

PREVALENCE COUNTS

CONTINUING THE RESEARCH AND ADVOCACY



BPD COMMUNITY

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THE YEAR OF CHANGES

October is a time for reflection at BPD Community. We reflect on the changes that have occurred over the previous year, we celebrate BPD Awareness Week, Mental Health Month and Carer's Week. We have good reason to celebrate too. What a year it has been!

"Who would have guessed that COVID-19 this invisible invader, would have caused so much distress to us as individuals and as a society. We have all felt the anxiety of uncertainty and the frustration that comes from feeling we lack control. But none of that is new to people with lived experience of BPD."

**- BARB MULLEN, EXEC CHAIR, BPD
COMMUNITY**



Barb Mullen, rewards Skippy her four legged friend. Working from home during COVID times has had benefits.

Photo: Supplied

You will be pleased to know that BPD Community has survived the challenges of this time. In fact, your BPD Community continues to develop and grow and speak for people of lived experience in Victoria. As we look back over the year, we are validated in our pride in our achievements.

BPD Community made a weighty submission to the [Victorian Royal Commission into Mental Health](#) and backed this up with a supplementary submission. We spoke to the Productivity Commission when it visited in Melbourne at the start of the year.



While we worked on these submissions we were behind the scenes, undertaking research into the issue of prevalence and what that means to us at BPD Community.

Meanwhile, we readily adapted to operating via Zoom. Our Family & Friends Group continues and grows. It will continue via Zoom after we are able to meet face to face, we have enough for two separate F&F Groups.

We sadly did not have our mid-year Info Night and even more sadly, could not celebrate face-to-face as we used to at our annual Celebration Night during BPD Awareness Week.

We did, however, produce some [COVID-19 Newsletters](#), [videos of survival tips and handy hints](#) as well as some [strategies and techniques](#) to help us through.

All of us have had to endure challenges that have caused us to change how we operate. But, life goes on and we all learn to adapt.

To celebrate BPD Awareness Week this year, BPD Community is publishing its paper on Prevalence of BPD which has been instrumental in lighting our way forward. In this issue of the newsletter, we will discuss its implications for BPD Community. [Click here](#) to access our Prevalence Position Paper.



WHY DO THE RESEARCH

[Prevalence](#) is the number of people who have BPD at any one time. It is important for planning because it helps estimate the 'burden of disease'. So, it is used by administrators to assess the need for treatment or services.

The more prevalent, the more money and resources for treatment, you'd think, right? Wrong. Not when it comes to BPD. For this reason, it is important to say out loud what the research says and how it can help us get the things that we need.



To speak up and out loud, it helps to know what we are talking about, what the key issues are. It helps to look at what it means to our people and our society. It helps to understand how our individual experience can add light to understanding.

HELPLINES AND RESOURCES

If you or someone close to you are in an emergency, danger or require immediate assistance call Triple Zero (000) for emergency services.

- [Lifeline](#) provides crisis counselling and suicide prevention services. Call 13 11 14 (24 hours a day, 7 days a week) or use their [online chat service](#).
- [SANE Australia](#) provides phone and online counselling. Call 1800 18 7263 (Monday to Friday, 10am - 10pm) or participate in their [online forums](#).
- [Tandem](#) provides support for carers of people experiencing mental health issues. Call 1800 314 325 or participate in their [online forums](#).
- [Beyond Blue](#) offers online and phone mental health support. Call 1300 22 4636 (24 hours a day, 7 days a week) or use their [online chat service](#).
- [1800Respect](#) offers confidential counselling, information and support for people impacted by sexual assault, domestic or family violence. Call 1800 737 732 (24 hours a day, 7 days a week) or use their [online chat service](#).
- [BPD Community's](#) Covid-19 strategies and techniques are available [here](#).

THE REASONS

It is not easy to answer the question, 'What is the prevalence of BPD in Victoria?'

Research is not easy and you can be sure that research into BPD is even harder than you'd want to know. But we do want to know!

We need to consider the following: who did the research? Did they have a clinician diagnose BPD or did they rely on self-reported BPD? Did they use the Diagnostic Statistical Manual or the International Classification of Diseases to diagnose BPD? Did they account for other co-occurring mental illness or not? Did they research in the general population or within a particular community, eg: uni students or health care settings? And, when was the research done?

You can see that, already, the situation can be confusing. So we sat down with the research and tried to make sense of it all.



It was helped by the work that others have done before us, however, this research was done with a purpose in mind. We knew the information was messy and we wanted to describe it in simple language. We wanted the research to help us at BPD Community say, "The prevalence of BPD in Victoria is...".

The prevalence figures range from 1% to 6%. So, what we have had to do was interpret the information in the research and base it on our understanding and our experience.

BPD Community works with a prevalence of 6% of the population. That means hundreds of thousands of people with BPD live in Victoria. And if we count two family members for every one, that is over a million people in Victoria with lived experience of BPD.

6%

Those of us who never heard of BPD until recent years can feel like we have had our eyes peeled open. As we look around, we can see BPD everywhere it seems. The experience of our BPD Community is that the prevalence of BPD is much higher than the official 1%. That 1% figure is based on research done in Australia over 20 years ago. The 6% figure is based on more recent research done in the USA. This is the figure accepted by the USA government.

The diagnosis of BPD is usually based on the DSM.

A FLAWED 'MEDICAL MODEL'

The DSM sets out nine criteria and a person has to have five before they can be diagnosed with BPD. This is firmly based on a flawed 'medical model' where symptoms are described and then treatment for those symptoms is given. The preferred treatment in the medical model is medication. Psychiatrists are medical doctors who specialise in mental health. They are immersed in the medical model.

WE WANT RECOVERY!

This medical model does not lend itself to considering recovery as we would understand it. The cessation of symptoms means nothing if the person with BPD can't get and keep a job, if the person is struggling with their personal relationships, if they cannot live independently without support. We want recovery.

DIAGNOSTIC ORPHANS

BPD Community knows that the strict diagnosis against the DSM criteria does not take into account people who fall just below the diagnostic threshold, the 'diagnostic orphans'. At BPD Community, we include them. That's why we believe a prevalence rate of 6% is more realistic.



*At the end of the day we can say with confidence
BPD has a prevalence of 6%*

PREVALENCE AND TREATMENT

One in six Victorians is directly affected by BPD. That is shocking, a million Victorians are struggling to cope with the effects of BPD. What is the mental health system doing?

1 in 6

1 in 6 Victorians are affected by BPD

According to Dr Sathya Rao, about 4,000 with BPD receive treatment support for their BPD in a year. Almost 99% of people with BPD do not get treatment support. To be more precise 1.14% of people with BPD get treatment support for their BPD.

Those who try to get treatment find it almost impossible unless they are seriously unwell and suicidal. Those with serious co-occurring mental illnesses such as drug or alcohol disorder or an eating disorder may get treatment for those illnesses.

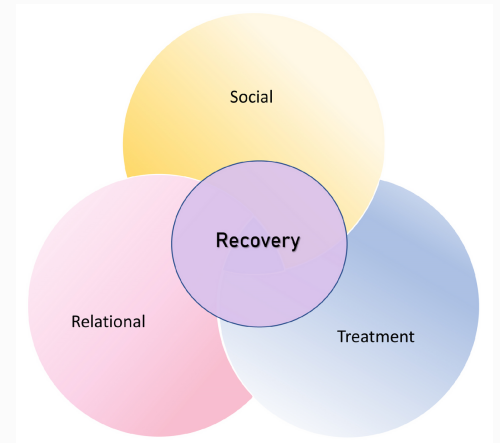
Those with PTSD or depression or

anxiety may get treatment for those disorders, especially within the private health system. However, treatment for BPD is hard to find.

Often the effect of this falls back on the families who may struggle to adequately support their loved ones.

[BPD Community aims to fill the gaps in this situation.](#)

With a focus on relational support, we hope to be able to meet the needs of people with lived experience of BPD.



“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.”

(Australian Parliament Senate Standing Committee on Mental Health, 2008)

BPD-informed care is what is required and it is usually not available.

So, what is the mental health system doing? It looks like it is doing its best to turn a blind eye to BPD and the BPD Community. BPD is not even counted in the National Health and Wellbeing Survey and the last time Personality Disorders were counted was in 1997.

SUICIDE AND BPD

As we cope with the effects of COVID-19 on our community, we are conscious of the severe repercussions the lack of usual supports has on our people with BPD and their families. Although the suicide rates in the first quarter of the year were not affected, with the increased pain of lockdown, we can expect it will have taken its toll.

An unpublished survey of the rates of suicide conducted by the Coroners Court of Victoria with Dr Sathya Rao of Spectrum found that one person with BPD a week was committing suicide. They studied the recorded cases from 2009—2013 and found that BPD was the underlying cause for 10% of all suicides.

A national suicide register was commissioned in 2019 and is due to be completed in 2022 (Dalzell, 2020). This represents a valuable opportunity to improve knowledge of suicide rates of people with BPD and other PDs, and associated issues.

A concerning finding was that 99% of individuals with BPD who died by suicide had attended mental health services in the 12 months beforehand, while 88% had in the six weeks before.

In the first quarter of this year, suicide rates had not changed markedly. We await the news of the statistics that will account for the effects of this extended period of lockdown as we surpass 100 days of continuous social isolation.



PREVALENCE POSITION PAPER

- 1.** BPD Community accepts a prevalence of 6% for BPD based on the research analysed in its Prevalence Position Paper.
- 2.** Sub-threshold BPD (diagnostic orphans) should also be considered in research and policy.
- 3.** There is a need for up-to-date prevalence data in Australia. This should involve new population-level estimates, and up-to-date data for various subgroups, including vulnerable groups. The upcoming Intergenerational Health and Mental Health Study is noted as a valuable opportunity to provide up-to-date data that can also be updated frequently in future years. National mental health-related reports, such as those by the AIHW, also should collect and report BPD data. The National Suicide Register should link suicides with mental health diagnoses, including BPD, to provide more data on suicide rates for people with BPD.
- 4.** The desirable key criteria for prevalence research involves:
 - a.** Using the ICD-11 as soon as this is widely implemented in Australia, and the DSM-5 until then.
 - b.** Until the ICD-11 can be widely used, aiming to measure the proportion of people with various numbers of BPD symptoms to provide a measure of the degree of BPD severity and to enable the detection of sub-threshold BPD.
 - c.** Using larger sample sizes and, where possible, expert-rated measures of BPD rather than relying on self-report measures.
 - d.** Analysing BPD prevalence in the general population rather than solely using clinical populations.
 - e.** Researching prevalence in various subgroups, including at-risk and marginalised groups.
- 5.** Stigma and discrimination are proposed as being factors contributing to the paucity of research into BPD and its prevalence and this must be addressed.