

ANNUAL REPORT October 2016

Replacing stigma and discrimination with hope and optimism.

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Chairperson's Report



In our short life, we have achieved much and this is made possible by our motivation to bring about change and the support that exists in the wider BPD community for what we do. As a Board we are constantly guided by our mission to replace stigma and discrimination with hope and optimism.

Our organisation BPD Community Victoria Ltd, has had a solid Board of Directors who both provide governance and who are also hands on in the organisation of our activities. It is a challenging role to be both Director and volunteer and the enthusiasm and commitment of the Board is commendable.

In the challenge of starting up from nothing, it can seem sometimes as if both everything is happening at once and also that it is all moving so slowly. When we look back and see how far we have come, we know we have achieved much; when we look ahead into what needs to be done, we can see so much that we could be doing.

It is just 18months since we became a company by law, only 6 months earlier we had begun our journey. It hasn't been smooth sailing, neither has it been easy yet we have consistently kept our eyes on our vision of a supportive community for all affected by BPD, those with lived experience, their families and those who work with them. Our major organisational achievement was to gain status as a Public Benevolent Institution with Gift Tax Deductibility.

We have been blessed to have the support of many who give freely of their time and expertise, without these people we would not have been able to succeed as we have. Our gratitude is extended to all those who have given so generously.

In all we do we are reminded to be guided by those principles that are integral to the recovery process in BPD: compassion, acceptance and being non-judgemental. With this in mind we face the year ahead and the challenges that will accompany what we do.

Cheers!

Barbara Mullen

October 2016



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Treasurer's Report

It was eighteen months ago we became fully established as a legal company. Soon after, in July 2015, MIND Australia donated \$3,000 for us to start our adventures. This report covers the financial period to 30 June 2016.

As a voluntary not for profit organisation we rely upon donations for the running of our BPD Community, however we also have been provided with major in-kind donations of time and resources by many people, to whom we are greatly thankful and appreciative. So as not to potentially embarrass any benefactors who have given of their time and talents, I will not name them, but I will give an outline of the value of their contribution.

In kind Contribution	Value	
Legal assistance	\$15,000	
This includes setting up BPD Community Vic as a company. The costs for registration with the Australian Charities and Not for Profit Commission		
(ACNC), ASIC, and obtaining Deductible Gift Registration with the ATO.		
Website Development	\$10,000	
Email list management	\$200	
Ongoing management of our Facebook page	\$1,000	
CRM development	\$2,000	
Art work	\$210	
Printing of pamphlets, handouts and business cards	\$1,000	
Facilities, storage and equipment hire for meetings, etc \$1,85		
Management Consultant assistance with our strategic planning \$2,00		
Carer's Group co-ordination	\$3,500	
Info Nights organisation and development	\$1,350	
Newsletter	\$1,350	
General Administration	\$42,000	
Volunteer support	\$200	
Total	\$81,660	

We have survived this past year and a half on very little income because we have had very low expenses, due to the in-kind contributions we have received.

Since June 30, we have been successful in obtaining a grant for \$2,500 from the City of Port Phillip which will be used for running the Carer's Group each month from Inner South Community Health Service's premises in Coventry Street, South Melbourne.

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Financial Position 30 June 2016

Assets	Cash at Bank	\$878.83
Liabilities	Nil	\$0.00
Net Assets		\$878.83
Revenue	MIND Australia donation	\$3,000.00
	Interest	\$0.13
Total Revenue		\$3,000.13
Expenses	Insurance	\$1,785.30
	Registration of Internet names	\$90.00
	ASIC fees	\$46.00
	Hall Hire	\$200.00
Total Expenses		\$2,121.30
Cash Balance Statement		
Opening Balance 1/07/2015		\$0.00Dr
Revenue		\$3,000.13Dr
Expenses		\$2,121.30Cr
Closing Balance 30/06/2015		\$878.83Dr



Organisational Development

For some time our community has numbered about 250 people with lived experience of BPD, their families and those who work with them. These are those who have chosen to join the community via our email list. This confidence in what we are doing also represents a wider community we have not yet been able to reach. This is our inspiration.

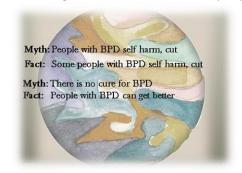
BPD Community has developed Position Papers to inform its work. In November, after an extensive period of consultation, the paper 'Carer's Concerns' was published and distributed amongst all the community. Then in February this year, the position paper 'How SAD' based on the latest research in stigma and discrimination in BPD was released. Both these papers inform our work. Currently work is being undertaken on developing a position paper for Consumer Concerns.



In response to the paper on 'Carer's Concerns', and following on from the first Australian Family Connections training program, BPD Community began the Carer's Group in South Melbourne. The work in developing BPD Community's model for Carer support has been tried and tested in this Carer's Group and forms the basis for BPD Community's plan to develop the HOPE Project to meet the needs of families of people with lived experience of BPD. It serves to develop a sense of a community that provides the foundations for recovery for those with lived experience of BPD.

Directly addressing stigma and discrimination is a challenging enterprise that requires diplomacy. Unlike other mental illnesses where the stigma and discrimination is felt in all aspects of our society, because BPD is a less known diagnosis, our stigma and discrimination emanates from within the mental health professionals and organisations. This is not to ignore the vitriolic message that is easily found on the internet which is evidence of a culture of negativity and ignorance. Using the paper 'How SAD', BPD Community was able to identify a training program that could be developed with a view to respond to the stigma and discrimination that exists amongst those who work with people

with BPD. In March, this training approach was trialled at St Vincent's mental health unit to an audience of over 70 mental health professionals. The audience was warm and responsive and the feedback was positive. Currently discussions are being held with a view to work with 'Borderline ED' to introduce this format into Emergency Departments. We have also been asked to present a training program for family workers in the Bayside Peninsula Mental Health Forum.



In our work we are conscious of our multi pronged approach to creating change. It is through developing community that we create a swell of support for the individuals and families and professionals who are affected by BPD this is turn helps us to address stigma and discrimination to bring hope and optimism to us all.



Information Nights

From the beginning it has been our Information Nights that provide a common meeting place for all those in our community. In October 2016, in line with BPD Awareness Week, our Celebration Night will be our last for the year, and our eighth since we began 2 years ago (2 before we became incorporated, 6 since then).

Roughly every quarter we hold an Information Night with a view to increasing awareness of BPD and to provide accurate information to address the misinformation behind stigma and discrimination. Our events have taken a format whereby the first two Information Nights of the year are dedicated to providing expert opinion, the third is dedicated to carer issues and the final one is a celebration of recovery and the work of the BPD Community.

Since this is our first Annual Report, it is appropriate to document all the events we have held to date:

DATE	TOPIC	SPEAKERS
11/02/2015	The Cost of Doing Nothing	Dr Jo Beatson – An analysis of the cost of not having treatment
20/05/2015	Treatment – what works	Dr Louise McCutcheon – Evidence based treatment and early intervention
26/08/2015	Carer's Concerns	Anne Reeve – Family Connections Barb Mullen – the final consultation for Position Paper, 'Carer's Concerns'
1/10/2015	Celebration!	Sinead Naughton – My Recovery Barb Mullen – The Year in Review
16/02/2016	Early Diagnosis and Treatment	Dr Andrew Chanen
5/05/2016	How SAD	Dr Sathya Rao – Stigma and Discrimination Barb Mullen – Presentation of Position Paper 'How SAD'
3/08/2016	Family Night	Helen Robinett – Letting go and staying on track Klavdia Vainshtein – Carer Standards
6/10/2016	Celebration!	Kate Brinly - My Recovery Barb Mullen – The Year in Review



Carer's Group - South Melbourne

The Carer's Group had its first meeting on 20 October 2015 and has met every month since. In that time, it has been a process of development of what has become BPD Community's model for a carer's support group.

The group began in response to the desire for a group of carers to follow on from a Family Connections training program. Family Connections is based on psychoeducation and the development of skills for families with a loved one with BPD. The need for ongoing support to maintain and develop the coping mechanisms so helpful in building relationships was evident. The focus of the group was to continue the support found in meeting and sharing as well as ongoing psychoeducation. The psychoeducation of the Carer's Group is loosely based on the core principles of Dialectical Behaviour Theory and Treatment which is the most established of the successful treatments for BPD.

BPD Community, aware of the importance of peer led support and of developing a sense of community, have worked to keep that focus: instead of the group being led by 'experts' as occurs in the only other support group for BPD in Victoria. This focus is seen as integral to changing the expectation of one service provision, to one of participation. The members of the group are able to create a participatory environment of equals on a journey of personal growth in learning and development and build their sense of community.

There is a core group of about 20 regular participants, of whom about half attend at any given time. Overall, there have been 38 individual carers who have attended at any one time. The group is still in its developmental phase, as is to be expected in the organic growth of individuals working out how to collaborate to create a caring community group.



The Carer's Group lights a candle at the start of each meeting to remind us that we are here for our loved one with BPD. The candle is a light to guide each of us and when all the candles are lit we can see that together the candles can create a strong light to see by. It is a reminder that together we can make a difference and bring light to a subject that can be so sad.

Our HOPE Project is designed to meet all the needs of carers of people with lived experience of BPD. Its two key arms are the Carer's Groups which we intend to have throughout metropolitan Melbourne, regional and rural Victoria, and a responsive Social Media. We expect to be able to take our model of a carers group to the conservative estimate of approximately 360,000 family members of someone with BPD in Victoria.



Consumer's Group

The whole purpose of the BPD Community is to support those with lived experience of this illness and to encourage their recovery.

Currently we are doing this through our Carer's Group in South Melbourne and with our plans to develop the HOPE Project. Our work in Stigma and Discrimination also directly addresses those in the mental health organisations and professions with a view to making it easier for people with BPD to gain treatment. Our Information Nights are designed to bring the whole community together, to provide a social environment where people can meet and learn of the latest developments in BPD.

We are yet to develop a 'Consumer's Group'. The challenges of this enterprise are many. When people are ill, it is not appropriate to provide an alternative to treatment. When people have recovered, the new life is so good and many want to leave the pain of life with BPD well behind them. The stigma of having BPD is keenly felt by those affected therefore it takes considerable strength for someone to be open about their illness.

Currently to be diagnosed with BPD requires a person meet at least five of nine criteria, this means that the manifestation of BPD could have hundreds of different permeations. The illness which often is most obvious in mid-teens can however be evident much earlier. There are people in their old age who have BPD. While superficially it appears most in women, it is suggested to be much more equally spread amongst the genders. All these factors means that people with lived experience of BPD do not easily fit a pigeonhole.

Some keen people with lived experience are currently trying to work through how we can develop a peer led support group based upon the current Carer's Group model. There is the hope that we can begin to pilot this in 2017.

The needs of people with lived experience of BPD to support recovery are not being met and there is much room to develop innovative programs that will do just this. The objective of creating a sense of community is a challenge where people are concerned with their individual recovery and their own journey. This is the challenge for BPD Community in the future.



Stigma and Discrimination

The people who work in the mental health professions are well intentioned, working in difficult and challenging environments. People with BPD experiencing the distress of their illness are not easy to work with. When this is compounded by a judgemental approach, it leads to blaming the person, not the illness. This attitude underlies much of the stigma and discrimination.

The discrimination that occurs as a direct result of the stigmatising of people with BPD is most distressing. An illness that is as painful as BPD should not be compounded with the pain of stigma and discrimination. That the stigma and discrimination that exists emanates from within the mental health professions and organisations is cruel. Those who we look to for access to treatments that lead to recovery are a critical part of the problems caused by stigma and discrimination.

The Position Paper, 'How SAD' considers the latest research to analyse the components of the stigma and discrimination that exists. At BPD Community we believe that this situation exists because of ignorance which leads to a lack of understanding. The way to address stigma and discrimination is then to provide opportunities for learning up to date and accurate information about the disorder.

The Position Paper 'How SAD' provides the basis for an analysis of how to develop training programs to address this concern. BPD Community has developed a strategic plan to address the concerns in all areas of the mental health professions who work with people with BPD. In March 2016, Barb Mullen addressed a group of more than 70 mental health professionals at St Vincent's as a part of the Eric Seal Presentation for the mental health unit there. With Prof David Castle and Dr Jo Beatson, the detrimental effects of prejudice and the myths surrounding BPD were discussed.

Planning has been taking place to bring training to mental health workers across the system.

Currently a small group of carers are working on their own presentations to present a carer's perspective on this issue. Also we have some keen people with lived experience eager to tell their stories to add to the perspectives on what BPD means to people.

A training program will be trialled at the Bayside and Peninsula Family Services Training Forum in mid Oct. This will form the basis for all training programs we can make available to mental health workers.

In the new year, BPD Community hope to be working with The Borderline ED to develop training targeting Emergency Departments, to address this issue. We hope to be able to call on a core group of carers and hopefully some people with lived experience of BPD to provide emergency department staff with first-hand experience on the effect of their work on others.

Meanwhile, BPD Community continues to work to address the issue of stigma and discrimination as it appears in the media and where appropriate on the internet. To date five separate examples of stigmatising or discriminating publications, or just plain misinformed publications, have been addressed. It is worth noting that no-one likes to see themselves as prejudiced, so addressing these concerns requires tact and diplomacy. The objective is to work with people not against them.



The Internet and Media

The new technologies open new ways to connect with our community, harnessing these media to help develop our sense of community, to provide accurate and up to date information and to provide the support that is so essential for recovery is our challenge.

The development of our web page at the start of this year has been a challenge to achieve with little money and little time to invest. Nonetheless it forms the basis of a strong internet presence to provide the information that is so important to people in our community. We can provide the latest in up to date information that is easy to access and easy to understand. Our audience includes all age groups, all works of life, those living with BPD and their families and those who work in the field.

We have a strong Facebook presence also, our work here is copied by others and this helps to further spread the story of hope and optimism that we promote. The purpose of our Facebook page has been to provide information, however this medium can be used to develop that sense of community further. To this end, the use of closed Facebook groups for our Carer's Group has been an innovation that will enhance the ability of the group to support each other and to enhance the peer support that is essential to see the sustainability of such groups.

Our Twitter account has been constantly active but is underutilised at the moment. A medium such as Twitter can be used for different purposes and knowing how best to utilise this is to be determined.

Our Newsletter is published quarterly and to date we have issued eight newsletters. With our newsletter we can communicate directly with our community. We provide a report on the previous Information Night for those who could not join us and we can keep people abreast of any news in the world of BPD.

Throughout the year we send out email updates as news arrives that would be relevant to our community. These are informal and infrequent in order to avoid email overload.

At the moment we are developing a co-ordinated approach to our media, using a Customer Relations Management approach, with a view to better meeting the needs of our people and to encourage a more participatory approach. Our goal is to develop a self-sustaining community that is energetic and motivated to work towards reducing stigma and discrimination for the BPD community at large.



Future Plans

Since we began our work we know we have made a difference already; we also know how much there is yet to do.

The world of BPD is fraught with division amongst those who determine how BPD is defined, what treatment can be funded, were the priorities are and who will miss out. The clinical world in Australia differs significantly from that in USA, which is different again in the UK and the rest of the world likewise. This is important for us to know but does not determine what we do. We know the pain that exists, caused by an illness that can ruin the lives of many that can crush the promise of people unable to fulfil their potential: an illness from which recovery is possible but which is denied.

Our immediate plans are to simply put our heads down and get on with making a difference.

We will continue to work to develop our HOPE Project aimed at developing targeted programs to meet the needs of families of those with BPD. The core of this project is the development of Carer Groups throughout Metropolitan Melbourne and regional and rural Victoria and the development of our social media for all 'carers'.

Our SAD project stands ready and waiting for the opportunity to develop a targeted approach to reducing stigma and discrimination amongst mental health professionals. In this venture we will work with other organisations as the opportunity arises while concurrently working with people with lived experience of BPD and family members to develop their own presentations to tell their stories. We will have a training package ready to roll in 2017.

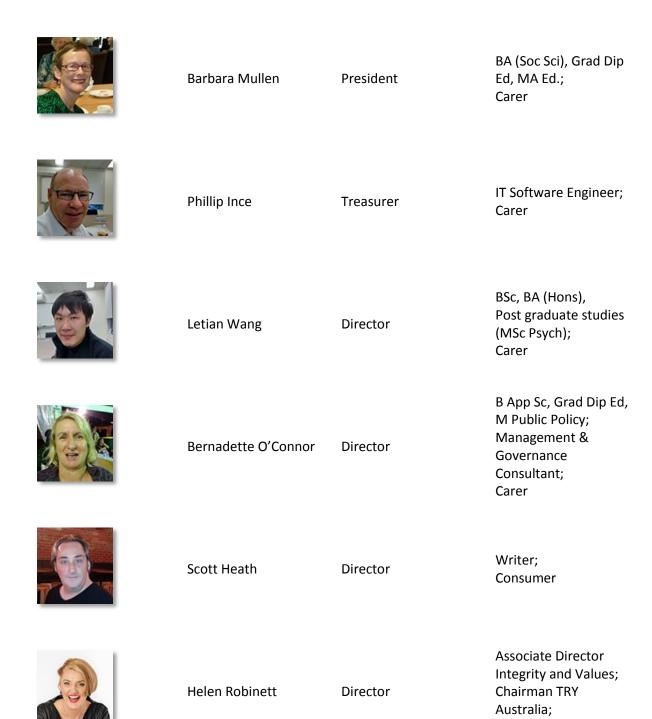
Always the needs of those living with BPD and those who have recovered from BPD are to the forefront of our minds. While all we do is to provide them with a supportive community to enhance their individual wellbeing, we will continue to strive to find ways to more directly provide support in a way that complements existing supports.

Our social media presence will underlie all these efforts and be a focus for all our community interactions.

We expect that the work we do in all these areas will in turn have an impact on those who make decisions on our behalf. We aim to be a unifying, collaborative voice where there are currently competing voices.



Board of Directors



Carer

