exists, and to creatively and innovatively fill these gaps according to individual needs. A core element of the work of this hub would be to focus on peer group work for supporting and strengthening relationships, leading to a journey of recovery that is tailored specifically to meeting the criterion of those affected by BPD. A similar model of BPD Community Co-ordination for families and friends of those with BPD will support the families and therefore serve to reinforce the support for those with lived experience.

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

Treatments:

A full and complete recovery from BPD is a realistic possibility.

There are many treatment types supported by meta analyses and more supported by research. More importantly, the guidelines include the key characteristics of successful treatment programs.

"Effective structured therapies share the following characteristics:

- *The therapy is based on an explicit and integrated theoretical approach, to which the therapist (and other members of the treatment team, if applicable) adheres, and which is shared with the person undergoing therapy.*
- *The therapy is provided by a trained therapist who is suitably supported and supervised.*
- *The therapist pays attention to the person's emotions.*
- *Therapy is focussed on achieving change.*
- *There is a focus on the relationship between the person receiving treatment and the clinician.*
- *Therapy sessions occur regularly over the planned course of treatment. At least one session per week is generally considered necessary."* (National Health and Medical Research Council, 2012)

There are places that offer treatment - both private and public. However, if you drop out of treatment, or are excluded from treatment programs, then you are lost again. Indeed, in their research, Carrotte and Blanchard (2018) identified numerous cases of people with a personality disorder, including BPD, experiencing an abrupt cessation of services, leading to "feelings of rejection, confusion and (…) dishearten[ment]" (p. 55). Some participants noted that they did not feel ready for their treatment to end, and that they were "not adequately transferred to another service" (p. 55).

Treatment in the public sector is only for those who are visibly most severely affected, who are lucky enough to be able to get in. The private sector is for those whose families can afford it.

An exacerbating factor here is that a large number of private health insurance companies do not cover mental health services on their cheaper policies, thereby increasing costs for consumers (Carrotte and Blanchard, 2018, p. 37). Additionally, there is also a limited availability of specialist services, both public and private, particularly in rural locations, and travel can further increase costs.

Carrotte and Blanchard (2018) found that most clinical specialist services in Victoria are located in Melbourne, and that this can lead to patients in regional or rural locations facing hours to travel to services and experiencing accompanying travel costs. For those services that are available there are often long waiting lists which can be up to two years, in both the public and private system, though particularly in the former (Carrotte & Blanchard, 2018).

Most people have no access to a recognised treatment program. Indeed, Carrotte and Blanchard (2018) recently concluded that "because of limitations in services, funding and uneven distribution of clinical skill, it is likely that many people with a personality disorder, including BPD, are accessing a level of support that is not sufficient for their needs – for example, accessing a style of psychotherapy that is not evidence-based for personality disorder, or accessing psychotherapy too infrequently to see meaningful benefits" (Carrotte and Blanchard, 2018, p. 43).

Recovery:

Recovery support in the system is negligible. BPD Community defines recovery as:

1) Achieving personal potential through productive work (usually a job).

2) Having at least two close long-standing and positive personal relationships.

Regardless of what definition is used, achieving recovery requires support so that the person with BPD can live as independent a life as possible. This support might be financial management support, housekeeping, accommodation support, employment support, therapeutic support, wellbeing support, and more.

A core component in recovery is a sense of belonging. The nature of BPD means that families are often fractured and unable to be a support for the person with BPD, for many reasons. This is one of the purposes behind the existence of BPD Community. We provide a sense of belonging for all who are affected by BPD.

Families:

Families of people with BPD are disadvantaged when their loved ones are not given a diagnosis. Without a diagnosis, families do not know what is wrong with their loved ones. BPD is not widely understood in the general community and most people have not heard of it. Families find themselves isolated and unable to support the ones they love. They are denied access to the psychoeducation that can help them improve their relationships with their loved ones, that can help them learn the techniques that can make a difference to their lives and the lives of their loved ones.

It is families who bear the brunt of a mental health system that does not support their loved ones. It is families who are isolated by the mental health system.

Trauma:

Trauma is widespread in our community. There are few in our community who have not experienced trauma. It is acknowledged that BPD has both a nature and nurture component, yet there is a concerted effort by some in the mental health community to rename BPD as complex Post Traumatic Disorder and to explain BPD as being the result of trauma.

Marsha Linehan (BPD expert and developer of Dialectical Behaviour Therapy) describes people with BPD as being like emotional burns victims and this is generally accepted as an accurate way to describe how it feels for people with BPD. Their emotions are raw, and they feel keenly. The techniques of validation, when used as a communication tool in the precise way it is required for BPD, are ways that a relationship with a person with BPD can be enhanced. It is recognised that a person with BPD responds positively to a validating environment and responds unfavourably to an invalidating environment. Our society today is pre-eminently invalidating; as is our everyday life. For a person with a predisposition to BPD, our society is harsh, isolating and cruel and this can be traumatic.

The difficulty with the focus on trauma specifically is the harm that it causes.

Parental blame is widespread. Those early years of childhood especially are important and if a person has psychological troubles, it is to early childhood that therapists like to begin. They look for trauma and look to blame parents. For a person with a predisposition to relational dysregulation, this focus can be very unhelpful. There are many family members who carry the pain of accusations of ‘abuse’ which are unjustified.

If a person with BPD looks to blame a family member as the cause of their illness, it cuts off a potential support for that person with BPD. Accusations can divide families and cause further harm.

The treatment for PTSD is different to the treatment for BPD. When people with BPD receive PTSD treatment, it can serve to reinforce non-existent abuse and cause further damage.

People with BPD often carry a heavy burden of shame and guilt. Their thoughts and behaviours are recognised by them as causing hurt and pain to others. A focus on looking for trauma as a cause of BPD can exacerbate this shame and guilt and cause further harm.

Those people with BPD who have not experienced trauma feel isolated within their community of people with BPD. This undermines how they see themselves and their recovery.

Suicide:

The suicide programs in existence are generic. It is widely acknowledged that people with BPD make up large numbers of those who suicide, with estimated suicide rates among people with BPD ranging from 3% to 10% (SA Mental Health Commission, 2016). Yet the current Victorian program does not specifically address the needs of people with BPD.

Recommendations:

The needs of people with lived experience of BPD are different to other mental illnesses, especially because:

- Relational dysregulation affects the family relationships
- Recovery is a realistic possibility

BPD Community recommends to:

- Recognise BPD as a legitimate diagnosis.
- Encourage the mental health professions to acknowledge a diagnosis of BPD.
- Equip GPs to provide provisional diagnoses and equip them to support people with BPD.
- Support Secondary Schools to help them better manage the needs of vulnerable teenagers.
- Address stigma and discrimination. In particular, the way that people with BPD are treated in emergency departments needs immediate attention.
- Fund programs that can offer support, such as the BPD Community Hubs.
- Support families with psychoeducation programs to help them manage highly volatile situations in the home.

Experience in an emergency dept

"My niece told me she went to the emergency dept at the Frankston hospital because she was really worried she would do something. She said she left after three days, with three temazapan. No, she didn't get a diagnosis. No, she wasn't given a referral. I don't think I was told anything."

'My 17 yr old niece, subsequently diagnosed with BPD was highly vulnerable. She subsequently fell out of the system.' 2017

Question 4: What makes it hard for people to experience good mental health and what can be done to improve this?

We live in an invalidating world, a world full of fears. People with BPD are especially vulnerable in a judgemental society like ours. Our community has experienced rapid and significant change which can be destabilising for those prone to anxiety. A sense of belonging can be hard to find for people with BPD. The stigma and discrimination they experience means that those they reach out to often reject them. The medical model fails people with BPD.

The current system is not working. There needs to be a social and healthcare policy framework that is specific to the needs of BPD, where the focus is on recovery as well as treatment. Recovery encompasses a broad concept of supports and services to meet specific individual needs. The current system is a hotchpotch of programs here and there.

Treatment

The cost of providing treatment supported by research, such as Dialectical Behaviour Therapy (DBT), is often referred to as too expensive. Yet there are privately run organisations in Victoria who offer only DBT; the difference between them and the public sector organisations is that they do not always have the expense of psychiatrists.

The lay person may struggle to understand the difference between a psychiatrist and a psychologist, and then the different types of psychologists add to the confusion. They look to psychiatrists as the head of the mental health food chain, in the expectation that they are getting the best possible care. However, it is psychotherapy that brings recovery, not medication.

Co-morbidity in BPD means that dual treatment programs should be the norm, particularly in relation to Drug and Alcohol Disorder, Eating Disorders, PTSD, Gaming Disorder and of course depression and anxiety. Presently, however, they are merely the exception.

According to an article published in World Psychiatry Association, BPD should be recognised in all levels of the health care system as a severe mental health disorder (Chanen, Sharp, & Hoffman, 2017). Secondly, BPD care from primary through to specialist care needs to be based upon evidence-based policies with the objective of designing a health care system response to prevention and early intervention, with young people and carers as a priority (Chanen et al., 2017). Thirdly, any kind of discrimination involved or existing in the current health care system needs to be eliminated (Chanen et al., 2017).

About 1.1% of people in Victoria with BPD receive treatment (public and private). Only those who can present as at serious risk, and those who can pass through the hoops, can find their way into the public health system. Anecdotally, it takes 11 years to gain a diagnosis. This means that most people are abandoned by the system.

BPD can be described as episodic; there are times of crisis and times when life can be more ordered. People with BPD find engaging with the system difficult for many reasons apart from the stigma and discrimination. Barriers to engagement include the ad hoc responses from the system and the hotchpotch of services. Although these barriers do reduce engagement, people with BPD reach out for help a lot, yet often when they are ready, the system is not.

Recovery

Recovery is broader than the current medical model allows for. The current funding focus which favours the medical model, disadvantages people with BPD and their families and makes recovery more challenging than it need be.

Recovery services are found in the community services sector, and include employment programs, accommodation and housing services, art therapy, mindfulness training, finance and budgeting support. They also include programs such as the Personal Helpers and Mentors Service (PHaMs), which are being phased out with the rollout of the NDIS (Australia Department of Social Services, 2019). Community health centres had occupational therapists, social workers and other health workers available to support people with mental illness.

Families are central to the successful recovery of a person with BPD. To ignore the needs of families for psychoeducation and support is to ignore the needs of people with BPD. Not all families are able to be there for their loved ones, whether they reject the person with BPD or whether the person with BPD rejects them yet still, a sense of connectedness, where there is acceptance and support is a key to recovery.

Community

Like everyone, people with BPD need to feel that sense of belonging. However, they and their families often feel isolated.

A community that supports recovery is the missing link in the care for people with BPD. BPD Community creates that sense of belonging, whether or not the person with BPD has a loving family to support them.

BPD Community's plans to create BPD Community Hubs that are specific to the needs of people with BPD and their families in all their diversity, is a way to work with what exists and to help improve the existing system. A BPD Community Co-ordinator will co-ordinate a plan to recovery for the person with BPD and will work collaboratively with services and agencies, identify the gaps, and find innovative and creative ways to fill the gaps. To increase that sense of belonging, peer-led group work is essential in this model. This plan is based on the last five years of working directly with people with BPD and their families and those who work with them. It is a model specific to the recovery needs of people with BPD and their families, designed to complement treatment programs. It is cost effective.

Recommendations

- Change the focus from treatment to recovery.
- Increase funding to the community sector for programs designed to complement recovery.
- Fund the only grassroots, independent, peer led organisation for BPD: BPD Community.
- Support the development of BPD Community Hubs: a combination of both a virtual and physical place where focus is on the development of personal relationships delivering support for individuals to attain recovery**.** This is a model able to work with existing services, that can be embedded within existing services wherever appropriate. The model is designed to be adaptable to what exists, and to creatively and innovatively fill these gaps according to individual needs. A core element of the work of this hub would be to focus on peer group work for supporting and strengthening relationships, leading to a journey of recovery that is tailored specifically to meeting the criterion of those affected by BPD. A similar model of BPD Community Co-ordination for families and friends of those with BPD that focuses on building the relational skills that make a difference for people with BPD, will support the families and therefore serve to reinforce the support for those with lived experience.

Question 5: What are the drivers and what needs to be done to address this?

There are a number of key drivers, which are listed below:

Drivers

Where people are shamed for experiencing mental health issues, such as the stigmatising of those with BPD.

The stigma emanating from the mental health system and professions contributes to significantly poorer quality and availability of services for people with BPD and their carers. This has already been discussed in detail in our response to question two, but to reiterate the main impacts:

- Discrediting of diagnoses, underdiagnosis, and misdiagnosis, lead to various issues, including undermining of recovery.
- Misinformation and outdated attitudes toward BPD can lead to messages being promoted that suggest to people with BPD that there is no possibility of recovery, thereby making treatment less likely to be sought out or known about in the first place.
- Both conscious and unconscious negative attitudes towards people with BPD from mental health professionals exacerbate issues for many people with BPD and undermine the quality and accessibility of services.

To resolve this, it is recommended that the Victorian Government:

- Take the focus off treatment and onto recovery
- Support up-to-date knowledge on BPD through education and research
- Include families in the treatment process of their loved ones
- Provide adequate access to treatments
- Provide adequate access to holistic supports for recovery
- Listen to independent grassroots peer-led organisations whose priority is empowerment of the community.

Where services are focussed on treatment and not support

In Victoria there is a significant imbalance between the funding and resources provided for treatment compared to recovery. The most recent data from the AIHW indicates that, across the 2016-2017 period, 10.7 consumers per 1,000 population accessed community mental health services in Victoria, compared to the national average of 17.2 consumers per 1,000 population (Australian Institute of Health and Welfare, 2018).

This will have been exacerbated in recent years, especially with the shift to the NDIS. The Victorian Government has pulled a significant amount of funding from community mental health services to fund the NDIS (Hancock et al., 2018). This has included withdrawing funding from recovery-oriented psychosocial rehabilitation and peer-supported community pathways (Hancock et al., 2018). This has meant that in the period through to June 2019, around 1,000 trained and experienced mental health positions were lost (Mental Health Victoria, 2018). This is especially problematic, as out of the estimated 150,000 people who experience severe mental illness each year, relatively few are eligible for the NDIS (Mental Health Victoria, 2018, p. 4). An implication of this is that many of these people, including many with BPD, are slipping through the cracks and receiving little support (Hancock et al., 2018). Already, as of 2018, there was evidence of an increased burden on acute and clinical services as a result (Hancock et al., 2018). This accords with the argument made by the National Mental Health Commission that siphoning funds from community mental health services “may produce short-term savings [and a quick-fix method of funding the NDIS] (…) but is likely to result in more severe needs in the longer term, and thus exacerbate the need for more complex support, rather than decrease system-wide demands” (Hancock et al., 2018; National Mental Health Commission, 2014, p. 26).

The recent loss of workers in the community mental health sector and related areas has had a direct and negative effect on the lives of people with BPD and their families. This has had a flow-on effect to programs such as our Family and Friends group where referrals are down. The loss of knowledge in the sector from those who lost their jobs, is significant. They are not waiting around for the government to change their mind and refund the organisations where they worked; they have gone to other sectors and their knowledge is lost.

The NDIS was always going to be fraught for people with BPD. Most who apply do not get accepted. The reasons for this are many, but suffice to say, the NDIS does not offer the solution for people with BPD and their families.

Where organisations compete for funds and struggle to collaborate

The piecemeal, short-term, and low levels of funding for mental health, particularly given the draining of funding from community mental health services, leads to significant competition between mental health organisations.

Given the vital roles that community mental health organisations can provide for all those who are affected by BPD, not just those who are eligible for the NDIS, here we reiterate our recommendation that the Victorian Government develop a mechanism to encourage a cohesive, collaborative approach amongst the Victorian BPD organisations.

Where special needs are not considered

A significant driver of poorer mental health outcomes relates to the pockets of society that feel excluded, that feel they do not belong, or who face other forms of disadvantage, including fractured and/or financially disadvantaged communities. Some of the particularly marginalised population groups include LGBTI people, older people, people with intellectual disability, people who experience substance misuse and mental illness, and culturally and linguistically diverse communities, including immigrant/refugee communities who have experienced severe trauma. The National Mental Health Commission noted these are among some of the population groups that face various barriers that need to be tailored for in mental health responses (National Mental Health Commission, 2014). In general, it is the most vulnerable that show where the money needs to be spent, where communities need to be empowered. However, given that only 1.1% of people with BPD currently receive treatment, the need for all people with BPD to have access to recovery-based programs is critical.

The needs of geographically isolated communities are exacerbated by the focus of a medical approach to mental health at the expense of a community approach focussed on recovery.

Recommendation:

- Support implementation of the BPD Community Hub model to support recovery that can work in any geographic location, and which is designed to be mobile and flexible, working with other services and organisations collaboratively.

Question 6: What are the needs of family members, carers and how to better to support them?

Family trauma

BPD creates trauma in families. The Private Mental Health Consumer Carer Network (Australia) (PMHCCN) recently conducted a study on the experiences of carers supporting someone with a diagnosis of BPD (Lawn, McMahon, & Zabeen, 2017). Almost half of the carers (48.8%) from the study's sample were parents or guardians of the person with BPD receiving the care, while 20.4% were spouses/partners (Lawn et al., 2017). The remainder were the persons' siblings, friends, or children, and around 4.9% of carers were not related. Parents experience the usual grief of having a loved one with BPD; siblings are challenged with the special needs of their sibling dominating family time and resources; the children of parents with BPD struggle immensely with what can feel like cruelty towards them, and partners question their own mental health as they try to cope with what they don't understand. SANE Australia's research report on understanding the needs of Australians with BPD highlighted that carers, families and support persons have disclosed going through their own challenges related to caregiving, "including depression and anxiety, impaired empowerment, financial burden and other types of burden" (Carrotte & Blanchard, 2018, p. 10).

Support needs

A lack of support is a further issue experienced by carers. In PMHCCN's study, 78.18% of carers expressed that mental health professionals had not assisted them to understand how to help manage the "early warning signs and risk of suicide or self-harm" in the person with BPD they care for (Lawn et al., 2017). Of further concern is that 82.73% had not been provided with a crisis plan from mental health care providers to help them manage crises with the person with BPD that they care for (Lawn et al., 2017). Sane Australia's research also found that carers generally report a low level of support. Around 34.91% of carers in the study stated that GPs are supportive, while 32.65% reported that Psychiatrists are not supportive of them. This is concerning for many reasons, not least of which is the impact that caregiving can have on carers. Carers in this study reported that caregiving is associated with "significant stress and worry", which is particularly pronounced where there is suicidal intent or attempts (Carrotte & Blanchard, 2018, p. 60). Furthermore, some carers felt that their caregiving led to "vicarious traumatisation and a decline in their own mental and physical health" (Carrotte & Blanchard, 2018, p. 60).

It is clear that family and friends need support, they need psychoeducation, and they need to feel the sense of support that being amongst those who understand brings. BPD is so isolating. Families and friends need to be a part of the treatment process, support planning, and decision-making. They should also be supported in their role; this includes providing carers with information about the illness, prognosis and treatment, as well as how positively they could respond during suicide attempts or self-harming of the person whom they care for. Sane Australia recommends a holistic approach to meet the needs of families and friends supporting someone living with BPD, with carers benefitting through peer support. It is usually the families who are left to provide for their adult children when mental health services are not available. They bear the burden of the emotional, behavioural and relational dysregulation. Parents will sacrifice their financial security in order to financially support their adult children.

> *"I wanted to let you know that I have had contact with my Mum for the first time in a few years….*
>
> *So in summary our first meeting was positive. I will go and see her again this weekend.*
>
> *So I wanted to thank you as I have learnt so much and hopefully going forward my Mum and I can start to have some positive communication. I will always remain on my guard but having more understanding of her condition will help me with strategies of how to cope and provide me with some self preservation not to be hurt so badly again."*
> and
>
> *"I am eternally grateful for all the help I received from attending the group sessions."*
>
> Adult daughter on the repair of the relationships with her mother with BPD, 2018

The evidence supports the proposition that carers benefit from forms of group education or ongoing support groups. It also demonstrates that the medical and mental health professions need to be doing more to be supportive of carers.

Family & Friend's Group

In 2015 BPD Community conducted a consultation with families of people with BPD to determine their concerns and their priorities. This formed the basis of our Position Paper "Carers' Concerns" (BPD Community, 2015). Subsequent to this, BPD Community has operated a monthly Family & Friends Group since 2015, helping about 70 individuals, with over 400 attendances since it began. BPD Community has developed a model of support and psychoeducation specifically for BPD carers, that can easily be adapted to communities throughout Victoria. It is designed to complement, and work in collaboration with, existing programs and services, such as Family Connections.

Following an independent evaluation of the program, a manual to support the model has been developed so that the model can be replicated. Currently a 12-part training program is being finalised. There are skills and techniques that work to build relationships with people with BPD to understand the difference between enabling and supporting. These are the skills that form the basis of the model of BPD Community Family & Friend's Group. The program is supported by its own page on the website: https://www.bpdcommunity.com.au/family-friends/family-and-friends-group

Monitoring of the program this year shows that of the 56 attendences, 94% indicated the session was very useful, and 6% found it useful. 99% said they felt more confident and felt supported, and 86% considered that their relationship with their loved one, had improved.

Fred's daughter struggled with mental health challenges for many years before finally getting a diagnosis of BPD. This diagnosis explained some of the behaviour he had been struggling with since their daughter was a teenager.

"From my daughter's very early teenage years we struggled with our relationship, we would continually argue. She was very defiant and argumentative. She would try to self-harm by trying to cut her wrists with bits of broken glass. This was heart shattering and we were at our wits end," Fred explained.

Although the diagnosis was a positive step, it wasn't until Fred and his wife joined the BPD Community Family and Friends program that they really began to understand what she was going through and how they could help her.

"Through the meetings, I was able to truly gain an understanding and awareness for my daughter's behavior and most importantly my own reaction to her behavior. It taught me that in order to help someone with BPD, you must first take care of yourself by understanding how to deal with it," Fred said.

"Since joining the BPD F&F Group I am delighted to say that there has not been a single argument between my daughter and myself. Thank you BPD Community" 2018

Despite the positive impacts of this program, it is unsustainable, it currently receives no funding.

Carers' Concerns

We have learnt much more since 'Carers' Concerns' (BPD Community, 2015) was first developed In October 2015, but the paper is still relevant.

Today, families want to emphasise that they are not a part of the problem, but rather are part of the solution. They are tired of being excluded, blamed, and isolated. Most of all, they are tired of seeing their loved ones ignored in a system that doesn't seem to care and are appreciative of those who are there for them and their loved ones. This includes the psychiatrists, psychologists, the nurses, social workers, counsellors and all in the system who do support them and their loved ones. To them, they have a powerful sense of gratitude.

In 2015, the need for a diagnosis was the number one priority for families (BPD Community, 2015). With a diagnosis, the families are in a position to advocate for their loved ones. When they knew what was wrong, they could begin to research where to get help for their loved ones. Concurrently, with a diagnosis, the families can learn how best to support their loved ones, to learn the skills and techniques that help to build relationships with people with BPD. It is very likely that this would still be the top priority of families today.

www.bpdcommunity.com.au

"We the carers of people with BPD want our loved ones to be well.

For our loved ones we want:

- *An early and accurate diagnosis;*
- *Emergency Department response based on knowledge about BPD and commitment to the addressing needs of people with BPD;*
- *Treatment readily available in the adequately resourced public system;*
- *A mental health system (private and public) that responds appropriately;*
- *To be a part of the treatment process.*

We want a mental health system that acknowledges that recovery is possible and that we are not the cause of our loved ones illness. We want a responsive non judgemental, non stigmatising, non discriminating mental health system with easy access to diagnosis and treatment that follows the National Clinical Practice Guidelines for the Management of BPD, and that includes us as part of the solution.

For ourselves we want:

- *Training in the techniques to help us support our loved ones;*
- *Support for ourselves in our roles as carers;*
- *Access to treatment in the public health system for our own mental health needs;*
- *Access to the latest research and information on BPD.*

We want a public mental health system that recognises the importance of the role of carers of people with BPD and is non judgemental, non stigmatising and non discriminatory. We want a system that supports the education, training, support and wellbeing of carers of people with BPD.

For our BPD community we want:

- *Research on all aspects of BPD, in particular the prevalence of BPD in Australia and in special communities such as prisons or communities which have experienced trauma;*
- *A funded strategy to address the stigmatising and discrimination that affects the BPD community, and therefore the wider community, one that targets the clinical and helping professions;*
- *A public and private mental health system that is responsive to the needs of the BPD community.*

We want an up to date, responsive mental health system that is non-judgemental, non-stigmatising and non-discriminatory.

Our priority is:

To advocate for early and accurate diagnosis of BPD."

Adopted Oct 2015. (BPD Community 2015)

Many families affected by BPD are so damaged that their family relationships have become fractured. Some people with BPD reject their family and some families reject their family member with BPD. A specialised therapeutic mediation facility available to families and people with BPD would be ideal, to facilitate reconciliation for those who want reconciliation. BPD Community would like to be able to establish this.

Recommendations

- Fund the BPD Community Hub for families. This would involve supporting families with individual support complemented with the Family & Friend's Group. Based on existing practice, these Hubs would work with existing services and agencies. The model can be easily adopted through Victoria.
- Fund BPD Community' Family & Friend's Group, and any replications of this model that may be subsequently run by other BPD organisations. This model focuses on providing family and friends of people with BPD with the skills and techniques that work to build relationships with BPD, while emphasising the differences between enabling and supporting.
- Encourage the medical and mental health professions and GPs to provide support for carers of people with BPD. This should include an emphasis on providing crisis plans for carers, where appropriate.
- Provide funding for BPD Community to establish a specialised therapeutic mediation facility that is available for people with BPD and their families, to facilitate reconciliation for those who want it.
- Encourage the mental health professions to acknowledge a diagnosis of BPD.

Question 7: What can be done to attract, retain and better support the mental health workforce?

BPD Community recognises that those who work in the mental health field are doing the best they can in a system that is not coping. The simple answer is to adequately fund the mental health system, but increased funding without fundamental changes to how the system works will mean the continuation of an inadequate system.

Serious research into how the system does and does not work would be illuminating.

BPD Community supports a diagnostic specific mental health system based in a community mental health approach to support recovery. We recognise that the mental health workforce will always struggle where the power relationships inherent in the medical model create challenges for any who do not have medical or clinical qualifications. To balance this, BPD Community recommends the empowerment of peer-led, independent, grassroots organisations to enable them to work collaboratively with all organisations to support recovery.

BPD Community aims to develop a quality assurance program to identify where a service and its personnel are BPD-ready. This will serve to support those organisations working with people with BPD and identify workforce needs as a part of that process.

Overall, to support the mental health workforce there also needs to be coordinated and sustained long-term planning and funding for the various mental health sectors. Presently, there is great uncertainty in the system, due to an overemphasis on short-term and ad hoc planning, with an absence of a coherent long-term vision. There needs to be certainty that the outcomes of the Royal Commission will be sustained, rather than simply planned ahead for only one or two budgetary or electoral cycles, and then potentially reversed without warning. A systematic and long-term plan would provide certainty for mental health organisations, enabling them to better plan for the future. It would also help with attracting and retaining a skilled mental health workforce, as they would have a reasonable assurance that jobs in the Victorian mental health sector are stable.

Question 8: What are the opportunities and how to realise these opportunities?

The lack of a focus on recovery for people with BPD means that opportunities to support people with BPD to achieve their potential are ad hoc and limited. Even following treatment, a supportive environment is critical to recovery; this is the missing ingredient.

The domains of emotional, behavioural and relational dysregulation mean that people with BPD struggle to maintain everyday relationships without support. Given that most people with BPD do not receive treatment, this support is essential. Currently there are no BPD-specific supports.

The purpose of BPD Community is to support recovery and that means empowering people with BPD to enable them to realise their potential through social and economic participation. All our programs are established to achieve that end.

Recommendations

The special needs of those with BPD need to be considered in BPD-specific programs with support personnel trained to work with people with BPD.

- Fund BPD Community to enable the organisation to develop its capacity.
- Fund a pilot BPD Community Quality Assurance program, to support other organisations to become BPD-friendly.
- Fund the BPD Community Hub so we can develop our collaboration with other organisations. For example, we have had initial discussions with the Western Communities Initiative Group (WCIG) to pilot a BPD-specific work program.

Question 9: Tell us what areas and reform ideas you would like to prioritise for change?

The Victorian mental health system should be:

Caring and supportive. Non-judgemental and approachable. Accessible to anyone regardless of income. Available to all, not just those in severe distress at the time of access. Not patronising but empowering. Not rigid, but flexible.

As it relates to BPD, this should be achieved through a number of efforts, including:

1) Prioritising capacity funding for independent, grassroots and peer led organisations such as BPD Community.
2) Providing more funding and support for community mental health organisations, ensuring that those without access to the NDIS are not disadvantaged.
3) Making strategic and sustained efforts to reduce stigma and discrimination in the mental health system and professions as it pertains to BPD, particularly through research and an increase in education on BPD.
4) Making recovery a greater priority in mental health policy.
5) Considering and responding to the needs of population groups who are particularly marginalised or otherwise disadvantaged.

Supporting people with BPD and their families towards recovery.

Resources towards recovery supports

If resources were put towards recovery supports, then the extreme reliance on treatment programs would be eased. Currently, lacking adequate supports, people are especially dependent on treatment programs to become well enough. Recovery is a challenge without the appropriate supports from a team of 'experts', e.g. financial, housing and housing management, community engagement, general health and wellbeing, legal support where relevant, employment support, etc.

Specialist BPD supports for those who are particularly disadvantaged.

This requires recognising that it is the most vulnerable who need our support. Identifying this does not imply a broad-brush approach to a particular community. It means a BPD-specific approach to a particular community, one that is culturally sensitive. This would have to be a long-term approach, one that is not responsive to short-term programs with a narrow focus. Given the importance of community in supporting recovery, it is crucial that the support of the vulnerable does not further alienate or disempower. If the focus is given to recovery and what is required to achieve recovery, then addressing the specific needs that BPD requires, as well as community needs, will bring better results.

In particular, the needs of prison populations and homeless require attention. The data on those in prisons with BPD is damning. For instance, Tye and Mullen (2006) conducted a study with female prisoners in two Victorian prisons, and found that 26% of participants were diagnosed with BPD, significantly higher than in the general community. Similarly, a survey in WA made an estimate that 23% of women and 15.8% of men within the prison system met the criteria for BPD (SA Mental Health Commission, 2016). To address this within the juvenile and adult prison populations could make a great difference on many levels, especially given the generally harmful effects that correctional settings can have for people with BPD (SA Mental Health Commission, 2016, p. 7). Indeed, the SA Mental Health Commission, in its 2017-2020 Action Plan for people with BPD, highlighted that "people living with BPD could benefit from diversionary, early release or resettlement programs particularly when evidence-based therapies are offered within these programs" (SA Mental Health Commission, 2016, p. 7).

Homelessness has also grown so much in recent years; again, the data on people with BPD and homelessness shows that support with a recovery focus could make a great long-term difference.

A focus that includes family supports and psychoeducation.

The core element of the BPD Community Hub for carers is the Family & Friend's Group. This can be easily implemented throughout Victoria. This could occur in collaboration with existing service providers who can provide after-hours facilities for the group and perhaps local co-facilitators, with BPD Community providing the intellectual property, training support for facilitation, admin support and ongoing training in psychoeducation and co-facilitation where necessary. The BPD Community Hub Co-ordinator for carers would conduct an initial interview with the family member (or friend) to ensure that the particular needs of that person would be met. The Family & Friend's Group support is complemented with individual support by telephone at times of special needs and informal catch ups. This is supplemented by the Family & Friend's page and the Family Toolbox on the website. With funding, more developed virtual support can be introduced.

Question 10: What can be done now?

Fund independent grassroots peer led organisations

BPD Community represents all those affected by BPD, not just those who are able to get a diagnosis and access treatment. We represent families, friends, most of whom have loved ones who are not in treatment. We also represent those who work with people affected by BPD, especially in the community sector. People who access currently available treatment number about 1.1% of people with BPD in a year, and concerningly the treatment is not necessarily research based; there is no quality assurance. BPD Community is not a traditional service provider, but is flexible, innovative and creative – we build the supports necessary for recovery, whether a person has access to treatment or not. We work collaboratively, not seeking to duplicate what exists, but rather aiming to fill the gaps.

Throughout this submission, we have noted our ambition to create a Community Hub: a combination of both a virtual and physical place where the focus is on the development of personal relationships in delivering the support and psychoeducation for the individuals to achieve recovery. This is supported by collaboration with other organisations. This will further sense of community, sense of belonging.

Again, the special needs of those with BPD needs to be considered in BPD-specific programs with support personnel trained to work with people with BPD. If we could develop our planned Quality Assurance program, then we could help other organisations be BPD friendly.

Change the focus

The medical model absorbs so much funding and is concerned with the treatment of symptoms, not recovery. The absence of symptoms does not equate to recovery. In relation to BPD, the ICD model that looks at functionality of the person is more accurate. Recovery in the mind of the person with BPD and their family is often very different to how the medical approach looks. Indeed, the National Mental Health Commission's 2014 review of mental health services recommended that, "the (national) mental health system (…) should be underpinned by a strong focus on prevention, early intervention and support for recovery that is not just measured in terms of the absence of symptoms, but in the ability to lead a contributing life" (National Mental Health Commission, 2014, p. 47). This reflects the fact that "the health system is just one part of the picture: housing, employment, education, justice and welfare play a significant part in people's recovery and ability to live contributing lives" (National Mental Health Commission, 2014, p. 38).

With this in mind, the amount of money that supports a 'patronising' medical model is embarrassing. Given that the stigma and discrimination that exists emanates from within the mental health system and professions, to continue in the same way is to perpetuate the problems. A paradigm shift in thinking about treatment and support is essential.

Recognise that it is the most vulnerable in society which need our support.

This has been covered in more detail in our response to questions 5 and 9. To briefly reiterate:

1) Certain population groups with BPD face particular risks and barriers, including LGBTI people, older people, people with intellectual disability, people who experience substance misuse and BPD, homeless and imprisoned people, and culturally and linguistically diverse communities, including immigrant/refugee communities (National Mental Health Commission, 2014; SA Mental Health Commission, 2016).

2) There is significant evidence supporting the need for these population groups to have mental health care that is tailored to their needs (National Mental Health Commission, 2014).

3) These responses should be culturally sensitive, involve a long-term approach, and consider recovery needs. There should be a BPD informed response. The response needs to be embedded within each individual community.

Make treatment and recovery supports for people with BPD a priority.

BPD is not like the other mental illnesses. It does not respond to a medical model – the evidence for medication's effectiveness with BPD is limited, yet people with BPD are often on a cocktail of drugs (Starcevic & Janca, 2018). People with BPD need psychotherapy for treatment and it should be the therapy that is supported by the research. More importantly, people with BPD need recovery-oriented support for themselves and their families. This will make the difference in the lives of those unable to access treatment; it will improve the efficacy of treatment when it does happen. The flow-on effect will be massive.

The BPD community needs specialised support especially because:

1) Full recovery is a realistic possibility (Sheehan et al., 2016)

2) Relational dysregulation means that the family focus of support is essential for recovery. Working with families to develop their relational skills needs to be a part of the recovery process for people with BPD, where possible.

3) People with BPD are significantly affected by the stigma and discrimination that exists in the current system. It has been noted earlier in this submission that anecdotally, before the lack of staff in the community sector occurred, a mental health worker at Star Health said 70% of her caseload was people with schizophrenia. She would have needed her workload increased by 300% for her to see the proportional amount of people with BPD.

If resources were put towards recovery supports, then the extreme reliance on treatment programs would be eased. As noted earlier, lacking adequate supports, people are especially dependent on treatment programs to become well enough. Recovery is a challenge without the appropriate supports from a team of 'experts' e.g. financial, housing and housing management, community engagement, general health and wellbeing, legal support where relevant, employment support, etc.

Instigate an education campaign.

Promote emotional intelligence at an individual and a community level and promote a compassionate society. People with BPD are 'like emotional burns victims' (Linehan); they are vulnerable to judgemental attitudes and behaviours. Ours is a harsh world with very angry people. Research into how to measure compassion that is evidence-based would provide a focus to change this.

Currently schools are promoting emotional intelligence in various ways and forms. It would be worthwhile for emotional intelligence to be assessible and skills in emotional regulation to be incorporated into existing classroom practices to build the capacity of the teaching staff and their students. This would require research into what is being done, and a program that can be easily absorbed into current curriculum and pastoral care outcomes, to be developed.

A direct public campaign to reduce judgemental attitudes towards individuals and that promoted compassion could have powerfully positive effects on the mental health of so many. This does not have to be mental illness focussed, but rather a campaign to promote kindness and compassion in general.

A government focus on promoting and addressing the need for compassion could be built into the tender system for government contracts.

Addressing stigma and discrimination

The importance of addressing stigma and discrimination, through a paradigm shift in thinking, has been emphasised throughout this submission. Given that this objective is critical to supporting changes in Victoria’s mental health system, our recommendations to address stigma and discrimination (earlier provided in our response to question one) are restated here:

- Take the focus off treatment and onto recovery
- Increase knowledge about BPD
  - Research into the situation in Australia in relation to BPD needs to be undertaken.
  - Provide education, training and the support needed for GPs to play a better role in the lives of people with BPD and their carers.
  - Provide education, training, and support for all community-based workers who would have contact with those affected by BPD.
  - Educate the teachers and professors in universities and other places of mental health education and learning.
  - Introduce training and education regarding BPD into these places of learning.
  - Include the perspectives of people with lived experience – including family members.
- Include families in the treatment process of their loved ones
  - Families are a part of the solution and need to be included along with people with BPD. They are the ones who know best what it is like and what they need.
- Provide adequate access to treatments
- Provide adequate access to holistic supports for recovery
- Listen to independent grassroots peer-led organisations whose priority is empowerment of the community.
  - Develop a mechanism to encourage a cohesive, collaborative approach amongst the Victorian BPD organisations *(and change the way BPD is a football fought over by the medical professions)*

Question 11: Is there anything else you would like to share with The Royal Commission?

According to an article published in the Australian & New Zealand Journal of Psychiatry, training all mental health staff to effectively work with individuals having any kind of personality disorder should be of utmost priority (Grenyer, Ng, Townsend, & Rao, 2017). In addition, the implementation of brief and long-term intervention services by mental health staff can reduce inpatient hospitalisation and emergency department presentation if it is prioritised. BPD Community understands that the focus on the medical model of treatment and on those with BPD who present as extreme and severe, means that most people with BPD and their families are ignored.

We acknowledge that the psychiatric field does not know all there is to know about BPD. The psychiatric system is structured to be paternalistic and alienating. The medical model does not have all the answers, but it drowns out other voices.

BPD organisations in Victoria are fractured and do not work collaboratively. There is room for diversity however that should include an independent voice for people with lived experience, ie BPD Community. BPD Community does not have feet at the table, even though it has built a community of over 380 people, most of whom are in Victoria: 69% of these are people with lived experience, just over twice as many family members as people with BPD, and 28% are people who work in the field.

BPD Community has built a solid framework to provide flexible, adaptable, creative and innovative responses and solutions that can fit differing geographic communities without the need to depend on costly physical premises and a costly medical model. Our short-term goals are to trial Community Hubs (referred to earlier), a sound, accessible Information Service including a specialised phone line, and a training program designed to address stigma and discrimination with broad applicability to meet the needs of professionals in the field and the general public. Ultimately, BPD Community aims to develop a quality assurance program to support organisations become BPD-Friendly. However, the current funding focus in Victoria excludes the participation of grassroots, peer-led and independent organisations such as ours.

People with lived experience of BPD need our organisation and they need a holistic approach to recovery that is flexible, innovative, creative and responsive to the specific needs of BPD.

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