

Towards developing a National Strategy for Borderline Personality disorder- a dollar a citizen per year will get us started in the right direction

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Objective of the paper

Objective of this paper is to trigger the commencement of a debate about developing a National Strategy for the management and treatment of Borderline Personality Disorder (BPD). The overarching objective is to make treatment accessible and available for every single person with BPD in Australia.

We invite thoughts, comments, and feedback from the broader Australian BPD community. All information received will be acknowledged as part of BPD Awareness Week and will be fed into a broader process designed to create a national road map for BPD in Australia.

Communication channels for feedback are detailed at the end of this paper.

Introduction:

Borderline Personality Disorder is a serious and a complex psychiatric illness. The prevalence of BPD in Australian community is around 1-4%. Therefore there are at least 240,000 Australians with significant BPD needing urgent care. With one in five psychiatric patients having BPD, it is common in mental health clinical practice, occurring in at least 10% of psychiatry outpatients and 20% of psychiatry inpatients. Within the primary care sector the prevalence rates are reported to be four fold higher than in the general community.

BPD usually emerges during adolescence (Chanen 2009). National Health and Medical Research Council (NHMRC) Guidelines for management of BPD (2012) suggests that BPD can be diagnosed from the age of 12. A recent report (Beatson et al 2016) has highlighted that BPD is also evident in older people who are more than 65 years of age. BPD impacts both men and women, although women are more often diagnosed with BPD in clinical settings.

People who experience BPD also have high levels of co-existing mental health problems (such as depression, PTSD, drug and alcohol use and eating disorders). People with BPD

experience significant disability and have a poor quality of life. They are often unemployed. About 40% of people with BPD are reported to live in dysfunctional relationships. About 85% of people with BPD self-injure and 10% of people with BPD complete suicide. Overall, people with BPD have high rates of mortality and morbidity. People with BPD as such have miserable and painful lives when their illness is active.

BPD causes significant distress to patients and their families and friends. Clinicians working with BPD also experience distress.

Unfortunately, BPD is also one of the most misunderstood and stigmatized of all psychiatric disorders. The Australian mental health workforce is poorly trained in the treatment of BPD and as a consequence regrettably the mental health workforces also tend to contribute to perpetuation of stigma and discrimination. BPD patients compete with other patients for mental health resources and are often left behind or excluded. Most BPD patients do not receive evidence based treatments.

In spite of the fact that the plight of people with BPD is quite confronting, we do not have a national strategy for addressing their unmet treatment needs. The NHMRC developed comprehensive and a world class clinical practice guidelines for BPD in 2012. However the implementation of the guidelines in the health sector has been minimal and disappointing.

On a positive note, plenty of good research has been done in the last two and a half decades in the field of BPD. The diagnosis of BPD is now well established. Brain mechanisms that are involved in the regulation of emotions in BPD are much better understood. It is now clear that BPD is an eminently treatable disorder and several effective evidence based psychotherapy treatments are available. It is also well documented that most persons with BPD achieve symptomatic recovery. Only a few people with BPD require lifelong treatment. A 16 year follow up study (Zanarini 2012) of BPD showed that up to 99% of patients achieved symptomatic remission for a 2 year period and 78% for an 8 year period. The study also reported a very low rate of relapse of BPD after achieving a period of symptom remission.

Unfortunately there are no medications to date that are helpful and specifically indicated or patented for BPD. However there are several well established evidence based effective psychological treatments for BPD.

Overall the therapeutic nihilism of the past has been replaced with hope and optimism, at least for those who work in specialist centres and amongst the scientific community.

Challenges facing us

Given the fact that we have a population prevalence of at least 1% of BPD, we have at the minimum 240, 000 people with BPD needing urgent care and evidence based treatments. We have a mental health workforce that is poorly trained in the management and treatment of BPD using specific therapies. The Australian Mental Health Services are not

ideally set up for managing BPD. They were set up to treat major psychotic and mood disorders predominantly with pharmacotherapy. Most people with BPD get management and not evidence based psychological treatments in mental health services. People with BPD and their families face significant stigma and discrimination and are frequently excluded when they attempt to access services from emergency departments and mental health services. It is appreciated that the mental health services are struggling with inadequate resources and it is people with a diagnosis of BPD who are most heavily impacted by this. Given the high rate of suicide and self-harm characteristics of BPD and the national intent to decrease the suicide rate, attention must be given to responding more positively to people with BPD.

NHMRC guidelines suggest making a diagnosis of BPD after age 12. Unfortunately most adolescents who suffer BPD do not get diagnosed with BPD until age 18. This means precious opportunity for early interventions is lost. Prof Chanen, one of the leading global experts on BPD has demonstrated that adolescents with BPD can be treated with treatments that are appropriately developed for them.

According to the NHMRC Clinical Practice Guidelines for the Management of BPD:

'in people aged 12-18, the presence of any of the following features indicates the need for a full assessment for BPD: frequent suicidal or self-harming behaviour, marked emotional instability, other psychiatric conditions (e.g. mood disorders, substance abuse disorders, disruptive behaviour disorders or anxiety disorders), non-response to established treatments for current symptoms, high level of impairment in general psychosocial functioning, self-care, and peer relationships and family relationships.

Although some clinicians have been concerned that it may be inappropriate to diagnose a personality disorder in a young person whose brain is still developing, current evidence shows that diagnostic criteria for BPD in a person under 18 years are as reliable and valid as in adults and the diagnosis is similarly stable over time as for adults. BPD diagnosed in adolescence is associated with serious and persistent morbidity in adulthood. Accordingly, the diagnosis can be made with reasonable confidence when a person aged 12-18 years meets diagnostic criteria for BPD.

The issue of whether or not to tell an adolescent that they have BPD has been controversial. Some health professionals have preferred to withhold the diagnosis, or even when confident of its accuracy, due to concerns about stigma and discrimination the person may experience as a result of the BPD label. However, prompt disclosure of the diagnosis has potential benefits. Young people often experience relief when they learn that the difficulties they have been experiencing can be attributed to an identified syndrome and that effective treatment is available'

The guideline document further states that:

'Increased rates of identification of people with features of BPD, including adolescents with early features of BPD in primary care and emergency departments could result in early referral to a specialist, specialised and allied health services for thorough assessment and earlier diagnosis, in turn leading to prompt treatment.

Effective identification and referral to people with features of BPD would necessitate adequate access to referral services in all regions, and effective referral pathways would need to be established within each service or organisation. The availability and affordability of such services varies across and within jurisdictions.

Early detection might lead to higher rates of BPD diagnosis and treatment. The care of people with BPD will require investment in resources, additional training and services. However, early

referral to effective treatment, particularly for adolescents and young people, is likely to improve long term clinical outcomes and result in decreased utilisation of health services over the person's lifetime. In contrast, delayed or incorrect diagnosis is likely to delay effective treatment and result in high use of health services.

The diagnosis of BPD in an adolescent or young person requires youth mental health experience and expertise. Early detection is likely to lead to higher rates of BPD diagnosis and treatment among adolescents and young adults, who will require access to appropriate youth-oriented treatment services. Increased demand may result in a requirement for expansion of youth-oriented treatment services and more health professionals may be required to undergo specific training'.

There are very few specialist personality disorder services that can advocate for BPD, educate and train mental health workforce in the treatment and management of BPD. Even well-established state-wide specialist services such as Spectrum, personality disorder service for Victoria can only provide some care for about 500 people with BPD in a year. Given the context most BPD patients are and will always be, treated within generalist rather than specialist mental health treatment settings.

There is a huge unmet treatment need for BPD. Primary care sector is again not equipped to adequately detect and manage BPD. Even if detected, general practitioners (GP) are faced with a paucity of specialist psychologists, psychiatrists and other mental health clinicians who are willing and able to take on the care and treatment of BPD both in public and private health settings. Private psychologists are not adequately covered under the Medicare to provide the comprehensive and long term psychotherapy that BPD patients require. The "Better access to mental health care" initiative was not set up to adequately service the needs of people with BPD, although expanding its scope can go a long way in servicing the needs of people with BPD.

There are several evidence based treatments for BPD, but the "big four" are the most popular ones. The big four treatments include the Dialectical Behaviour Therapy (DBT), Mentalization Based Treatment (MBT), Schema Therapy (ST) and the Transference Focused Therapy. The most evidenced based treatment of all BPD treatments is DBT. It is likely that majority of clinicians who are currently treating BPD patients in Australian setting with evidence based treatments use a DBT approach. MBT and ST are also popular.

Unfortunately, DBT is an expensive treatment costing \$ 687/month and a total of \$ 8,000 per patient. If we were to organise DBT for every single Australian with BPD (taking 1% prevalence rates and 24 million populations) we need about \$ 2 billion. Although it has been well demonstrated internationally that it is cost effective to treat rather than not treat BPD, it is not easy to convince the funding bodies to come up with a new funding of \$ 2 billion to treat BPD with treatments such as DBT. It is also unclear if DBT should be the treatment of choice as it is not a treatment accepted by all patients or clinicians. We now have some evidence that there may be other less expensive treatments that are equally effective (e.g. Good Clinical Care, Structured Clinical Management, General Psychiatric Management etc.). However some experts believe that we should stick to well established evidenced based treatments such as DBT, MBT etc.

Further we do not have well-articulated models of care for management and treatment of BPD. In its absence patients often receive chaotic and non-evidence based care.

Tolkien II Report (by Gavin Andrews 2010 for WHO) stated that we currently treat 15% of BPD patients and in a chaotic manner. The report suggested that ideal treatment would be with a 30% coverage using a stepped care approach from GP to Specialist care. However this recommendation is less ambitious.

In summary BPD patients face stigma, discrimination, rejection and labelling. Care is usually limited to management in Emergency Departments, psychiatry in-patient facilities and CATT teams. People diagnosed with BPD are also often excluded from treatment at Emergency Departments and crisis services leaving their families to struggle on their own which often jeopardizes the health and well-being of families/carers. Of those who are able to access Emergency Departments, psychiatric in-patient facilities and CATT teams they often receive management only and not psychotherapeutic treatments that have the capacity to actually help them recover.

Progress that has been made so far

It needs to be acknowledged that in spite of the challenges ahead, progress has been made. Some of the highlights of the progress made so far are:

1. Last 10 years has seen a considerable interest in BPD in Australia. Ms Julien McDonald has led the establishment of the Australian Borderline Personality Disorder Foundation and has been successful in bringing together consumers, carers and clinicians advocate, debate and address the care needs of people with BPD.
2. Janne McMahon, the Patron of the BPD Foundation has been a tireless advocate for BPD and she has been a beacon of hope for BPD movement in Australia.
3. The Australian Senate has declared first week of October as National BPD awareness week. This is expected to further galvanise the BPD movement in Australia.
4. The BPD Foundation has been successful in bringing together consumers, carers and clinicians on a single platform to discuss the care of BPD across the country. Five National BPD Conferences have been held in various states of Australia and 6th National BPD conference is due in October 16.
5. The BPD Foundation is in process of forming branches in each state of Australia and currently has branches in Victoria, NSW and SA. The Foundation will then be well positioned to keep people in each state informed about services and developments in their state via the Foundation website. Each branch can progress advocacy for BPD in accordance with the needs of people in that state supported by the Foundation. The Victorian branch has compiled a guide to services in Victoria and information is being compiled detailing services in all states that can be accessed via the Foundation website.
6. The NHMRC Clinical Practice Guideline for the Management of BPD was published in 2012. This is a comprehensive and a world class guideline.
7. Prof A Chanen has established the Helping Young People Early (HYPE) program and developed clinical interventions for adolescent population. He has been strongly advocating for early detection and early intervention of BPD through the establishment of appropriate

youth services. He also put Australia on the world map by his pioneering work in early detection and early intervention for BPD and by leading the International Society for Study of Personality Disorder. He was the immediate past President of the International Society for Study of Personality Disorders (ISSPD). He is a leading advocate for BPD in Australia.

8. Project AIR initiative for Personality Disorders in NSW has been established under the leadership of Prof Brin Grenyer and it has pioneered advocacy, training, clinical interventions for BPD in the state of NSW. He has also pioneered the development of brief interventions for BPD in public mental health settings.
9. NEA-BPD Aust (National Education Alliance of Borderline Personality Disorder Australia) has been established under the energetic leadership of Ms Anne Reeve to change the way BPD is perceived and treated, with evidence-based training and education for families and clinicians. Within a short period after establishment the NEA-BPD has become very active.
10. Spectrum, a centre of clinical excellence for personality disorders is a state-wide specialist service in Australia which provides treatment to BPD patients, supports primary and public sectors mental health services, justice systems and forensics. Spectrum has played a significant role in advocating for the care of people with BPD. Spectrum provides extensive training and workforce development opportunities. Spectrum works with persons who are highly suicidal and belonging to the age group of 16-64 years. Spectrum has treated people with BPD in Victoria in the past 20 years and trained thousands of clinicians within Victoria and across the country.
11. There are also several local initiatives such as the BPD Vic Community led by its passionate President Barbara Mullen, in Victoria..
12. Prof Mears and his team in Sydney have been running services for BPD using the unique Conversation model treatment. He pioneered this treatment.
13. At least in Victoria, most private hospitals have BPD specific treatment programs (e.g. DBT) for those who have access to adequate private health insurance.
14. There have been several research publications in the field of BPD and Prof Chanen has led the research aspect of BPD in Australia.
15. There are a few places where family support services are beginning to emerge. Family Connections and Spectrum Family support initiatives are some of the examples of such initiatives.
16. The College of Psychiatrists has recently embarked on developing a consumer and carer guide for BPD.
17. Head Space programs support BPD patients.
18. Numerous training opportunities have been organised for clinicians to up skill their knowledge and therapeutic skills across Victoria, SA, NSW and WA. Several international speakers have delivered training events in several places in Australia (Prof A Bateman, Prof M Linehan, Prof A Fruzzetti to name a few).
19. SANE Australia has taken a special interest in providing information about BPD and provided a scholarship to Sonia Neale to travel internationally to explore treatment advances in other parts of the world.
20. A National BPD Expert Reference Group was set up by the previous Labour Federal Minister for Mental Health.

The above list is no doubt not comprehensive and does not cover all the excellent initiatives across the nation.

However, in summary although some progress has been made, in many states there is limited help available for people with BPD and access to care is near to impossible for most people with BPD.

Tasks ahead for us

- To increase awareness and understanding of BPD amongst the general community.
- To ensure that every single Australian who experiences BPD is able to access evidence based BPD treatments in an atmosphere that is free of stigma and discrimination.
- To ensure that every single family (parents, partners, children, carers) who have a relative with BPD is adequately supported and educated while they share and support the journey of treatment and recovery of their relative.
- To ensure that every single clinician who comes across a person with BPD during the course of their work is adequately educated, trained, supervised and supported to treat BPD using evidence based interventions.
- To replace the current stigma and discrimination surrounding BPD with hope, optimism and compassion.
- To implement the NHMRC clinical practice guidelines (2012) for management of BPD across the health care sector.
- People with BPD, their families and carers and clinicians interested in working with BPD- all should come together under a single platform to advocate for the change.
- Acknowledge that people with BPD suffer severely. Their families and carers share the burden. Clinicians caring for people with BPD are also impacted when they are not adequately supported.
- Addressing the major gaps in service provisions across Australia.
- We need to advocate for BPD and educate policy makers and influence funding bodies.
- Empowering existing health care sector (GP, public mental health services, psychology, nursing, social workers, private psychiatry etc) to respond to BPD appropriately:
- We need to advocate for inclusion of BPD in the training curriculum for psychologists, mental health nurses, social workers, psychiatrists and GPs. Colleges of psychiatrists, psychologists, nursing, social workers and GPs are all important stakeholders.
- Emergency services staff such as police and ambulance requires education and training in care of BPD.
- BPD patients can often struggle with child custody matters. Child protection services and Family and Children's courts need to be further educated regarding the impact of BPD on mothers with the disorders and their children. The protective services and courts also need to be educated re the potential for recovery from BPD and the impact of loss of child custody on mother's mental health whilst maintaining a focus on the best interests of the child.
- Children who have been subjected to traumatic experiences and or environments should receive early interventions and supports. Similarly care providers who are in those environments need education and support.

- We need to establish a BPD research centre of excellence for the nation.
- We need dedicated BPD specialist centres of clinical excellence across the nation to:
 - advocate for BPD and create awareness
 - teach and train mental health workforce and primary sector in working with people with BPD and their families/carers
 - support and resource the activities of other organizations providing education/training to people with BPD and their families/carers e.g. NEA-BPD in Australia, the Bouverie Centre
 - treat the most complex and severe BPD
 - provide consultations and supervision to clinicians treating BPD in public and private settings
 - develop locally relevant models of care for BPD
 - support and resource the Australian BPD Foundation in its BPD advocacy work
 - take up clinical research and treatment quality assurance activities
 - considering the Spectrum funding example, a recurring annual funding of \$ 24 million will help set up a national research centre and state-wide/territory wide specialist centres of clinical excellence across the nation. In other words “a dollar citizen per year” will fund the establishment of such centres across every state and territory of Australia. Although this will not provide treatment access to all BPD patients, it will help remove stigma, improve education and training for clinicians, treat severely unwell BPD patients, develop local models of care, enhance advocacy and help the existing mental health workforce to manage BPD patients better.
- NHMRC Clinical Practice Guidelines for the Management of Borderline Personality Disorder documents the following regarding Specialised BPD Services:

“where available, health professionals should consider referring people with severe and/or enduring BPD to a specialised BPD service (e.g. Spectrum Personality Disorder Service for Victoria) for assessment and ongoing care”. The NHMRC Guidelines set out the role of the specialised BPD Service as:

 - *Providing treatment for people with BPD who have complex care needs or those at high risk for suicide or significant self-harm*
 - *Providing consultation to primary care services and mental health services*
 - *Providing education, training, supervision and support for health professionals, including support for rural and remote services, education for local general mental health services, and consultation and advice for GPs managing BPD*
 - *Health promotion and advocacy (e.g. raising awareness of BPD and reducing stigma)*
 - *Providing education for families and carers and supporting them*
 - *Undertaking research to develop better treatment models for BPD*
- We need to collaborate with Coroner’s courts regarding examination of factors involved in adverse outcomes for BPD and its interaction with health sectors.
- Drug and alcohol centres should be sensitized and trained to screen for BPD
- People with BPD involved in Forensic and Criminal justice systems also need to be treated with evidence based interventions.

- We need to thoughtfully consider how the National Disability Insurance Scheme will work for people with BPD.
- Disability support pensions (DSP) for BPD are double edged swords. On one hand a significant number of people with BPD are unemployed and financially disadvantaged and require the assistance of DSP. On the other hand it has been documented that engaging in meaningful work can improve the clinical outcomes. This again requires thoughtful consideration.
- To develop a dedicated nationwide 24 hour telephone helpline for BPD and families.
- Develop a strategy for addressing BPD in rural and remote locations. Telehealth options require consideration to address this issue.

Potential solutions

- Declare BPD as a **PUBLIC HEALTH PRIORITY in Australia.**
- To develop a **POPULATION HEALTH APPROACH** to care for BPD.
- Establish a **NATIONAL TRAINING FRAMEWORK** for BPD in collaboration with existing BPD training organizations and initiatives e.g. Spectrum, NEA-BPD, Project Air, Australian BPD Foundation (A national training framework should address the needs of mental health workforce and primary sector to work with people with BPD and their families/carers. It should also train peer consumer and carer workers to provide peer support and to lead peer support groups under supervision of a clinician).
- Establish state-wide/territory wide **specialist centres of clinical excellence for BPD (such as Spectrum in Victoria)** in every single state and territory of Australia.
- Establish a National Research centre for BPD
- Develop **models of care for BPD** in health services.
- Support the Australian BPD Foundation as the BPD awareness raising organization, advocate and provider of information about education and services for people with BPD and their families/carers
- Establish a **National Suicide Registry** for BPD in order to estimate the true mortality rates for BPD in Australia.
- Commission a **National BPD treatment implementation research**
- Establish a **National Registry of all accredited and evidence based treatment providers** for BPD and make all clinicians, BPD patients and their families should have access to such a registry to enable access to currently existing treatment resources.

Questions that need to be debated

- **Short term strategy:** What changes are urgently required to be made in order to save lives where possible?
- **Long term strategy:** What is the long term strategy to achieve the goal of caring for every single Australian with BPD?
- How do we bring all stakeholders who are currently engaged in advocating for change to come together under a single banner and have a **unified approach?**

- How do we differentiate the roles of the various organizations (clinical and NGO) involved in provision of information, education, training, service provision and advocacy to best effect and encourage collaboration?
- What is the strategy for advocating with governments, political parties, various colleges and universities and health departments?
- How to best support families of those with BPD?
- How to up skill current mental health workforce and how to ensure that subsequent generation of clinicians are adequately trained in BPD care?
- Out of the available evidence globally, what particular treatment/s should be considered for a population based approach for BPD?
- Can we advocate for additional Medicare funding to help psychologists take up structured treatments of BPD in private settings?
- How can we advocate for and up skill psychiatrists so that private psychiatrists can take up structured psychotherapy utilising the currently available Medicare funding.
- Should we advocate for the model of state-wide specialist units for BPD or advocate for better care of BPD with in current mental health systems and Headspace units?
- Should we advocate for a research centre of excellence for BPD that can act as a think tank for BPD in Australia?
- How do we support early intervention programs

Following questions were raised in the NHMRC guideline document:

Organising healthcare services to meet the needs of people with BPD

- What type of services maximise effectiveness and safety and minimise harm (taking into account long-term outcomes) for the delivery of specific treatments for people with BPD? (for example, day hospitals, inpatient, therapeutic communities, use of enhanced care programming, team-based or individual based care, partial hospitalisation)
- What is the role of inpatient (e.g. acute, forensic) care in the management of people with BPD?
- What is the role of specialist services (including community-based) in the medium and long term management of people with BPD?
- Is long-term inpatient care in the treatment of BPD effective?
- Are particular therapies suited for particular service settings?
- How should healthcare professionals from other healthcare settings care for people with BPD? (primary care, accident and emergency, crisis services, crisis houses, acute care)
- Which treatment pathways, care processes and clinical principles (case management, care coordination, care programme approach and so on) maximise the effectiveness of care and reduce harm?

- How can healthcare professionals involved in the care of people with BPD best be supported? (supervision, training, caseloads and so on)

Supporting families and carers

- Do families (including children) and families/carers of people with BPD have specific care needs?
- If so, what specific interventions should be offered?
- Do family or carers, through their behaviour, styles of relating and relationships, influence clinical and social outcomes or wellbeing for people with BPD?
- If so, what interventions should be offered?

Comments, Thoughts, Suggestions and Feedback

Please email all correspondence to bpd_national_strategy@bpdfoundation.org.au

Creating a National Model of Care for BPD.

We invite comment and suggestions from our Australian BPD community. What are your priority, current gaps and needs in treatment? How do you think we can we best meet these?

Creating A National Tertiary Training Framework for BPD.

We invite comment from registered and trainee Psychiatrists, Psychologists, Therapists as well as professional body's and relevant heads of tertiary institutions to comment on this. Is there sufficient focus on BPD in the current tertiary curriculum? What inclusions would be desirable?

Creating A National Framework for Family and Carers:

How can we best support the needs of family members and carers? How important is it for families to be included in treatment? Would a 24 hour telephone helpline be beneficial? Can carers access sufficient evidence-based treatment, knowledge and skills to best support their loved ones?

Developing A Centre of BPD Excellence in Each Australian State: Is this a good idea? What are the pro's and con's of this idea? What would the ideal centre of excellence look like? What services would it offer? Would it be inpatient or outpatient? Would it cater for co-occurring disorders like substance abuse and eating disorders? Do holistic treatment approaches figure in this model?

Clinician Accreditation for treating BPD. Should this be instituted? Clinicians, carers and consumers - we invite your thoughts and experiences on this.

Australian BPD Research. What are the priority research areas and why? Is a National Centre of BPD Research the best solution or could the research sit under other mental health research organisations?

Hospital Emergency Departments, Police and Ambulance Services. We invite suggestions and comment on the services and care delivered by these front line agencies.

Acknowledgements:

Thanks to Ms Julien McDonald, Ms Anne Reeve and Guy Ellies for their most helpful comments and feedback in the preparation of this document.