SUPPLEMENTARY SUBMISSION

THE ROYAL COMMISSION INTO MENTAL HEALTH VICTORIA

Speaking to Borderline Personality Disorder (BPD) and a Theory of Recovery

BPD Community asks the Commission to consider the issues raised in this supplementary submission.

Since its inception in mid 2015, BPD Community has tried to steer a clear path in order to address its vision to replace stigma and discrimination with hope and optimism. With limited resources we work to improve the lives of those with BPD and to make sense of what is and what could be.

With the Productivity Commission and the Royal Commission both occurring simultaneously and in the light of the changes that the NDIS has brought about and the subsequent effect of lack of funding here in Victoria, making sense of this world of mental health has created an opportunity to see things with greater clarity. Since our initial submission to you, we have had the opportunity to redefine our understanding of BPD in relation to the mental health system and subsequently define our theory of recovery.

INTRODUCTION:

Prior to the intervention of COVID-19, BPD Community was preparing to present to the Commission at a focus group. This we learnt today has been cancelled. We wish therefore to submit this paper for the consideration of the Commission.

We consider the discriminatory consequences of the stigma that exists within the mental health system and the mental health professions, highlighting four key concerns: treatment, diagnosis, research and the mental health professions.

We explore the current dominant mental health model, the medical model with its central focus on treatment, and offer an alternative perspective. This perspective is more a Recovery Support model. This perspective gives weight to Social and Relational Supports as well as Treatment Support and sees them as complementary. Currently the social supports are seen as subsidiary, as adjuncts to treatment. Relational supports are rarely considered and when they are considered, they are subsumed within the medical model. All attention appears to be given to treatment, none to recovery.

Finally, we offer a solution in the model of a BPD Community Hub to clear the current impasse that exists for people with lived experience of BPD.

BPD COMMUNITY:

We are a Victorian based independent, grassroots, peer led charity for all people affected by BPD. We have a turnover of less than $15,000 a year. Our reach is greater than our turnover however and our influence is even greater. Our community of 360 people consists of approximately 19% of people with BPD, 46% of family and friends and 27% people who work in mental health (the rest are supporters). Our Family & Friends Group has operated since 2015, the data for this year indicates: 100% found the sessions useful, 97% feel more confident in knowing what to do, 97% felt supported by the group, 96% felt the group had helped them build a more positive relationship with their loved one. These figures are supported by the data from our Info Nights also.

Where possible, we develop collaborative relationships with other organisations to support our programs. For example, we held a 12 hour BPD Ambassador Training Program with the support of Mental Health Victoria. Star Health, a community health centre in South Melbourne, supports our regular Info Nights and our Family & Friends Program and our Board meetings. SANE now hosts our Family & Friends Group meetings. Since COVID-19, all our opportunities to meet face to face have gone. We are trying to adapt now to Zoom, but that requires a different approach for this different medium. To see our supporters: https://www.bpdcommunity.com.au/who-we-are/our-supporters

STIGMA:

Stigma and the subsequent discrimination in relation to BPD emanates from the mental health professions and the mental health system. Our research shows us that it has two main arms:

1) Blamed:
   The person with BPD is blamed. They are stereotyped and rendered irrelevant. They are blamed for their illness: labelled difficult, manipulative, liars and attentions seekers. Further, parents of BPD are stigmatised, stereotyped and sidelined. Parents are often deemed to be the cause of their children's mental illness because of childhood abuse.
2) Discredited:
   The diagnosis is discredited. It is underdiagnosed, misdiagnosed or not diagnosed at all. There are arguments about the name BPD and whether it should be renamed Complex PTSD. People with BPD have difficulties in locating a professional who offers treatment and a belief that recovery is not possible for someone with BPD and that treatment doesn't work is alive and well within the medical community.

The effects of this stigma are many, for example:

- **Treatment:** As mentioned above, it's notoriously difficult to find treatment for BPD. One of the members of BPD Community, a mother, rang 43 Psychiatrists and Psychologists to find treatment for her young daughter. As soon as BPD was mentioned (2015), it was explained to her that there were no places available in the schedule. The waiting list at Spectrum has increased substantially and the approx. wait time today for a diagnosis is a 6 months minimum. When asked in May 2016, Dr Sathya Rao of Spectrum, indicated by his estimation that there were about 4,000 people in Victoria, in both the public and private system who were being treated for BPD in a year - not taking into account the appropriateness of that treatment.
- **Diagnosis:** A consultation with our carers in 2015 determined that the number one priority of carers is to get a diagnosis for their loved ones. Generally, it's accepted that most people with BPD do not receive a diagnosis; for those who do, anecdotally it is between 7 – 11 years to get a diagnosis.
- **Prevalence:** BPD Community accepts the research adopted by the Federal United States government which indicates a prevalence of BPD of about 6% as at 2016. Unfortunately, the data relied upon in Australia dates back twenty years or so and ranges from 1 – 4%. BPD Community is currently preparing a Position Paper based on the prevalence research to illustrate the rationale behind our choice of a figure of 6%. Going by the updated figure of 6%, this equates to about 350,000 people in Victoria with BPD. If we allow two 'carers' for every person with BPD, that is 700,000 meaning **one in six Victorians are directly affected by BPD**.
- **Systemic discrimination:** As mentioned above, treatment for BPD is not widely available and many mental health professionals don't understand the complexities of BPD and are therefore unable to

support people with BPD. In addition to this, the mental health system is inadequate and not designed to accommodate people with BPD and their co-morbidities. Research shows that if you treat the co-morbidities and not the BPD, then the co-morbidities will reoccur. Successful, holistic treatment depends on BPD being successfully treated alongside any co-morbidities. Both these circumstances exacerbate the situation that people with BPD and their families find themselves in.

Concern One: **Treatment**

Whichever prevalence figure is applied, based on the estimate provided by Dr Rao, more than 90% of people with BPD do not have access to treatment.

- Based on a prevalence of 6%, approximately 1.14% of people with BPD receive treatment in a year.
- Based on a prevalence of 4%, approximately 1.66% of people with BPD receive treatment in a year.
- Based on a prevalence of 1%, approximately 6.66% of people with BPD receive treatment in a year.

Whether the treatment is research-based and non-effective, or recovery-focused and effective, is another concern. For example, if the treatment is directed at trauma, it requires careful consideration because it can re-traumatise the person with BPD, thus increasing their ill health and even further reducing their access to recovery.

Concern Two: Diagnosis

Without a diagnosis, access to information, resources and support is an ongoing struggle.

If a person with BPD has a therapist who withholds a diagnosis, the consumer then becomes dependent on that therapist. This disempowers the consumer. The consumer is inhibited in seeking complementary or alternative supports and may then be vulnerable to misinformation.

When the family of a person with BPD has access to relevant information, they are in a position to learn how to improve their supportive relationship with their loved one and reduce their enabling behaviours. There are techniques specific to working with people with BPD that family and friends can learn.

Concern Three: Research into BPD

There are conflicting opinions about the use of the term BPD, with significant mental health professionals arguing that it should be renamed Complex PTSD. This is a divisive situation given many people with BPD do not identify as having experienced trauma, in particular childhood trauma. This perspective often translates into 'blame the parent', a situation experienced by many parents of someone with BPD. In some instances, insinuating that BPD stems from childhood trauma had led to allegations of abuse where none has occurred.

There are no up to date, accurate figures on prevalence of BPD in Australia. Most research into BPD is from a 'medical model' perspective to the exclusion of other, non-clinical perspectives. This disadvantages the research and continued learning on BPD and creates a narrow view.

Concern Four: Poorly trained and poorly supported mental health professionals

People with BPD are regularly turned away or dismissed when they seek help, including both from the Emergency Department or by a private practitioner. This constant rejection is debilitating and leads to a lack of trust in the system.

When a co-morbidity, e.g. drug and alcohol dependence, is treated without attention to the BPD, then the drug and alcohol dependence will in all likelihood, reoccur. When relapses occur, the person with BPD is likely to blame themselves for their continued failure to recover and less likely to seek help again.

When people with BPD are considered to be attention seeking 'drama queens', their cries for help will become attempted and successful suicide. A recent Spectrum study (yet to be published) that was conducted in collaboration with the Coroner's Court of Victoria has demonstrated that BPD was the underlying cause in an estimated 10% of all suicides. The study also found that, on average, there were 50 BPD-related suicides in Victoria per year, amounting to one BPD suicide per week. Of those with BPD who died by suicide, 99% had presented to mental health services in the preceding 12 months and 88% had presented to mental health services in the preceding six weeks.

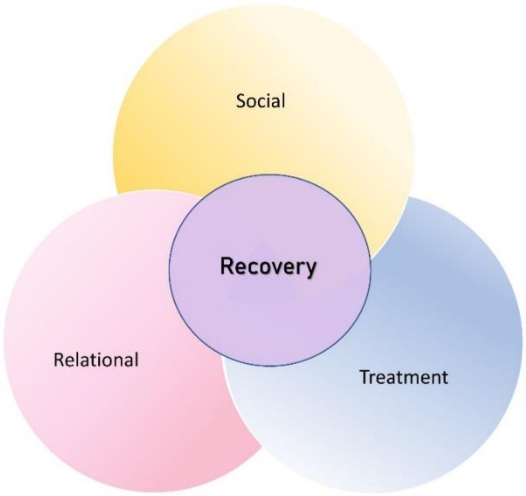
It's the experience of BPD Community that most people who work in the mental health system are not skilled in being able to support people with BPD. Those that claim to be able to support people with BPD may not be equipped to do so. Training for mental health practitioners is available and is not extensive. Most importantly, BPD is not taken seriously by mental health planners.

THE MEDICAL MODEL

The medical model disadvantages people with lived experience of BPD, it privileges treatment of the individual, especially with medication – and medication does not affect BPD. Treatment is concerned with addressing symptoms. Recovery should be the objective. When the medical model considers social supports, such as employment or housing support, they are considered adjuncts to treatment rather than being an essential support. Finally, when the issue of 'Relational Support' is considered within this blinkered context of the medical model it is also unsatisfactory. Families are essential to recovery, yet they are rarely seen as a part of the solution. While BPD families are often fractured and most are trying their best to support their loved ones 24/7. The medical model has failed people with lived experience of BPD.

BPD Community suggests a different model:

The three essential supports for **Recovery** from Borderline Personality Disorder



Treatment support:

To provide every person with BPD access to timely and effective psychological treatment now, is unrealistic; currently between 90 – 95% of people with BPD do not have access to treatment. It is important to note that psychotherapy is the recommended treatment for BPD, although appropriate medication interventions may help with co-morbidities.

Social Support:

Instead of housing and employment issues as being considered as subsidiary to the central focus of treatment, they should be given more than equal significance. Further, financial and budgeting support, household management support and all the other myriad of social supports should be recognised for their contribution to recovery.

Complementary treatment supports such as Art Therapy, Music Therapy and cultural supports have been shown to have a significant, positive impact. People with BPD experience more physical health problems: physical exercise programs and medical focussed supports should be easily accessible.

Relational Support:

This is the forgotten component of recovery. When we consider relational support, we recognise that it often involves friends, however, the burden usually falls to families. Sometimes the burden is so great that families feel they need to protect themselves by withdrawing from contact with the person with BPD. Some families are dysfunctional and feel that they cannot offer support. Even if the family is able to support their loved one with BPD, the person themselves may reject this support. For recovery, a person with BPD needs to be supported by those they love and those who love them. This cannot be assumed to happen given the nature of BPD.

BPD has five domains of dysregulation: emotional, behavioural, relational, identity and cognitive. For a person with BPD to achieve recovery, all these domains need to be regulated. However, the current approach to 'treatment' and the medical model, almost completely overlooks relational support.

1) The time a person with BPD spends with a mental health professional is small in comparison to the time spent with their family and informal supports. When a person with BPD leaves their therapist's office, they return to live amongst those who love and support them. Oftentimes this is in their family home. When things go wrong, it's the family who are called upon to provide the support required. Very often the support that is required is financial.
2) When relational dysregulation occurs, families often bear the brunt of the dysregulation of the person with BPD. This often spans decades of trauma for the whole family as the family member with BPD grows into adulthood. Sometimes a person with BPD has been seen to be 'difficult' from infancy. The dysregulation of a person with BPD can undermine the family dynamics as siblings are overlooked for the needs of the person with BPD. When a parent is the person with BPD, the children bear the brunt of the dysregulation and the uncertainties that result. Relationships between spouses suffer when one person has BPD. These difficulties often result in mental health concerns for those who live with a person with BPD.

3) A child raised by a person with BPD who has not recovered, grows up in a BPD environment where emotional dysregulation, for example, is normalised. The result can be subsequent and inter-generational familial dysfunction.
4) BPD Community has developed a model of support for families and friends that is based upon psychoeducation and training in the core techniques to improve relationships with someone who has BPD. This model empowers the family to support their loved one with BPD and discourages enabling behaviours. This is specific to the needs of those who love someone with BPD. It is based upon the successful therapies that treat BPD. Generic mental health support programs do not address the importance of the BPD relationship building techniques.
5) The mental health system with its stigmatising and discriminatory behaviour in relation to BPD, also stigmatises and discriminates against families of someone with BPD. This has been covered in part above. It is the experience of BPD Community that family members are desperate for support and psycho education so that they in turn can better support their loved ones with BPD. This is denied them when:
    a. No diagnosis is given. With a diagnosis, information and support can be sought.
    b. Families are blamed. When a family is blamed for the condition of their loved ones, they are excluded from the support they need and they can be prevented from providing support to their loved ones.
    c. The specific needs of people with BPD and their families and friends are not understood or acknowledged. BPD is different to other mental illness especially because of the nature of relational dysregulation. Generic services to support families and friends do not meet the specific needs of BPD families and friends.
    d. No support is offered to families. There are some supports available to families yet clinicians, organisations and services fail to refer families to specific BPD support programs.

CONCLUSION

The mental health system privileges the 'medical model'. BPD Community believes that the stigma and discrimination that exists in relation to BPD emanates from the mental health system and mental health professionals who are, in fact, seen as having the solutions to mental health problems. Even with the best intentions, individuals within this system will be compromised. Treatment options for people with BPD are extremely limited. Effective and timely treatment is only available to those who know how to find it and who can afford it. Further, the medical model is not concerned with recovery. Recovery from BPD is a realistic goal, however, currently the mental health system is too often a barrier to recovery.

BPD Community recommends a Recovery Support Model where the three components of treatment, social and relational supports are seen as complementary. Of these, social and relational supports should be a priority. A person's mental health can progress when a holistic, encompassing approach is administered but if only treatment is considered, a person's mental health may not sustain improvement.

SOLUTION

BPD Community has developed a BPD Community Hub model which can be adapted easily and cost effectively to geographic areas, complemented by a virtual community hub using the latest technologies to widen reach. The objective is to replace the existing stigma and discrimination with the hope and optimism of recovery. The purpose is to create a sense of community of interest and a community of practice. This would be supported by information services and products that are accessible, research based and easy to understand and supplemented by training specific to people with BPD, their families and friends and those who work with them.

The BPD Community Hub would be an exemplar of BPD informed relational support with an active focus on recovery through ‘life coaching’, peer groups, supplemented by purpose designed training programs and co-ordinating/case managing treatment and social supports. The design is to encourage creative, flexible and adaptable approaches to meeting the needs of all people with lived experience of BPD.

In conclusion, BPD Community recommends this flexible, cost effective approach to supporting those with lived experience of BPD (consumers and carers):

1. BPD informed ‘case management’: co-ordination of treatment and social supports;
2. Individual ‘life coaching’;
3. Group peer support, (building relational supports is essential);
4. Training programs to meet the needs as they are identified (again with a focus on relational support).
5. Identify gaps in treatment and social supports and work to fill those gaps;

Note, this approach is for all people with lived experience but can be adapted to suit specific needs. It is for example understandable that people with BPD would require more individual support, ‘life coaching’ and case management, than a family member might. The needs of family members may be effectively met through peer support groups. The ‘BPD Community Hub’ is designed to be flexible and adaptable to the needs as they arise. The individual would not have a time limit to their participation, it would be needs based.

This community approach would be aimed at working with and within existing organisations in geographic areas. It is designed to create flexible BPD informed supports outside of a medical model, strengthening the three core components of recovery from BPD. It is designed to empower people with BPD and their families and friends. It is designed to support people with BPD in their journey to recovery.

This is the work that BPD Community has begun and works to develop.

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