

To join our email list, email: barb@bpdcommunity.com.au

Notice to our people with lived experience: our next Info Night will not focus on carers alone!

We would like to encourage all current members of BPD Community to come along in June (see the back page).

We create community when we share experiences and this happens when we get together. It's good fun when we do this!

INSIDE THIS ISSUE:

Challenges	2
Good news	2
Some hints	2
Psychosocial disability explained	3
Our Info Night	3
Work together	3
Suicide Prevention	4
What is being done	4

Ch..ch..changes

If we want change to happen, we have to work at it.

In 1981 it was International Year of the Disabled. That was a massive achievement made possible by the work of those with disabilities and their families. That year was full of activism across communities throughout the country but it was the work of previous years that made this possible.

As a result of the work of these people, attitudes changed. Stigmatization was addressed, and discrimination was systematically challenged. Today it is not perfect for the disabled, but it is so much better than what it was in the 80s.

The NDIS was introduced with the needs of the physi-

cally disabled in mind. Then the needs of those disabled by mental illness were included. Some people were asking out loud—if you are 'disabled' what does it matter whether the cause is a physical or mental condition?

Now, the NDIS is being rolled out in stages across the country. It is a national scheme with funding also from the states. In Victoria, the government determined to use the funding that went to services such as the Personal Helpers and Mentors Scheme for the NDIS, with the view that when the NDIS was fully rolled out, the NDIS would cover such costs.

So, here we are today. The PHaM Scheme is still working until the NDIS is rolled out. But what is happening

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with the NDIS?

The figures suggest that 10% of people with a psycho social disorder (this is explained inside) are deemed eligible for the NDIS. This mainly affects those with serious schizophrenia while those with BPD struggle to get accepted.

We all know how hard it is to get adequate and appropriate treatment for our loved ones. Will the NDIS make it happen? Not at this rate. Few are getting into the scheme, when it's rolled out we will lose programs like PHaMs, meanwhile our own Family & Friends Group that has been going since 2015, can't get funding.

One person can make a difference but imagine what it would be like if we joined forces—we could all make change happen.

New Family & Friend's Group

A new Family & Friend's Group will start up this March 21st, in Dandenong.

The model for this group has been developed over the years: it has been operating in Sth Melb since 2015. It is designed to complement the Family Connections training program to provide a continued support, focus on learning and developing capacity to give back to others over time. In this way it maintains its peer led, self sustainable emphasis.

Working with ERMHA and Mind, BPD Community is taking it's model to a very different community. This could not happen without the encouragement and support of the local agencies.

When we get funded to do this work, we might be able to introduce a group nearer to where you live

To join the Dandenong group rsvp to barb@bpdcommunity.com.au

Challenges

The NDIS was established to support those with permanent disabilities. It is an insurance scheme paid for like Medicare, with contributions from each state also.

One conundrum for us in the world of BPD is that while we know BPD is recoverable, we know this is not realistic without treatment. Our struggles are to 1) get a diagnosis and 2) to find treatment. The reality for most with BPD is that there will be periods when all seems to be progressing and then something will trigger a setback. Some liken it to a roller coaster:

Can't change
the direction of the wind
but I can adjust my sails to always reach my destination

- Jimmy Dean

struggling to get up to the top, then screaming wildly to the bottom. It is no wonder BPD confuses us until we learn enough about what is happening and why. That is why a diagnosis and subsequent evidence based treatment is so critical for us.

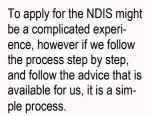
A diagnosis might be helpful to get onto the NDIS, but it is the effect of the illness on our day to day lives that is important.

Although treatment can lead to a reduction in symptoms, it doesn't take into account what recovery might be. Here again is another dilemma, it might seem self evident, but recovery is one of those concepts that is controversial. Many of us think that treatment will provide the answers, but for many, learning how to live independently and achieve personal goals might require different supports.

The NDIS is designed to provide the supports necessary to enable a person live as full a life as possible given their disability. Our challenge is in qualifying for the NDIS.



Good news



There are supports aplenty to help us through this process. A good starting point is to set aside some serious time to study the website:

https://reimagine.today/

This site is designed to support people with a mental illness and their family and friends, to help them understand the information and what they can do. There are many whose job it is to help you. The professionals who work with you already and the organisations who are funded to support you.

There is also a fair bit of misinformation to be found, so it pays to choose your supports wisely. The process teaches us to be active participants in our own recovery and to work with others.

Some Hints

- A successful applicant offers the following advice to those applying:
- 1. Get support for yourself during the process.
- 2. Learn to be patient and cope with the seeming continual change.
- 3. Specific diagnosis is not a guarantee of a psychosocial disa-
- bility. So, get documented reports, supporting evidence to explain the behaviours that cause difficulties in day to day life.
- 4. Focus on the impact of the mental illness on daily life.
- 5. Think about both what is useful for you and what isn't useful.
 6. Talk to others who
- 6. Talk to others who have been through the

process if you can.

- 7. Make sure counselling is included for carers.
- 8. Find a good support co-ordinator. Check out if they understand and have worked with BPD and the NDIS.

To sum up: be patient, learn and understand, reach out for support, prepare and plan.



"Learn to be patient"

Psychosocial disability explained

Psychosocial disability is an internationally recognised term under the United Nations Convention on the Rights of Persons with Disabilities; it is used to describe the experience of people with impairments and participation restrictions related to mental health conditions.

The NDIA says: "Whilst not everyone who has a mental health issue will experience psychosocial disability, those that do can experience severe effects and social disadvantage. People with a significant disability that is likely to be permanent may qualify for NDIS support."

BPD is often described as being on a spectrum, a range of colours. This has been helpful in understanding what BPD is because each person experiences it differently. It doesn't help us understand it in terms of psychosocial disability though. We need to look at it through a different lens for the NDIS.

One example of a psychosocial disability is a deficit of working memory. Working memory is that part of the memory which holds in conscious thought our everyday activities or thinking.

When our working memory is impaired as a result of constant emo-



tional dysregulation and cognitive dysregulation, everyday activities can be challenging.

Of course we can see how that would make everyday life challenging.

Lack of organisational skills affects functioning and ability to negotiate housing needs, establish income through Centrelink, make and socialise with friends, shop, cook, organise our household and keep appointments.

Relational dysfunction also makes holding down a job a challenge. Emotional hypersensitivity can be challenging in many workplaces.

Once we think about psychosocial disability, how to work with the NDIS becomes easier.

Our Info Night

At our first Info Night of the year, Sonia Savanah from Carers Victoria spoke to a keen audience on the NDIS from the 'carers' perspective.

These occasions are a great chance to get together and catch up as well as learn.

The focus of this night was to make sure carers understood they could put in a statement on their own behalf, for their loved one.

It was an excellent night all round.



Work together

The NDIS is an attempt to change focus to whole-oflife needs as compared to medication and crisis driven service delivery.

It is important to us all that it works well for us.

People with BPD need more than treatment, they need support targeted to their needs.

We know how many people with lived experience still live at home because they are unable to support themselves. They are often vulnerable to exploitation. Many will find themselves homeless, and our prisons are crammed with people with BPD. People slip outside the system because they struggle to keep appoint-

ments.

The pain of these experiences for the person with BPD and the burden on families is intense. Maybe iff we work together, we can help create the necessary changes we need.

Info Night-Tues 19 June 6.30pm

Suicide Prevention

The fear of suicide is a constant in our lives. BPD is a cruel condition, the psychic pain seems endless. When there is a predisposition for impulsive behavior, the threat of suicide is increased. Suicide ideation is a constant in the lives of many, combined with identity dysregulation and feelings of shame and lack of worth. Active self harm is a way of trying to deflect the pain, but can be a form of rehearsal also. Drug and alcohol abuse might be a form of slow suicide too.

It is helpful to understand this topic to do what we can to work towards preventing suicide. The questions might be: what can I do myself to prevent my own suicide or the suicide of a loved one? What can BPD Community do for suicide prevention? What can the mental health system do for suicide prevention?



Our next Info Night will tackle these questions and more.

Suicide is a crippling personal loss for families, and the loss of potential life of our young people especially, is a social loss. It is preventable. Join us and learn what is being done and what you can do too.

TITLE: Suicide Prevention PRESENTED BY: Alison Asche PhD

TIME: 6.30pm DATE: Tues 19 June, 2018

PLACE:
Star Health
341 Coventry St
Sth Melbourne

Please RSVP to: barb@bpdcommunity.com.au

What is being done

Alison Asche PhD



Alison Asche's unassuming and down to earth approach is matched by her humanity and gentle touch. Currently she is coordinating the place based suicide prevention trial in the Greater Dandenong area, an initiative jointly funded by the Victorian Government and Primary Health Networks.

Suicide is preventable, as we know.

The years of potential life lost accounted for nearly 100,000 years in 2016. This is because so many

young people commit suicide.

Suicide is a tragedy on many levels. It is however, both men and women well into adulthood with the higher age specific suicide rates.

Females may frequently attempt suicide, but it is males who are three times more likely to die by suicide.

Understanding suicide is the first step towards doing something about it. Alison will be able to update us on this topic.