SUBMISSION TO THE PRODUCTIVITY COMMISSION

re Borderline Personality Disorder

This submission aims to highlight the special needs of those affected by BPD which affects their capacity to be as productive in our society as they would wish. The submission highlights the issues of stigma and discrimination, prevalence, family & friends, treatment, the cost of doing nothing and the struggle of grassroots organisations such as BPD Community.

INTRODUCTION:

This submission does not address the generic concerns that do exist within the mental health system. Instead we wish to draw to the Commission's attention the understanding that Borderline Personality Disorder is unlike the more commonly recognised mental illnesses. These differences make the situation for those affected by BPD so much worse. The primary concern for the Commission would be that BPD is a condition for which complete recovery is a realistic possibility. However, appropriate treatment and support for most is denied.

People with BPD can struggle to be productively engaged with their community. Their families and friends experience special burdens also and it is not unusual for parents and spouses (partners) to struggle to maintain employment and other social activities. To understand this special burden, we wish to draw the Commission's attention to stigma and discrimination in relation to BPD, prevalence of BPD and families and friends of those with BPD. The challenges of lack of treatment and the difficulty faced by grassroots organisations such as BPD Community, are also explored.

1) Stigma and discrimination.

Stigma and discrimination emanates from within the mental health professions and system. It takes two main forms:

a) The person is blamed for their illness. People with BPD are seen as the problem, not their illness. They are considered to be liars, manipulators, attention seekers and really in control of themselves.
These highly derogatory judgements could be based on a lack of knowledge or understanding of BPD and the techniques essential to work with them.
The medical model of care does not work with BPD, medication does not help with BPD (it does though with some co-morbidities that occur with BPD). It is important to note that unless the BPD is successfully treated, then co-morbid conditions will continue to reoccur.
BPD underlies other conditions especially anxiety, depression, drug and alcohol disorder, eating disorders, PTSD and other personality disorders.
Psychotherapy is the basis of successful treatment for BPD, in particular Dialectical Behaviour Therapy (DBT) has been well researched. DBT has been available since 1980.

b) The diagnosis is itself subject to ongoing debate within the professions. Anecdotally it can take up to 11 years before a diagnosis can be obtained. Many practitioners refer to stigma and discrimination as the reason for not giving a diagnosis, they prefer to treat symptoms. Not having a diagnosis adds to the stigmatising and the discrimination – it does not avoid it. It denies the person access to other forms of information and support.
There are claims that BPD is really Complex Post Traumatic Stress Disorder – this is disturbing because the treatments are different. Treatment for PSTD can be harmful for a person with BPD.
The DSM definition of BPD is clumsy and in need of rewriting however, the parties who needed to agree on the changed definition and criteria couldn't agree on the last occasion of revision of the DSM. The criteria hasn't been substantially changed since 1980.

These two explanations for the stigma and discrimination explain why there is so little research on BPD.

2) Prevalence

Accurate prevalence for BPD is a challenge. BPD Community accepts the prevalence of 6% because it is supported by research and it fits with our experience.

We accept this figure based upon research from USA (Huang et al (2008): Prevalence, Correlates, Disability, and Comorbidity of DSM-IV Borderline Personality Disorder: Results from the Wave 2 National Epidemiologic Survey on Alcohol and Related Conditions, Journal Clinical Psychiatry. 2008 Apr; 69(4): 533–545.) and accepted by the national government of USA in the Report to Congress on Borderline Personality Disorder, by the US Dept of Health and Human Services Substance Abuse and Mental Health Services Administration (2011). HHS Publication No. SMA-11-4644) and reinforced more recently in research undertaken in Poland which suggest BPD has a prevalence of 7% (Gawda, B., & Czubak, K. (2017). Prevalence of personality disorders in a general population among men and women. *Psychol Rep, 120*(3), 503-519.). This reports also highlights the high co-morbidity rates with other Personality Disorders.

Research in Australia is confusing and outdated. The SANE paper (Carotte and Blanchard (2018) Understanding how best to respond to the needs of Australians living with personality disorder, Prepared by SANE Australia for the National Mental Health Commission) provides a discussion of the Australian data. The official Australian figure for prevalence is 1-2% or sometimes as high as 4% depending on who you speak to.

The question of prevalence is critical. If 6% is accurate, then in Victoria, 350,000 people have BPD. If for every person with BPD we allow two loved ones, then 1 in 6 Victorians are directly affected.

Most of these have no diagnosis, less are receiving treatment and of those receiving treatment, even less are in receipt of the recognised successful treatment programs (refer Clinical Practice Guideline for the management of Borderline Personality Disorder (2013). NHMRC, Commonwealth of Aust)

Hundreds of thousands of Australians are suffering unnecessarily and their productivity is compromised.

3) Families and Friends

The circumstances for families and friends of people with BPD are also different than for other mental illnesses.

People with BPD experience relational dysregulation. This means that those who are closest to them are often subjected to the more extreme behavioural and emotional dysregulation. This is a burden that affects the mental health of these loved ones. Parents especially experience high levels of anxiety and depression. This directly affects their productivity.

Family members of people with BPD have often experienced years of trauma within the family caused by the dysregulation of their loved ones. In particular, families can find their finances compromised because of the demands of their loved ones whose ability to manage their lives is compromised. The financial support to pay for private treatment is an added burden for many. Anecdotally, BPD Community can attest to parents using their super to support their loved ones to try to keep them from going on the streets. Financial support for adults with BPD who are unable to manage their finances means parents can face choices such as seeing their adult child on the street or themselves unable to be financially independent.

4) Treatment

The National Guidelines for the Clinical Treatment identifies many successful treatment types. (NHMRC, 2013) It says: "*People with BPD should be provided with structured psychological therapies that are specifically designed for BPD, and conducted by one or more health professionals who are adequately trained and supervised."* It adds, *"Doctors should not choose medicines as a person's main treatment for BPD, because medicines can only make small improvements in some of the symptoms of BPD, but do not improve BPD itself."*

A person with BPD tends to reach out for help. The discrimination they face within the mental health system often means they are rejected and this only serves to worsen their condition. Lack of knowledge of what BPD is means that families feel isolated when they seek support. By the time a person with BPD reaches adulthood, they may have been rejected, misunderstood and blamed for their condition many times by those they seek help from.

Currently in Victoria, there is a waiting list of some 3 months at Spectrum, the Victorian centre for personality disorders, to get into treatment there is a wait of another 4 months or more. Only the most severe cases gain access to this treatment. So, treatment in the public sector is available to those who can wait and whose symptoms are severe. People with BPD are 45 times more likely to commit suicide than the general public and severe equates to suicidal but not everyone with BPD self-harms or is actively suicidal. Those who access treatment in the public sector tend to be more resourceful, they can wait and display severe manifestation of illhealth.

For others there may be support in the generalist public mental health services where discrimination favours those who respond to the medical model of treatment.

The private system costs families thousands of dollars to attend specialist BPD treatment centres where programs such as DBT are offered (over $10,000 for a year long DBT Program). For those less well-resourced there are individual therapists who charge on average over $200 a session.

"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."

For the person with BPD the most important aspect of this is the relationship between them and the therapist and secondly that positive change does occur. In the ad hoc system of treatment available to most people with BPD, this is not realistic. People with BPD reach out constantly and feel constantly rejected. This adds to their sense of being discriminated against.

BPD is like a quiet epidemic that is swept under the carpet – and recovery is a realistic possibility.

5) The cost of doing nothing.

Below is a list of aspects of life with BPD that are a cost to our society. BPD Community apologises for the lack of referencing in places, these points were highlighted in a presentation by Dr Josephine Beatson, Melbourne in 2015 at a BPD Community Info Night.

- People with BPD are more likely to be on the Disability Support Pension than those with anxiety or depressive disorders
- People with BPD tend to have poor physical health
- 10% of people with BPD die by suicide
- Inability to go to work or school productively, and full-time, is the strongest predictor of failure to achieve recovery or loss of recovery in BPD (Elliott B, Weissenborn O. Employment for persons with BPD. Psychiatric Services 2010, 61(4): 417)
- In a 10 year prospective study that people with BPD tend to use outpatient treatment over long periods. They may also take psychotropic medication over long periods, often 3 or more medications 6 years or more. (see above reference to the unhelpful use of medications in BPD) Inpatient treatment is usually intermittent and decreases over follow-up. These findings accord with Australian experience. (Zanarini M et al. The 10-year course of psychosocial functioning among patients with BPD etc. Acta Psychiatrica Scand 2010,122 (2): 103-109.)
- BPD is significantly associated with arteriosclerosis or hypertension, hepatic disease, cardiovascular disease, gastro intestinal disease, arthritis, venereal disease. These results were confirmed after adjustment for sociodemographic variables, Axis 1, and other Axis 11 disorders. (Zanarini et al, 2010)
- People with BPD who experience stigma have lowered self-esteem. Stigma can damage an already damaged sense of self. Social isolation may result. Or they may avoid seeking help or treatment. Turning to alcohol, drugs, or other acts of self -harm can also result.
- Families and carers can become isolated in their 'BPD world'. This can be related to the level of the patient's distress and related acute symptomatology. It can also be related to shame and stigma re the family member's illness.
- BPD is overrepresented in most studies of prison inmates. Female prisoners exhibit higher rates of BPD, often associated with a history of Child Sexual Abuse, perpetration of impulsive and violent crimes, comorbid antisocial traits, and incarceration for domestic violence. (Fossey, M & Black G: Under the Radar Women with borderline personality disorder in prison 2010, Centre for Mental Health, UK). Studies of male prisoners have revealed the presence of undiagnosed and untreated BPD in many cases.
- BPD Community has a number of adult children whose mothers have BPD. The adults have experience psychological problems associated with their mother's BPD that lasts well into adulthood. This burden is increased as the mother age and require more support from their children. Macfie, J. Development in Children and Adolescents Whose Mothers Have Borderline Personality Disorder, 2009 Child Dev Perspect; 3(1): 66–71. doi:10.1111/j.1750-8606.2008.00079.x..
- People with BPD are often involved in aggravated and simple assault, disorderly conduct, driving under the influence, drug abuse violations. These behaviours may be interrelated with drug and alcohol disorders.

6) **BPD Community currently offers a variety of programs to achieve its mission. However it receives no funding.**

Since Oct 2015, BPD Community has had a Family & Friend's Group meeting monthly. It has had a total of 381 attendances, reaching over 68 individuals. The quarterly report for 2019 indicates a usefulness of the sessions at 90%, 98% indicated they felt more confident, 99% felt supported and 78% reported an improvement in their relationship with their loved one with BPD.

We have held 15 Info Nights with a total of 356 attendees since 2015, issued 15 newsletters and issue monthly email updates.

We have done this and more and receive no funding. This is unsustainable. With a small amount of funding, our capacity to reach out to the BPD Community and replicate programs such as the Family & Friend's Group would make a world of difference. Our plans to support with people with lived experience and help fill the gaps currently in the system will not happen. This is unproductive.

WHO IS BPD COMMUNITY?:

BPD (Borderline Personality Disorder) Community is a grassroots organisation based in Victoria. It was established in mid 2015 in response to the absence of support for those affected by BPD in Victoria. It is independent of other organisations but works collaboratively with them where it can. Its mission is to replace stigma and discrimination with hope and optimism and to create a community to support recovery.

BPD Community has no paid staff, its annual budget is less than $10,000. It exists because of the support of volunteers and pro bono support, which is significant. It offers a range of programs aimed to provide support and up to date, research-based information. It has a vision to do much more, when possible. Without a marketing campaign BPD Community is a Victorian based community of over 360 people of lived experience with BPD, their families and those who work with us, as well as those who support the work we do.

We regret that our submission to the Productivity Commission is limited by the constraints that BPD Community faces.

ATTACHMENTS:

To support this submission, please find attached the following:

- **How SaD**: a Position Paper of BPD Community.
  A brief analysis of the research available on stigma and discrimination as it relates to Australia was undertaken. These findings form the basis for this papers description of stigma and discrimination as it affects BPD.
- **Carers' Concerns**: a Position Paper of BPD Community.
  An extensive consultation of family members of people with BPD who were in BPD Community in Oct 2015 was conducted. The paper attached was developed and presented to the community at its Info Night of Oct 2015. At this meeting the priority for Carers was 'getting a diagnosis'.
- **A Brighter Future**: a Case for Support.
  A pamphlet that presents easily accessible information as to why those affected by BPD should be supported.