SUBMISSION

in response to

Victoria’s next 10-year mental health strategy
Discussion Paper

Prepared by

BPD
COMMUNITY

ONTENTS

INTRODUCTION

Borderline Personality Disorder (BPD) is a serious mental illness that today is significantly stigmatised and discriminated against. This stigma, prejudice and discrimination is a result of lack of knowledge and understanding.

Within the mental health system and its various components there is much discussion and academic debate which expands and enriches our knowledge of BPD and it should inform the therapeutic approaches and support services available to those affected by the disorder.
The NHMRC Guidelines (2012) provide relatively up to date information on BPD, however, misinformation and generalisations abound which in turn affect common understandings, treatment choices and research decisions.

"Borderline personality disorder (BPD) is a common mental illness characterised by poor control of emotions and impulses, unstable interpersonal relationships and unstable self-image." (NHMRC Guidelines, 2012).

A lay person looking for information on BPD might visit The Better Health Channel which says: "*Borderline personality disorder (BPD) is one of a group of psychiatric conditions known as 'personality disorders'. BPD is marked by distressing emotional states, difficulty relating to other people and self-harming behaviour."* They might then visit the SANE website and download the BPD factsheet which introduces the subject with: *"Borderline Personality Disorder (BPD) is a mental disorder. People affected by BPD frequently experience distressing emotional states, difficulty in relating to other people, and self-harming behaviour."*

Not all people with BPD self harm.

These two examples, apparently insignificant are repeated throughout the readily accessible information. The misinformation covers many aspects of the disorder, not just to do with self harm. The SANE factsheet for BPD before it was revised this year said: "…*While there is no cure yet, BPD is a treatable disorder."* These inconsistencies cause confusion for the lay person seeking information. They create an environment of misinformation for clinicians and mental health professionals also. They are not a part of the rich debate surrounding BPD.

The consequence of this for those affected by BPD is a mental health system where gaining an accurate diagnosis, treatment options in the public and private system, is for the lucky minority.

A successful outcome in a 10 Year Mental Health Plan for Victoria would be one that addressed the stigma, discrimination and prejudice that exists in Mental Health in Victoria. We are all working to improve mental health for Victorians: we want to change the system to allow it to guide the continuous improvement and transformation of the way we support social and emotional wellbeing, enable recovery, and work with partners to achieve this.

THE VISION:

Borderline Personality Disorder (BPD) is a significant mental illness. The main concern for people with BPD, for the families of those with BPD and for those who work with BPD is the stigma and discrimination that exists. This stigma and discrimination is born of lack of knowledge or lack of understanding and unfortunately exists in the clinical professions and in support professions. This stigma and discrimination is the greatest impediment to recovery. The lack of recognition of the issue of stigma and discrimination in clinical and allied fields seems a further indication of the ignorance of this significant mental illness that affects 2% of the population.

> "*There is perhaps no serious mental illness more maligned and misconstrued than borderline personality disorder" Joyce Burland PhD, Director of the American National Alliance on Mental Illness Education, Training and Peer Support Center. 2007*

Consequently, while the vision outlined in the Discussion Paper would be supported, the information and understanding of mental illness as it relates to BPD in particular, is questioned. Until this aspect of stigma and discrimination is addressed in a comprehensive and co-ordinated approach, the vision is irrelevant for those who are affected by BPD.

SCOPE:

While BPD affects all levels in our community, there are particular groups within our community who suffer especially. The known genetic factors in BPD, make it especially important that the illness is addressed to prevent its continuance through families.

Yes, the indigenous population has a special need in relation to BPD. It is a community that has experienced powerful generational trauma. It is also a community that has its own special community and cultural needs.

Other communities that are particularly affected by BPD are found in the prison populations, both male and female; isolated rural communities; and those communities in our midst who experience generational unemployment and other indicators of social and economic disadvantage. The special relationship between trauma and BPD would indicate that migrant and refugee communities also are at risk.

BPD is often misunderstood as a behavioural problem of adolescents, diminishing the seriousness of this mental illness. While it often manifests itself in these years, BPD can exist throughout all age groups. It can be evident in young children as well as the elderly and all ages in between. Every group has its own special needs.

Similarly, BPD is primarily identified in young women. However, research suggests that it is just as much in the male population, but undiagnosed or misdiagnosed.

WHY A NEW STRATEGY FOR MENTAL HEALTH IS IMPORTANT TO THE BPD COMMUNITY:

BPD has been under the radar in Mental Health strategies to-date.

In a 2014 report Spectrum suggested there were conservatively potentially 60,000 people with BPD in Victoria: Adult Mental Health Services (AMHS) treat about 600 and Spectrum treats about 200 (Rao, 2014). Of the remaining 59,200, they have to manage with the private health system or no treatment at all. This is for a disorder where treatment can lead to recovery. The consequence for this lack of recognition and treatment is excruciating psychic pain for the consumer and their family. It comes at a terrible cost to the community at large.

"Even among other mental illnesses, BPD is surrounded by a phenomenon that maybe termed "surplus stigma." Issues that promote stigma and, thus, further the BPD misunderstanding include: 1) theories on the development of the disorder, with a suspect position placed on parents similar to the erstwhile schizophrenogenic-mother concept; 2) frequent refusal by mental health professionals to treat BPD patients; 3) negative and sometimes pejorative web site information that projects hopelessness; and 4) clinical controversies as to whether the diagnosis is a legitimate one" (Hoffman, 2007)

As the numbers above indicate, the problem is worse than lack of treatment. It is the lack of diagnosis and misdiagnosis that comes first. People with BPD and their families can be ignored and overlooked in the mental health field.

It is to be hoped that a new mental health strategy will include BPD relevant objectives and actions, including addressing stigma and the subsequent prejudice and discrimination.

DO THESE QUESTIONS REFLECT WHAT IS MOST IMPORTANT TO YOU?

The most important principle for those affected by BPD is access to services that will provide diagnosis and treatment within a stigma, prejudice and discrimination free mental health system.

The Principle "Population based planning" says "services will be planned and funded….across the spectrum of severity". While this is supported in principle the BPD community is sceptical of its application given the existing experience regarding stigma and misunderstanding of the condition within the mental health system. Unless this is directly addressed people affected by BPD will continue to be denied access to appropriately resourced services and skilled, effective treatments.

TAKING AN OUTCOMES APPROACH:

Outcomes are appropriate but what is the base against which they are measured? How are they measured and by whom? What are the accountability measures? Further, given the current distorted view of mental health in Victoria because of stigma, prejudice and discrimination, the BPD Community lacks confidence in this process. It is hoped that these concerns can be addressed in the 10 Year Mental Health Plan.

ENABLING GENUINE CHOICE:

The description of this outcome is unrealistic for those affected by BPD. The mental health system is an inexplicable maze for those outside it. People with BPD and their families often have negative experiences when interacting with the mental health system; it feels like a battleground trying to get any help.

Data indicate, on average, that five years elapse before BPD is accurately diagnosed in a patient. (Hoffman, 2007)

For Consumers:

People with BPD are consistently undiagnosed or misdiagnosed. When they do gain a diagnosis, they have to be lucky to get access into the public health system. Finding and affording treatment in the private health system is also a challenge. Given the difficulties inherent in having BPD, this situation is a tragedy.

For Carers:

Carers primary concern is for a timely diagnosis for their loved ones. When a carer finds out their loved one has BPD, then everything can begin to make sense and then they are able to learn how to best support their loved one. A carer wants treatment and recovery for their loved one, with a diagnosis comes the knowledge and understanding that recovery is possible. Without a diagnosis, any notion of any sort of treatment is irrelevant.

SUPPORTING CHILDREN AND FAMILIES:

"…children of parents with MDD (major depressive disorder) and BPD are at a particularly elevated risk to experience a major depressive episode…such increased risk may be due to children of parents with MDD and BPD exhibiting higher levels of cognitive and interpersonal vulnerability to depression than children of parents with only MDD." (Abela, Skitch & Auerbach 2005)

Children who live in a family with a mental illness suffer. Parents with BPD struggle to do their best for their children and their illness is cruel for both them and their children. To stop the 'intergenerational cycle' timely, targeted intervention is required. Currently, people with BPD find it a challenge to access treatment, let alone any specialised intervention.

Consumers:

Accurate, timely diagnosis and treatment is essential. The outcome only considers the children of a family with mental health issues. Parents who have BPD require support and treatment as a priority.

Carers:

Living in a family where BPD exists has repercussions for all family members. BPD is an illness of relationship impairment, unstable self image and emotional dysregulation. For parents, siblings and wider family, the pain of living with someone they love who hurts so much and is hurtful in their illness, is severe. For the children and grandparents and wider family where a parent has BPD, their lives are is fraught with pain and anxiety. Support for children and families, is essential.

IMPROVING ABORIGINAL SOCIAL AND EMOTIONAL WELLBEING:

Undoubtedly BPD would be a concern in indigenous communities with the all of the co-morbidities that occur with BPD. It would be valuable to point out that it is accepted that unless BPD is treated, then other conditions such as substance abuse, depression and anxiety will continue to reoccur. Of course, accurate diagnosis is central to proper treatment.

Other population groups also are disproportionate in their representation of BPD. In particular prison populations, where also the indigenous are over represented. In the UK, studies suggest that BPD in prison populations could be as high as 1 in 5 for female prisons. (Fossey & Black 2010)

Other populations that have experienced significant trauma could be expected to be overrepresented with BPD, especially refugee and migrant populations

According to NSW School of Psychiatry, Professorial Chair of Trauma and Mental Health, Dr Zachary Steele, who has worked with asylum seekers suggests there is no doubt being in a detention centre can transform adults in a short space of time. He is reported as saying: "We see detention create borderline personality disorder in healthy adults in 12-18 months." (news.com.au 2014)

PREVENTING AND REDUCING SUICIDE:

People with BPD are at enormously elevated risk for both attempted and completed suicide. 16.2% of people who completed suicide had a personality disorder (Arsenault-Lapierre et al., 2004). A longitudinal study showed that 10% of BPD patients eventually complete suicide over a 27-year period (Paris & Frank, 2001). It was estimated that around 85% of BPD patients had at least one suicide attempt in their life time (Black et al., 2004).

Despite the association between BPD and suicide, existing services responsible for addressing suicide attempts and behaviour do not meet the needs of people with BPD and are sometimes actively harmful. Emergency line operators and nurses often have a stigmatized and erroneous view of BPD. People who are suffering excruciating psychic pain are treated as attention seekers and are denied service. People who have attempted suicide multiple times before, while at higher risk of completing suicide according to research (Black et al., 2004), are deemed by many in the system unlikely to actually proceed with the threat. These 'attention seekers' are subsequently denied access to services. Further, because people with BPD have severe interpersonal problems that can affect their interaction with health professionals, staff members of the health system often fail to meet their needs

"…a standoff between patients and mental health professionals such that the harder patients with Borderline Personality Disorder try to communicate their distress and frustration to others, the more they feel rejected and driven away by service providers. Thus a vicious cycle develops which is of course ultimately dangerous and demoralising for the patients with Borderline Personality Disorder ...They feel scape-goated by the mental health system and indeed are, with respect to both policy and practice and do not therefore receive the treatment which has been shown to be effective."(Dr Martha Kent, 2008)

and exacerbate the consumer’s pain through victim blaming, defensive responses and negligence.

To advance the prevention of suicide among people with BPD, many changes to the current system are desperately needed: health professionals, including psychiatrists, nurses and emergency line operators, need to receive better training on the symptoms and features of BPD to combat their stigmatized view. Diagnoses of BPD should be made available, and the elevated risk of suicide for people with BPD need to be taken seriously when decisions about admission are made. While specialist care would not always be available in the public system, psychologists and psychiatrists need to be better informed of principles that could improve generalist treatments such as those laid out in the NICE and NHMRC guidelines. Psychoeducation, training and support network aimed at suicide prevention should be made available for people with BPD and their family members, and the content should be properly adapted to meet the specific needs of this community.

People with BPD receive the cruellest of treatment in the emergency wards. The story is told of the young woman who went to emergency with cuts to her wrist across, she was told she wasn’t serious and that if she was she would cut her wrists longitudinally. She did a few days later and died. To people in the BPD community this does not surprise.

Consumers:

It is stigma, prejudice and discrimination that turn people with BPD away from emergency. It is stigma, prejudice and discrimination that influence CAT teams to treat people with BPD so poorly. We recognise also that these services are constrained due to lack of resources, however, taking this into account, it is people with BPD who are most disadvantaged.

Further, if people with BPD had a diagnosis and access to treatment appropriate to their needs, they could learn how to manage their impulsive behaviours and their psychic pain to prevent suicide.

Carers:

The distress of a parent of a suicidal adolescent is excruciating. When that parent tries to get help for their child and is treated with the usual dismissive responses reserved for BPD situations, that pain is exacerbated. Too many parents lose their children to this disease, and this is completely preventable. Suicide in adolescence and adulthood is also a factor for people with BPD and the families of these people are also left with the terrible pain of the inexplicable.

With a diagnosis and correct treatment lives would be saved. With a correct diagnosis families would learn how to support their loved ones. With a correct diagnosis people with BPD and their families would have hope. With a mental health profession that was willing to correctly diagnose and treat people with BPD, then there is less room for stigma, and discrimination - it is ignorance and lack of understanding that underlies the current situation.

REDUCING DISADVANTAGE AND INCREASING SOCIAL AND ECONOMIC PARTICIPATION:

> *"My adult daughter can visit her psychologist 10 times a year and get a rebate. The psychologist charges $200 a visit. I see no chance of recovery for her, her life is a mess, she hasn't worked for years – at least she is not on the streets." (2015)*

If people with BPD were accurately diagnosed and treated, they would be unlikely to be homeless or imprisoned and more likely to be employed and contributing productively to our society. Issues related to co-morbidity (dual diagnosis programs) would be able to be addressed also, reducing drug & alcohol problems, eating disorder problems, lessen depression and anxiety rates. How so… because BPD is a treatable condition, recovery is possible.

Consumers:

When parents of people with BPD get together it seems that all their children are highly intelligent and creative. People with BPD whether highly intelligent and creative or not, have a potential that is not realised. All the ambitions of childhood come crashing down with BPD and the future becomes very uncertain and for the individual concerned, they are often dependent on parents, regardless of their age. Long term unemployment, homelessness or supported housing, medical problems caused by unhealthy lifestyles are the foreseeable future of those with BPD without a diagnosis and appropriate treatment. As is known, people with BPD often have co morbidity with a wide range of other mental illnesses. This then is compounded when they have children and a circle of deprivation is begun. In old age the hoarder living in an impoverished physical mess is likely to have BPD.

Carers:

Parents have impoverished themselves in trying to support their children with BPD. Grandparents watch as their grandchildren live poorer lives on all levels due to their parents' BPD. Support services, unless they are trained in working with people with BPD, are unable to help even with the best intentions and the people with BPD fall through the cracks.

RESPONDING TO NEED WITH EFFECTIVE, COORDINATED TREATMENT AND SUPPORT:

Effective co-ordinated treatment and support presupposes that a diagnosis has been made. In the BPD world, getting a diagnosis is the first hurdle to overcome. Lack of information and understanding of what BPD is leads to stigmatisation, prejudice and discrimination. The first step to meeting this outcome would be a concerted campaign of education and training through all areas of the mental health field: a campaign that acknowledged that BPD is a serious, significant mental illness; a campaign that incorporated basic first aid techniques when dealing with people with BPD. At the same time, treatment for BPD should be available for consumers, treatment based on the implementation of the 'Clinical Practice Guidelines for the Management of Borderline Personality Disorder'. With effective, coordinated treatment and support, the world we live in would be so very different. Based on the data available, there would be about 59,000 people in Victoria, their families and friends able to live without the constant pain that BPD means, that equates also to 5,900 who are less likely to suicide.

Treatment needs to be available in both the private and public mental health system for both consumers and for carers. It needs to be realistic in terms of length of treatment. It is much more effective if there is one off treatment of one or two years for someone with BPD compared to a lifetime of pain, intermittent treatment, dependency on social support systems and non productive contribution to society. The fallout effect of a life and potential wasted because of lack of treatment, on those closest to the consumer, is tragic. Adequate and appropriate treatment that leads to recovery is cost effective.

Consumers:

The lucky few gain access to treatment, whereas most people with BPD live a life of pain and hardship with little support from the mental health system. Sadly, too often within the mental health field itself, hurtful experiences occur for those affected by BPD. Other difficulties occur because the person with BPD can be unwilling to accept treatment when it is available or more often, the treatment is not timely and the waiting period of many months means the person with BPD feels unable to access it. Worse still are the experiences of ineffective or inappropriate treatment which are disheartening and discouraging. Often people with BPD are medicated and the focus of treatment is on medication while the evidence shows that medication does not affect BPD, although it can help with anxiety, psychotic and depression symptoms. Again it is emphasised that unless BPD is treated, comorbidities are likely to continue.

Carers:

Carers are often devastated to be consciously excluded from information on the treatment process and from learning of treatment progress. When the person with BPD is a child, under the age of 18 this is especially devastating for the parent. When the child is self harming and the parent is on continual suicide watch, to be excluded by the treating mental health practitioners, is especially cruel and harmful.

Carers of adult children are often the ones who are paying for the treatment. They are still excluded from any feedback from the mental health practitioner. The ‘mother blame’ syndrome is still a powerful factor. Parents are treated as if they are irrelevant while they are in fact central to the recovery of their loved ones. Because the nature of the illness involves relationship impairment, that key relationship of a parent and child, regardless of their age, is critical to the recovery process.

A partner of a person with BPD can be in an especially difficult situation, faced with decisions about what is best for their relationship and for their own children. A parent whose partner has BPD has to put the care of their children first. A partner needs to know that treatment is progressing or not from the clinician's point of view, it is important for them to understand what is happening.

People with BPD have a different reality from the reality of those who love them. People with BPD struggle with their interpersonal relationships, carers of people with BPD are the ones who are (usually) always there for their loved ones. Often the reality for the person with BPD is markedly different and sometimes the therapist accepts that reality, not appreciating that the description given by the person with BPD is not at all accurate. If there was room for a carer to be aware of the treatment process, and if there were opportunities for feedback, then the therapist may have a clearer insight into the degree of distress and the carer may have more confidence in the treatment process. Afterall, when therapists no longer see the consumer, their loved ones are left to pick up the pieces.

The need for carers access their own support services is important. Psychoeducation and training in techniques to improve communication and interpersonal skills is essential for the loved ones of people with BPD. Individual counselling for the depression and anxiety that is often a part of the life of a carer is also essential.

RECOGNISING AND RESPONDING TO THE EXPERIENCE OF TRAUMA

"Some clinicians and researchers have promoted trauma-focussed therapies, such as individual trauma-focussed cognitive behavioural therapy. However, approaches focussed solely on trauma have not been demonstrated to be the most effective treatments for people with BPD." National Guidelines 2012)

Trauma is a controversial topic for both people with BPD and their family members. Past research suggest that up to 58% of people with BPD also meet the criteria of PTSD, up to 81% of patients report having endured some form of childhood trauma or negligence, especially childhood sexual abuse (Herman, Perry, & Van der Kolk, 1998; Zanarini et al., 2004). This has led to the proposal of reconceptualizing BPD as a trauma spectrum disorder, such as complex PTSD(cPTSD), by a minority of experts (e.g. Herman, 1992), This proposal is being debated in the scientific community and no consensus has been reached (Resick et al., 2012). The difference between complex PTSD and BPD appears to be in the definition of trauma and whether there is a change in previous personality characteristics.

What is trauma?

"…the diagnostic criteria for post-traumatic stress disorder (PTSD) require that the individual has been exposed to 'a stressful event or situation of exceptionally threatening or catastrophic nature likely to cause pervasive distress in almost everyone' (according to ICD–10) and eliciting a response involving 'intense fear, helplessness or horror' (according to DSM–IV). However, more recent research shows that the events resulting in most diagnoses of PTSD are actually quite common and that none of these traumas is so powerful that exposure typically leads to the disorder (Kessler 1999: p. 55). The disorder is more frequent and severe in victims of natural than of man-made disasters (Lifton 1976: pp. 10–14), and is

less likely to occur in well-integrated communities than in fragmented ones (Quarantelli 1985: p. 192). These findings tie in with the main conclusion of treatment guidelines published by the National Institute for Health and Clinical Excellence (NICE), which singles out the lack of social support as the most important risk factor for PTSD (National Collaborating Centre for Mental Health 2005: p. 94).” (de Zuleta, 2009)

“…the key diagnostic symptoms of PTSD, DSM–IV also refers to ‘an associated constellation of symptoms’ that ‘may occur and are more commonly seen in association with an interpersonal stressor’ such as childhood sexual or physical abuse, domestic violence, torture, or being a hostage or a prisoner of war (American Psychiatric Association 1994: p. 425). This combination has been variously referred to as complex PTSD (Herman 1992a) and ‘disorders of extreme stress not otherwise specified’ (Pelcovitz 1997). The list resembles very much the symptoms of DSM–IV borderline personality disorder except for the last item, referred to as ‘a change from previous personality characteristics’ which is probably best covered by the ICD–10 diagnosis of ‘enduring personality change’. (de Zuleta, 2009*)*

The importance of differentiating between PTSD, complex PTSD and BPD is in part because of the difference in the treatments for the disorders.

Another critical feature of trauma and BPD is the relationship between the person with BPD and their parents. People with BPD are often hypersensitive and have relationship impairments. People with BPD self report abuse: sexual, physical and emotional. As carers will attest, this is not always true.

“People with BPD are like people with third degree burns over 90% of their bodies. Lacking emotional skin, they feel agony at the slightest touch or movement.” Marsha Linehan

“The overwhelming majority of articles on families and BPD presume childhood trauma, which then equates to poor parenting and neglect. Sexual abuse is considered one of the strongest antecedents for BPD. But, 1) not all people who report such abuse develop BPD and 2) sexual abuse is more commonly associated with adult depression. BPD patients were significantly more likely to report verbal, emotional and physical abuse but not sexual abuse by parents. If sexual abuse is reported it is most likely to be by someone known to the person with BPD.” (Lefley 2005)

“While there is acknowledgement of a genetic predisposition to BPD, the research literature emphasises retrospective self reported histories of childhood abuse. So this leads to a conclusion that parents of children with BPD are more abusive than other parents and this abuse is serious enough to lead to disassociation, hypersensitivity to stress and an inability to relate meaningfully to other people.” (Lefley 2005)

For a person with BPD, trauma is informed by hypersensitivity so that what would be life as usual for a person without a predisposition to BPD, becomes traumatic to a person with BPD.

We do agree with the proposal that trauma informed care skills are important for people with BPD. It helps the staff members of the health system see the emotional and interpersonal disturbances presented by people with BPD as the consequence of past trauma rather than character flaws. This could help reduce stigma and create a more constructive therapeutic relationship. In addition, people trained in trauma-informed care would understand emotional sensitivity to triggers and provide much needed validation and support to people with BPD, a communication strategy that has been shared and emphasized by several effective treatments for BPD (e.g. Dialectical Behavioral Therapy, Linehan. 1993; Good Psychiatric Management, Gunderson 2014).

However, care must be taken when addressing the issue of trauma among people with BPD because of certain distinctive features of BPD. People with BPD tend to present with genetic high interpersonal sensitivity from a young age, this could also create a dysfunctional pattern of interaction between caretakers and the child (Gunderson & Karlen, 2008). This pattern may be highly distressful for the child to the point of being subjectively traumatic. Nevertheless, if the family environment and parental care were responsible for BPD, then the siblings of people with BPD would also have BPD.

Core symptoms of BPD include splitting and cognitive distortions, which could potentially affect the reporting of more extreme cases such as childhood sexual abuse, this reported abuse may be particularly unreliable (Paris, 1995). Therefore, clinicians must be careful when examining the claims of abuse. They should validate the feelings and experiences of the patients without making unsubstantiated judgments of the parents and loved ones of people with BPD.

We recognize that this is a grey area. Abuse does exist and could account for a significant proportion of BPD cases. On the other hand, the experience of the parents and caretakers need to be taken seriously, and they need to be involved in the treatment process whenever appropriate without being subjected to discrimination and stigma.

Treating BPD simply as a trauma-induced disorder and/or blaming parents for causing it could be extremely unproductive.

Consumers:

People with BPD self-report abuse: sexual, physical and emotional. People with BPD are often hypersensitive. People with BPD struggle to understand why they have the psychic pain they do have and search for explanations of why it is so. It is in adolescence that the symptoms of BPD are especially dominant. Adolescence can be an especially trying time for a young person seeking their independence from their family, when BPD is added into the mix, life for the young person is painful. People with BPD are often impulsive and this makes them more vulnerable to the abuse of others also, especially sexual abuse. The emotional dysregulation of people with BPD can challenge their romantic partners and they can as a result be more vulnerable to domestic violence.

People with BPD feel abused. This also includes abuse by a mental health system that does not take them and their illness seriously.

Carers:
So many parents have felt the ongoing pain of being unfairly accused of abuse. The child whether an adult or an adolescent, is often dependent upon them financially and parents will still be there to support them, knowing all the while that they are accused of being abusive. This is usually an accusation of emotional abuse but also physical and even sexual abuse.

Then, sometimes parents hear for the first time of allegations of serious abuse to their loved one by another person, as a result of a therapeutic session. An allegation which they have not heard of before.

At a recent Carers gathering (BPD Community Information Night, 26 August 2015) of the Carer's present all indicated their loved one had been previously been misdiagnosed, most commonly with PTSD.

Husbands and wives of someone with BPD, especially if they are parents, often find themselves accused of abuse of their partner and their children. Children become pawns in false accusations of abuse. A person accused of abuse can feel like a pariah and if the accusation is unjustified, the repercussions can be most disadvantageous.

DEVELOPING A CAPABLE AND SUPPORTED WORKFORCE:

Given that it is in the mental health system, both private and public, that the stigma, discrimination and prejudice that is most destructive for people with BPD and their families: this outcome is critical for the BPD community.

- BPD needs recognition as the significantly serious mental illness that it is.
- All levels of the health professions need to have up to date information and training on BPD.
- The *'Clinical Practice Guidelines for the Management of Borderline Personality Disorder'* should be the bible for those working in the mental health field.
- Given the nature of the illness, carer participation in all aspects of the mental health system relating to BPD, is essential.

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CONCLUSION

BPD Community believes that the most important difference for those affected by BPD (the consumers, the carers and those clinicians who work in the field), will occur when stigma, prejudice and discrimination are directly addressed.

BPD community identifies as a priority gaining an accurate diagnosis and subsequent access to treatment in the private and/or public mental health system.

BPD Community supports the recommendations of the National Health and Medical Research Council’s “Clinical Practice Guidelines for the Management of Borderline Personality Disorder”.

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CARER CONCERNS

Preamble:

As carers[1] of people with Borderline Personality Disorder we feel our needs are not recognised and not met. While our needs have much in common with the needs of all carers, we believe that because of the nature of BPD and because of the stigma and discrimination that exists within the helping professions, our needs are different.

BPD is a serious mental illness where the person has difficulty developing and maintaining positive personal relationships. The person with BPD will often rely heavily on the carer in a demanding and draining close relationship which can include refusing the support of and completely rejecting the carer (and other family members). Those closest to the person with BPD are often challenged in their relationship since the reliance for care can occur simultaneously with rejection, or the rejection can be so absolute as to shut family and loved ones out of the person's life completely.

BPD can be damaging to all family members and as a consequence the mental health of carers is often vulnerable.

BPD is stigmatised and discriminated against in the general community, this is complicated by a general lack of knowledge of the illness. However, it is the stigmatisation and discrimination in the services that are supposed to be a support that hurts the most. From psychiatrists to nurses, to admin staff, help line personnel and social workers, discrimination is a unifying feature of the experience of all carers and people with BPD. This is compounded by the lack of access to services and treatment for our loved ones. Given the nature of BPD, when our loved ones are ready to accept treatment, it is often not available or not appropriate to their needs.

People with BPD often have complex difficulties with co morbidity, in particular drug and alcohol related difficulties that require a dual treatment program. Depression and anxiety are familiar problems for people with BPD, as are eating disorders. A flexible public mental health system with appropriate case management is essential. If the BPD is not treated, it is recognised that the co-morbidity disorders cannot be treated successfully.

People with BPD may be living in difficult circumstances. They may be homeless, long term unemployed, in debt or suffer other living difficulties. They need supports outside of therapy, to assist them with finding employment, helping them with their accommodation, household management and budgeting. People with BPD are overrepresented in prisons. People with BPD who live in rural areas have geographic isolation and compounded lack of access to services. People with BPD may be adolescents, they may be elderly – people with BPD have age related special needs. People with BPD need more than just therapy.
We the carers of people with BPD want our loved ones to be well.

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[1] SUPPORTING PEOPLE IN CARE RELATIONSHIPS IN VICTORIA, CARERS RECOGNITION ACT 2012

WHAT DO WE WANT?

For our loved ones we want:

- An early and accurate diagnosis;
- Emergency Department response based on knowledge about BPD and commitment to the addressing needs of people with BPD;
- Treatment readily available in the adequately resourced public system;
- A mental health system (private and public) that responds appropriately;
- To be a part of the treatment process.

We want a mental health system that acknowledges that recovery is possible and that we are not the cause of our loved ones illness. We want a responsive non judgemental, non stigmatising, non discriminating mental health system with easy access to diagnosis and treatment that follows the National Clinical Practice Guidelines for the Management of BPD, and that includes us as part of the solution.

For ourselves we want:

- Training in the techniques to help us support our loved ones;
- Support for ourselves in our roles as carers;
- Access to treatment in the public health system for our own mental health needs;
- Access to the latest research and information on BPD.

We want a public mental health system that recognises the importance of the role of carers of people with BPD and is non judgemental, non stigmatising and non discriminatory. We want a system that supports the education, training, support and wellbeing of carers of people with BPD.

For our BPD community we want:

- Research on all aspects of BPD, in particular the prevalence of BPD in Australia and in special communities such as prisons or communities which have experienced trauma;
- A funded strategy to address the stigmatising and discrimination that affects the BPD community, and therefore the wider community, one that targets the clinical and helping professions;
- A public and private mental health system that is responsive to the needs of the BPD community.

We want an up to date, responsive mental health system that is non judgemental, non stigmatising and non discriminatory.

Our priority is:

To advocate for early and accurate diagnosis of BPD.