



BPD COMMUNITY

Volume 1, Issue 6

March 2016

The quarterly newsletter of
BPD Community Victoria Ltd.

People like

YOU

change lives!

STOP PRESS

Professor Alan Fruzzetti will be delivering comprehensive DBT clinician training in Australia. Early registration discount closes 15 March. For more info go to:

<http://www.bpdaustralia.com/>

If you wish to join our email list, just drop us a line to:
bpdcommunityvic@gmail.com

Our Community is growing

Summer seems to come on in a rush and by the time you recover from Christmas and holidays, everything just happens in a rush. We have hit the ground running this year.

BPD Community continues to grow and we continue to break new ground. Our focus firmly remains on our mission to replace stigma and discrimination with hope and optimism. There should be some real news on that throughout this year.

One way we work to address that is by providing up to date research based information and to the end, Prof Andrew Chanen spoke to our community

recently on the importance of Early Intervention. Every time Prof Chanen speaks, there is more to learn. For those wishing to pursue that topic, our Facebook page 'BPD Community' has a link to an article by him. Also, his publication in the Lancet of last year, is available on the web. Finally, we should have a video recording of his talk uploaded to the web shortly.

That brings us to the next bit of big news. We are now accessible online through our website! By the end of February we will be able to launch:

www.bpdcommunity.com.au
We are now online and have lots of valuable information there for our community. The site will continue to be developed an extended, we have

plans to provide innovative features throughout the year.

Of course any new venture is bound to strike problems, so if you see something you think we should take note of or correct, please don't hesitate to let us know. Feedback on any aspect of our work is always welcome.

We are pleased to finally have printed material such as pamphlets, so if you know of a place that would benefit from having a bundle of pamphlets to circulate, let us know and we will get them to you.

Next Carer's Group:

6.45pm to start at 7pm,
Tuesday 15th March
ischc South Melbourne

The Carer's Group

Our Carer's Group continues to meet at Inner South Community Health Centre opposite the South Melbourne market in Coventry St.

The evenings are divided up with the first hour spent discussing our situations and the second hour is spent on an aspect of learning beneficial to us.



We have a few new people who have joined us (welcome newbies!) and as the year progresses we expect this group to expand.

The need for family members of people with BPD is so great that we plan to be able to develop this model and take it

closer to where people live. The challenge is to do this carefully and properly. We rely on your patience and understanding in these ventures, without paid staff and funding, these things take time.



Your chair awaits you...

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Prof Andrew Chanen chatting
with BPD Community Chairper-
son, Barb Mullen

A packed room, an eager audience



There was lots of animated discussion afterwards.

Early intervention is essential on so many levels: of this we were reminded at our last Information Night.

Thirty-eight eager listeners and Prof Andrew Chanen comfortably filled the Tom Hills Room at Inner South Community Health Centre. We sat back to hear a thorough and detailed talk on a wide ranging number of issues related to Early Intervention.

There are a number of reasons that appeal to different audiences as to why early intervention is critical. One is because it is when the disorder first appears and if it is treated, chances are that

treatment will be more successful. It will save years of living in pain for the person with BPD and improve their opportunities of a 'normal' life involving work, family and all that is taken for granted by others.

The health dollar goes further if early intervention is common practice. It means that because the chances of success are greater, then it saves the mental health system all the admissions and readmissions that occur as the disorder becomes more intractable in adulthood. For the person with BPD the disheartening effects of half hearted treatment programs that don't quite fit and their early with-



drawal from treatment programs that is so common, will be minimised.

The sad knowledge that when left untreated, the life for a person with BPD becomes more challenging as they age. They may become more adept at managing their situation but the psychic pain continues. As we age, our personality and our behaviours often become set and we find change a difficult process.

Early intervention is something that all in the BPD Community can agree with.

The cost of not intervening

A research paper done in Maastricht, Holland, (van Asselt et al, 2007) came up with the evidence for what we already experience. BPD is costly in many ways.

They found that excluding consideration of the healthcare costs, the total societal costs are substantial.

For the person with BPD there are out of pocket expenses for things such as cigarettes, shopping, (binge) eating and extremely high phone bills. These make up the greatest out of pocket expenses well above the average person. Then there were costs of presents for others and medication expenses.

Another significant cost to society is productivity costs. Where people with BPD were employed, they had greater absence from their jobs. Of course there were many not working and this is a significant cost to society.

It really makes sense to treat the illness, if only to save money in the long run.

"Another significant cost to society is productivity costs."

Diagnosing young adolescents

There is resistance to diagnose BPD in young people. This resistance is historical and in part a result of a philosophical concern relating to the development of personality. Some would suggest this is just another aspect of the stigmatising of BPD.

There have been many studies that have challenged this viewpoint.

In 2013, two researchers, Glenn and Klonsky published their findings of a group of adolescents in psychiatric care. After thorough assessments of these young people, the conclusion was reached that BPD can be reliably and validly diagnosed in adolescents as young as 12 to 14 years old.

When we read the words reliable and valid, we rec-

ognise this is the language of research that says that the study will withstand rigorous investigation and the results can be duplicated.

Still today, people with BPD struggle to get a diagnosis. With a diagnosis comes understanding and knowledge and the possibility of the hope of recovery.



Early diagnosis has been around for years

The UK National Institute for Health and Care Excellence (NICE) Guidelines of 2009 do not mince words in its discussion of the importance of treatment for young people.

The guidelines suggest there may be 1-3% of the general population under 18 with BPD, while acknowledging it could be as high as 14%. Suggestions indicate that in outpatients, it could be from 22-49%.

It is acknowledged that adolescence is a time of major developmental transition and young people experience frequent major distress. Consequently it is not unusual for the difficulties of a young person with BPD

may be dismissed. The phrase they'll grow out of it, is one frequently heard.

The danger of this is that the distress these young people experience is invalidated and the behaviours can become more firmly entrenched.

Clinicians are reluctant to diagnose BPD in young people for a number of reasons: Uncertainty about whether it is possible to diagnose in young people; Whether it is appropriate to diagnose at a time of major developmental change; Concern over the negative consequences of diagnosing BPD.

Further many clinicians do not believe that making a diagnosis will add to their understanding of the young person.

The first two reasons are a result of misinformation. The third reason given is stigmatising of BPD. The last reason is based on the belief that the clinician has ownership of the diagnosis.

Carers in Victoria last year said loud and clear that being given a diagnosis for their loved one, is their main concern. This is especially important when their child is an adolescent. With a diagnosis comes the possibility of learning strategies to support their child.

For the person living with BPD, a diagnosis can ease the sense that they are not able to cope with the rigours of adolescence. The knowledge that they have an illness which hampers their life can bring relief. This can also give the young person some sense of control over their treatment.

In what other medical field is a diagnosis withheld?

Young people with BPD are liable to experience difficulties with school life and home life. They are in the position of feeling they have little control over what happens. To withhold a diagnosis is contributing to a young person's pain in the present and in the future.

It's a different world today



Impulsive emails, attention seeking on Facebook, nasty comments and cyber bullying, sexting and more. The life of a young person is a constant social media challenge.

The Dutch study of costs of BPD identified increased phone costs. Young people more than others need to feel con-

nected with their peers. With this longing to be a part of a wide network comes danger if your behaviours are maladaptive, impulsive or emotional. Not only can a vulnerable young person easily become a victim of social media they can also post information that will be a permanent record they would rather forget.

The benefits of this new world of connectedness however has its positive side. The help and support available online for people with BPD is significant. It can create a sense of community and your peers understand and can guide you in the right direction. There are many blogs of people with BPD which are illuminating and of obvious benefit to the blogger.

It is important however to be a careful internet surfer. There is much misinformation and hurtful commentary. Social media does not provide a solution, it is just a medium for people to connect.



Prof Chanen is on YouTube

Prof Andrew Chanen spoke for well over an hour and covered a lot of ground not touched on here. His presentation included much research supported data. He really shared his depth of knowledge freely and extensively.

We captured the talk on video and it has been uploaded onto YouTube:

<https://www.youtube.com/watch?v=Ef6VlehzTc>

(You will need to copy and paste the link.)



Here Prof Chanen addresses the question: Why is equity and inclusion so contentious for people with BPD?

Prof Chanen made the point that BPD is not included for some reason in the top 10 mental illness categories and consequently is not counted when it comes to policy. He made the point quite clearly that for change to occur, it needs to come from the bottom up, it needs a community response.

The work that we are doing at BPD Community is critical to bring about change and it will take the support of all our community to bring about the changes we need.

On this note, we would like to encourage you to continue to learn about BPD and how it affects every person in our community differently.

We would like to encourage you to participate in any opportunities that arise. To gain strength from the support we can provide to each other and to consciously build a community that will be able to knock on the doors of the decision makers and say: "We want equity and inclusion for our BPD Community."

The May Information Night

Passionate about change

Dr Sathya Rao is an expert on BPD: he is the Executive Clinical Director of Spectrum, the Personality Disorder Service for Victoria. He has a great depth of experience in the field and has his fingers in many BPD pies. He is passionate in his dedication to working for people with lived experience of BPD and committed to bringing about change to improve their lives.

It is stigma and discrimination that is perhaps the greatest impediment to the improvement of services for people with BPD and Dr Rao suggests this is a sad state of affairs. He is dedicated to changing this. Dr Rao wants to speak to you about this situation, he wants to explain what this stigma and discrimination is and suggest why it exists. He believes that when we can understand why things are the way they are, then we can learn ways to bring about change. It is replacing stigma and discrimination with hope and optimism that is central to his message.

But you don't look like one of those people with BPD!



That's because I am disguised as a human being today.

Change doesn't come easily, it requires informed planning and support within the community. Dr Rao encourages you learn and understand why stigma and discrimination exists so that you too can join in and support the change that is needed.



Dr Sathya Rao at the 4th Annual BPD Conference, 2014

TITLE: "How SAD"

PRESENTED BY: Dr Sathya Rao & Barb Mullen

TIME:
7pm

DATE:
Wednesday, 4 May 2016

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

Please RSVP to:
bpdcommunityvic@gmail.com

"How SAD"

In February, the Board of BPD Community adopted a position paper on stigma and discrimination called "How SAD".

In it, the paper describes the various ways that people with BPD are stigmatised in the mental health system. Briefly it identifies:

People with BPD are seen as less deserving. This includes a misinterpretation of the behaviours of people with BPD and outdated attitudes to the diagnosis of BPD.

The patient is seen as the problem not the illness. This includes the clinicians use of a 'neutral stance' which is felt as invalidating. Also if a clinician thinks people with BPD are difficult it can lead to a self fulfilling prophecy.

The consequences of stigma have wide ranging effects. Stigma and discrimination is invisible, so it can be ignored. There is much misdiagnosis and underdiagnosis. It is under-researched when compared with other mental illnesses.

There is hope and optimism because the solution to the stigma and discrimination that exists can be resolved with up to date, research based information and training of those who work with people with BPD.

To address this sad situation, BPD Community is developing a strategic plan of action. All will be revealed at the Information Night.



BPD does not discriminate