BPD COMMUNITY

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The quarterly newsletter of
BPD Community Victoria Ltd.

People with lived experience of BPD, their families and those who work with them, that's the BPD Community...making a difference!

STOP PRESS

Mind Recovery College has a campus in Cheltenham and throughout country Victoria. Courses are available primarily to those with lived experience as well as for their families. To see the Course Guide go to: http://www.recoverycollege.org.au/

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To join our email list, email: bpdcommunityvic@gmail.com

INSIDE THIS ISSUE:

Challenging times

To replace stigma and discrimination with hope and optimism is a challenge. Stigma and discrimination affects all of us and it requires all of us to work together to bring hope and optimism.

So how we create this change we want, requires us to consider exactly what is it we want to change.

It also means taking action to bring about the change we want to see.

This newsletter is dedicated to understanding the stigma and discrimination in our world of BPD. When we understand what it is, then we can look at the different ways we can work on creating change. Yes, it requires work because nothing changes just because we want it to change. And entrenched attitudes will not change unless there is a groundswell of support.

We all know for example that mental health is grossly underfunded. We have an election campaign at the national level, look how much attention is given to mental health.

Mental Health is not a great vote winner, because we haven't made it one. The data suggests that one in five of us is affected by mental illness, but we do not speak out about it.

The reason we talk in whispers about mental illness and about BPD is because of the stigma that exists. The stigma exists because we as a society, do not understand it, we are not informed.

In our BPD community the stories of the difficulty in finding treatment are legion, the harsh insensitivity of the emergency departments are reknown, the tales of the challenge of getting help when the world is crashing down around us are deeply etched in our memories. The most damaging stigmatising and discrimination occurs in the mental health system itself.

This is what we want to bring hope and optimism to. To tackle stigma and discrimination, we need to speak up and out loud.

The BPD Challenge...

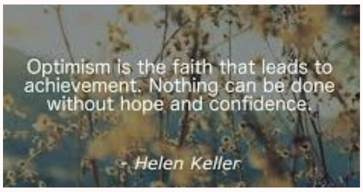
With many mental illnesses, we all have some knowledge. We have heard of depression, anxiety, schizophrenia but what is known about BPD in the wider world?.

If we wish to find information about BPD, it isn't easy. If we want to understand how the mental health system works, that's a minefield to the uninitiated.

We can struggle to get our head around the often difficult terms and concepts used. Trying to understand the criteria for BPD itself is a challenge. Finding out that you are considered a 'consumer' or a 'carer' can be hard to swallow.

Imagine how it is for those working in the field who do not encounter BPD in their training, those who don't chose that elective or who miss the lecture that day. Those on the front line of services such as the police, the paramedics and so forth.

It is time for correct, accessible information for all of us in the BPD community.



Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence.

- Helen Keller

Never give up

Dr Sathya Rao impressed the audience with his compassion at the Information Night, How SAD.

With gentle patience he led the audience through the concerns he encountered, drawing heavily on his experience while making reference to the research available.

To have to say that having BPD is not the fault of the person with BPD seems absurd. However the stigma that is so pervasive and that leads to discrimination is apparently based on this central precept. Sathya made the point that BPD is a condition of the brain and mind, and a judgemental approach to BPD underlies its stigma.

Using the analogy of a car, Sathya took the audience through an explanation of what it means to have BPD.

He said that the emotional system of a person with BPD is like a car with a hypersensitive accelerator and poor brakes. The driver is the person with BPD.

We can all remember what it was like learning to drive, how nervous we were at the start, how we needed lessons and practice. We have all sat in the driver's seat and had someone in the passenger seat sweating away and telling us how to drive, what to do and even yelling at us for missing the turn or braking too slowly or accelerating too fast.

Not only does the person driving have to cope with a car that that requires more focus and concentration to learn to operate, those in our passenger seats, even when they say nothing, communicate their anxiety, impatience and frustrations.

It gets so that the driver can end up being their own worst critic, thereby compounding the difficulties.

The person in the driver's seat is doing the best they can. As is the person in the passenger seat.

Sathya reminded us of the BPD Conference we had here in Melbourne in 2014 where at the 'Consumer Panel' the plea was made to "Never give up on us".

> *"We can all remember what it was like learning to drive a car."*

Why stigma exists today

There are 5 main reasons for stigma and discrimination according to Dr Rao:

1. Historical misinformation;
2. Lack of training and knowledge;
3. Mental Health Services are not set up to treat BPD;
4. Minimal resources are available;
5. The symptoms of BPD can be challenging to treat.

It is the stigma and discrimination that occurs in the mental health professions and in the system itself that underlies this.

People with BPD are referred to disparagingly as 'attention seekers', 'drama queens' , 'manipulative' and so on.

BPD is not seen as a legitimate illness and in an under-resourced mental health sector with a poorly trained workforce, BPD comes last.

So, people with BPD are medicated, admitted to hospitals when the self harm is serious, not given treatment plans and even refused treatment.

There is no population health solution to BPD.

> **"'attention seekers', 'drama queens', 'manipulative' and so on."**

Being non judgemental

BPD causes distress to everyone affected, Dr Rao said. The person living with the experience, their family and those who work with them—all feel the pain and confusion of BPD itself. And then there is the pain and confusion of a mental health system that is not equipped to deal with BPD. All of us feel this double burden.

Blaming the other person for the distress we feel is ineffective. In his presentation, Sathya made the point clearly, "Let's stop blaming each other because BPD causes distress to all", he said.

Being judgemental is unhelpful, blame is designed to make the other person feel guilty, it is hurtful in itself. And it doesn't encourage change.

Dr Rao has a perspective based on decades of experience and as the head of Spectrum, he has a vision of the way forward. He asks us all to support clinicians who work with people with BPD, and he identified the need for resources, education training and support for clinicians.

Sathya asks us to demand compassion and care for all those who make up our BPD community.

From SAD to HOPE and OPTIMISM

BPD Community has developed a position paper “How SAD”, to guide its mission to replace stigma and discrimination with hope and optimism.

Last October, Dr Jo Beatson and Barb Mullen first got together with a view to nailing down what the research said. Dr Beatson is known for her work in BPD in Victoria, she is preeminent in the field. Barb Mullen, a carer, is the Chairperson to BPD Community. Jo and Barb believe that this paper succinctly describes the key elements of stigma and discrimination in relation to BPD.

It was at the last Information Night that the paper was presented to the public.

So, what is this paper all about?

First we need to understand what stigma and discrimination means. Stigma is a mark of disgrace, it sets people apart. The effect of stigma is discrimination which is the unjust or prejudicial treatment of those affected by BPD. It is helpful to recognise that everyone in the BPD community is affected by stigma and discrimination, not only the person with lived experience.

BPD Community claims that BPD is the most highly stigmatised mental illness based on the evidence that shows that the stigma and discrimination is embedded in the world of the mental health professional.

In 2006, the Australian Parliamentary Senate Select Committee reported that a *‘diagnosis of BPD closes the door to already limited mental health services.’* Then in 2008, *‘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.’* Since then there has been some change on the ground, but not enough. The change that occurs depends on the goodwill and efforts of individuals There is no state wide or nation wide plan to change this.

The position paper “How SAD”, by providing an analysis on the latest research on the subject, shows us the way forward.

A key aspect of stigma and discrimination is that the people with BPD are often seen as less deserving of treatment than others who are mentally ill.

We misinterpret the behaviours of people with BPD and believe that the person has control over their behaviour. This judgemental attitude treats people with BPD as lacking in morality or willpower and that all they need is self control.

Outdated attitudes to a BPD diagnosis abound. It may not be considered a legitimate diagnosis, that it is untreatable and that recovery is not possible.

The consequences of stigma

Stigma and discrimination abounds when the patient is seen as the problem.

Traditionally in psychotherapy, a ‘neutral stance’ is maintained by the therapist. This is the opposite of what a person with BPD and their family needs. They need a therapist who they can trust and develop a relationship with. A neutral stance encourages a distancing power relationship between the parties when a collaborative emotionally supportive environment is essential.

Further, when the patient is seen as the problem, a self fulfilling prophecy results. ‘It can activate the patient’s self critical tendencies and a cycle that involves self loathing and self injury…’ (Aviram, 2006)

The consequences of stigma have wide ranging effects.

Stigma and discrimination can be invisible:

- BPD is not included amongst the main mental illnesses, so for example, a study into stigma in the media, didn’t include BPD in its research.

- when a therapist turns down a referral they are unlikely to recognize if their decision has been unconsciously shaped by pre existing stigma.

BPD is misdiagnosed and under diagnosed:

- when the diagnosis is not considered legitimate or when giving a diagnosis is seen as contributing to stigma, people with BPD go undiagnosed and underdiagnosed. Most commonly misdiagnoses are with bipolar and complex PTSD. When a patient does not get a diagnosis then the way forward with treatment is undermined and the families are misled and misinformed in how to be supportive.

Research into BPD is underfunded. Research is essential to continue to correct the misinformation that abounds.

What can be done

With a solid understanding of stigma and discrimination, we can see what needs to be addressed.

All those who work with people with BPD need to have up to date, accurate information about BPD. Still today there is disagreement about the prevalence of BPD. A key element of developing a planned approach to treatment of people with BPD is to understand its prevalence in the community and who it affects.

Those who work in the field of mental health need to have accurate up to date training on all aspects of BPD. A part of this is training in understanding the stigma and discrimination as it exists today; information on all aspects of BPD; and most importantly, this should be informed by the experience of the person with BPD and their family.

Those who will be working in the mental health field need training in all aspects of BPD as described above.

The voices of those with lived experience of BPD and the voices of their families need to be heard.

People with BPD need co-ordinated support to encourage a fully functioning participation in the community.

The families of people with BPD need their critical role in recovery recognised and they need to be included in the management plan. They also need the support of the community.

Research into BPD in all its dimensions, relevant to Victoria, is essential if we wish to progress.

BPD Community is dedicated to replacing stigma and discrimination with hope and optimism. If you wish to participate in this work, you are encouraged to join us. Whether you are a person with lived experience, a family member or a person who works in the field, you are welcome. *Our BPD Community is a place for all of us to work to create change, to create hope and optimism*.

The August Information Night

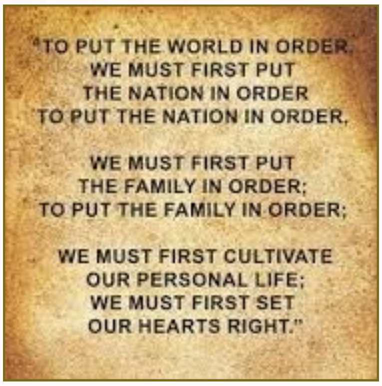
A Family Night Out

BPD Community is for everyone who is affected by BPD, those with lived experience, their families and those who work with them. If we are to replace stigma and discrimination with hope and optimism, then we will need to work together. All members of our community have much to learn from each other and our Info Nights are dedicated to giving a voice to every one and to be relevant to everyone.

It was just a year ago that at the August Information Night we presented the BPD Community position paper, "Carer's Concerns". This August we again dedicate to Carer's Concerns. Helen Robinett, a single mum, will present her experience in the world of BPD.

The families of those with BPD are deeply affected by the illness of their loved ones and they feel the stigma and discrimination that their loved ones face as well as the stigma and discrimination they themselves face. Often it is the family member who is able to speak out to create the change needed for their loved ones and this can be done when families join together in a community to make their voices heard.

Helen Robinett



"TO PUT THE WORLD IN ORDER,
WE MUST FIRST PUT
THE NATION IN ORDER
TO PUT THE NATION IN ORDER,

WE MUST FIRST PUT
THE FAMILY IN ORDER;
TO PUT THE FAMILY IN ORDER;

WE MUST FIRST CULTIVATE
OUR PERSONAL LIFE;
WE MUST FIRST SET
OUR HEARTS RIGHT."

At BPD Community we work to create a sense of community for all those affected by BPD, we aim to support all the groups and we work to make it possible for all of us to support each other in our common goal of creating hope and optimism. On Wed 3rd August Helen will tell her story, explaining her experiences and her hopes.

This is a night that would help those who work with people with BPD understand a little of the different experiences encountered by families where there is BPD. It is a perspective that is usually unheard. People with lived experience of BPD may be interested in the wider implications of their illness and how their experience can be seen differently. Family members themselves know that when they meet, that while each person has a very different experience, nonetheless they all feel the same grief and the same frustration at their helplessness.

TITLE: "A Family Night Out"

PRESENTED BY: Helen Robinett and
Klavdia Vainshtein
TIME:
7pm

DATE:
Wed, 3 August 2016

PLACE:
Tom Hills Room
Inner South Community Centre
341 Coventry St (opp market)
Sth Melbourne

Please RSVP to:
bpdcommunityvic@gmail.com

A Mind for Standards of Care.

Klavdia Vainshtein has been integral to the development of the newly published "Mind's approach to working with families and carers". This has been coincided with the launch of National Standards called "A practical guide for working with carers of people with a mental illness".

These two excellent documents outline how organisations can change their practice to involved all families of someone with a mental illness be a part of the solution. Klavdia will introduce us to the ideas of these booklets and how they can be used by all mental health professionals. They also inform people with BPD and their families on best practice in mental health treatment.

Klavdia has dedicated herself to provide organisations with strategic directions to improve how they work with people. Her job at Mind is as the Victorian Family and Carer Consultant.

The National guide can be down-loaded at:
https://www.mindaustralia.org.au/resources/families-and-carers/a-practical-guide-for-working-with-carers-of-people-with-a-mental-illness.html