Australian BPD Foundation Limited

Submission to the Royal Commission into Victoria's Mental Health System

Submitted by: Ms Rita Brown, President
Australian BPD (Borderline Personality Disorder) Foundation Ltd

Recommendations:

1. **THAT the Royal Commission's deliberations consider the needs of older persons living with Borderline Personality Disorders (BPD) to improve access to the spectrum of available services to improve their quality of living in their older years and reduce the stigma and discrimination directed towards them from many health and aged care services and;**

2. **THAT the Royal Commission's report identifies the human right for those living with BPD to be treated with respect, dignity and understanding from those who work in the aged care community and residential sectors. This requires an adequately skilled and supported workforce and;**

3. **"THAT the Royal Commission report the necessity for older persons living with BPD (who are either living in the community or in a residential aged care facility) to be given the opportunity to maximise their mental health as they age by having access to 'gold standard' clinical treatments. This recommends ongoing psychology services, other mental health and support services to maximise the quality of their remaining years. These services must be affordable and funded through the Medicare reimbursement model or, until the gap in the mental health of those older persons living with BPD has been overcome, from an ongoing Special Purpose fund.**

Introduction.

The following submission to the Royal Commission into Aged Care Quality and Safety is provided to bring attention to an at risk cohort of older Australians living with BPD (Borderline Personality Disorder), the majority of whom have lived their entire adult lives without effective therapeutic intervention for their mental illness and will enter old age in distress and most likely to distress those staff who lack understanding of BPD and the knowledge (education) on how to best support this cohort. As a consequence, they may be reluctant or unable to support and care for them in an appropriate way in either a home care setting and/or in residential aged care facilities.

THE SUBMISSION.

BPD Background

The Australian BPD Foundation is a not-for-profit volunteer run organisation. Our vision is that people with BPD are acknowledged as having a legitimate mental illness and require access to appropriate treatment and support for themselves and their families/carers.

The mission of the Foundation is to promote a positive culture to support the recovery journey of people with BPD and their families/carers. The Foundation also supports clinicians, health care personnel and researchers working in this field.

What is Borderline Personality Disorder (BPD)?

- Personality Disorders are a cluster of mental illnesses that are estimated to affect up to 5% of the Australian population.[1] BPD is one of these disorders. BPD is estimated to affect 1% of the general Australian population with the incidence of residents who would meet the criteria for a diagnosis of BPD being as high as 10% within the residential aged care population (recent [unpublished] research undertaken by Spectrum Personality Disorder Service in Victoria).
- BPD is characterised by pervasive and persistent instability of sense of self, difficulty in regulating emotions, extreme sensitivity to perceived interpersonal slights, and by impulsive and often self-destructive behaviours.[2]
- These disorders cause significant interpersonal difficulties, social and occupational dysfunction and adverse impacts on families and others.
- BPD is often under-recognised due to its presentation with common psychiatric co-morbidities including substance abuse, eating disorders, depression, anxiety, and Bipolar affective disorder.
- The impact of BPD on the wellbeing of consumers and carers is severe.[3] Consumers often live with constant and intrusive suicidal thoughts and a feeling of deep shame. Carers live with constant anxiety, lack of support and information to appropriately cope with their family members emotional dysregulation, their suicidality or self–harming and managing the impact of caring on their own physical and mental health.[4] Many carers experience vicarious trauma.

- The evidence-based gold standard for treating those living with BPD is psychotherapy. However the lack of access to such services, the onerous financial burden in seeking any private services, the invisibility of any services in the majority of regional, rural and remote locations (which particularly impacts on Australia's First Nation peoples living with BPD), the history of stigma and discrimination from existing mental health services and from general health services, coupled with an overwhelming lack of understanding and knowledge about BPD, results in the unacceptable statistics below. A situation which, unless reversed, follows those living with BPD into old aged and to an early death.
- The rate of presentations in Emergency Departments by people with BPD is very high. Recent estimates indicate that around 26% of people presenting to emergency departments for a mental health crisis have a personality disorder. [5]
- Personality disorder diagnoses is linked to a high risk of suicide – approximately 10% with many more deaths failing to meet the strict criteria for the determination of death by suicide.[6]
- Most of the research in Personality Disorders is on Borderline Personality Disorder (BPD), as it is the most commonly presenting problem to general and mental health services where those living with the disorder commonly complain about the distress and stigma in accessing and navigating the system. [7]
- As with many other Australians living with a chronic mental health condition, their physical health and life expectancy is commonly less than what could be achieved with appropriate clinical interventions and support. As a result, their overall health status and longevity is compromised. [8]
- The incidence of BPD seen in parents who come to the attention of Child Protection Services is approximately 30%.
- The incidence of BPD within forensic services is estimated to be 20% and within aged care 10% of patients in residential aged care services have significant personality disorder related clinical issues.
- The prognosis should not be so stark. BPD commonly manifests in adolescents and early adulthood, in both males and females, although the symptoms could have been present in childhood. If access to skilled and knowledgeable clinicians is available early and referral to psychotherapists can be ensured on an ongoing basis, a normal and productive life can ensue.
- The current situation in Australia does not reflect this pathway. The majority of those living with BPD approach their old aged (usually at a younger age than the rest of the population) having experienced less than acceptable supports and clinically validated interventions. [9]
- Until fairly recently the Australian, and indeed the international research, has concentrated on the manifestations of this debilitating mental health condition in the younger adult when the condition frequently reaches crisis point and urgent help is necessary. As a result, research has

focused on clinical aspects and the evidence base for psychotherapeutic interventions to enable those diagnosed with BPD to manage their condition and lead a normal life. There is a paucity of attention directed to the needs of older persons living with BPD and the voice of the older person living with BPD is muted.

BPD in older Australians.

Australian research into those with older persons living with BPD is limited. The clinical consensus suggests is a growing prevalence of borderline personality disorder in residential aged care residents with all the related difficulties in management, in staff attitudes and the stability of the residents. Beatson et al (2016) wrote: "*Staff in geriatric residential facilities, including psychiatric facilities, often lack education about BPD, their phenomenology, treatment and nursing care. The introduction of educational programs that increase empathy for the intense suffering of these patients would decrease the likelihood of iatrogenic damaged or treatment breakdown that can otherwise occur".* [10]

Improvement in this area is further compromised because there isn't a national strategy to educate health professionals to follow the published evidence based treatment guidelines. In spite of the Government monies allocated to mental health services in Australia, BPD is not recognised as a National Mental Health Priority.

It is worth noting that public sector psychiatrists in adult AMHS (Adult Mental Health Services) are limited to treat those aged less than 65 years. After 65 years those with BPD come under the remit of the aged care services in which, to date, there is limited expertise and time to deal with people with BPD in either a home care setting or a residential aged care facility.

In 2017 a UK a research reported that the phenomenology of BPD in the aged living in care settings frequently includes a continuation of the traits that were evident from the onset of the disorder although some tend to attenuate. It also stated that clinical experience revealed the disorder traits can remain with a risk to the safety of the resident, care staff and fellow residents. [11] This is not inevitable. In all settings, it depends on past access to treatment, the efficacious of the treatment regime(s), the access to specialist follow up and maintenance support, the severity or otherwise of the disorder and the presence of any co-morbidity/Dual diagnosis.

Some USA studies are more optimistic with one study *The Longitudinal Course of Borderline Personality Disorder* stating "Prior to advances in research and treatment development in the last 30 years borderline personality disorder (BPD) was historically viewed as a chronic, if not lifelong, disorder that was not amenable to change. Since this time, several small-and large-scale studies of the naturalistic course of BPD have been conducted. Generally, findings from these studies "…….. suggest that the course of BPD is much more variable and that many patients experience promising outcomes". [12]

Unfortunately, Australia cannot point to 30 years of gold standard psychotherapy treatment for those diagnosed with BPD. Here, there is a wave of older Australians who have lived with BPD and now require

community based aged care services such as that available through the Government's Home Support Program and/or Home Care Packages and others needing to move into a residential aged facility. One delegate to the 8th National BPD Conference held in Brisbane in September 2018 recounted that she had muddled through her life and now requires care and support to remain living in a community setting which she is unable to access.[13] Her trajectory is stark with premature admission to a residential aged care facility most likely where it appears unlikely she will receive appropriate treatment, care and support.

It is can be postulated that many older Australians with BPD residing in residential aged care facilities or receiving home care services, who have not received adequate treatment in their earlier lifetime, will exhibit the similar desperate traits as described in the UK study noted above. This is a disastrous outcome for them, the care staff and the aged care system. It is likely to manifest in increased discrimination against these home care clients and/or aged care residents, use of inappropriate medications, staff stress and stress on the person and family of the resident/client.

This is not the standard that reflects well on the Australian aged care system.

It requires urgent national policy directed to addressing that those growing old who have BPD to be able to obtain access to adequate mental health and physical health treatment regimens before they age. When they do age, they should continue to receive services and support from specialist services such as mental health nurses, psychologists and psychiatrists. After all, specialist services is available (albeit in short supply) for other older persons with a physical chronic physical health condition. Critically, for those with BPD, services and support should follow them from the community setting into their residential aged care facility.

It requires that those who reach old age have access to a caring and supportive aged care regime that recognises that the least restrictive and the most helpful life choice for them is living at home where they are supported by trained and skilled community staff, visiting mental health staff and have access to therapeutic services as required.

It requires that age care providers, either in the community or in residential aged care, do not discriminate against service or care for those with BPD because they may be more difficult than many other older people. The duty of care of those in the aged care systems is to all older persons. This group who have lived with a chronic mental health condition all their lives do not require psycho- geriatric aged care accommodation, just services and support enabling them to live with dignity and support in the most appropriate and less restrictive setting for the individual.

Finally, and no less importantly, Governments (especially State Governments and Territories) must address the lack of treatment to Australia's First Nation people and others who live in regional, rural and remote settings. In the overwhelming majority these Australians, whether First Nation people or other country people, have grown old without any treatment to mediate their BPD to assist them to live a

normal and satisfying life. This is an alarming statistic considering it is now the year 2019, with so much technology, aviation options and communication mediums available.

Achieving a satisfying life for older persons living with BPD can only occur if and when they can claim to have received throughout their lives respectful, supportive and compassionate mental, physical and geriatric health care across the continuum of their life regardless of where they live.

In summary:

1. BPD is a debilitating mental illness which is further compromised by discrimination from many mental health practitioners and a lack of understanding by many practitioners about it. This includes other health practitioners working in the general health services and in the community.

This comes to a head when those living with BPD grow old and have to try and access support and care through Government support packages and/or seek access to a residential aged care facility that is ill equipped to accept them because the staff are not appropriately trained to care for their specific needs.

2. Access to necessary psychotherapy services over their lifetime since diagnosis has been limited both in the public sector, where resources are obviously stretched, and in the private sector because of the consumer's financial constraints. The accepted gold standard treatment at this time is individual weekly psychotherapy sessions for 12 months and followed up as required. Currently only 10 sessions annually are covered by the Medicare. Any such therapy ceases when an older person enters a residential aged care facility.

3. As can be read above, without intervention the majority of those living with BPD and their carers lead daily lives marked with dysfunctionality, distress and, in many instances, despair. Their interactions with services personnel will likely be unproductive and disheartening, leading to further maladaptive behaviours and internal misery which will shadow them into their older years. Their carers will also experience distress and misery. The institutional model of management in the majority of current residential aged care facilities poses further difficulties for those with BPD.

4. Much could be achieved to help eliminate the distress of older persons currently living with BPD, and improving many future lives, if the Commission takes note of the 3 Recommendations and information made in this Submission and includes them in their recommendations to Government.

For further information and oral testimony please contact:

Ms Rita Brown.

Rita Brown

President Australian BPD Foundation
rbrown@bpdfoundation.org.au OR 0458 469 274

References.

[1] Howes, G. I. L. E. S., Simonsen, E., Ndetei, D., & Barrett, B. (2010). Personality disorder: a new global perspective. World Psychiatry, 9(1), 56-60.
2 American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th edition, Text Revision (DSM-V-TR). Washington DC: American Psychiatric Association; 2013
3 Lawn,S., &, & McMahon, J. (2015). Experiences of family carers of people diagnosed with borderline personality disorder. Journal of Psychiatric & Mental Health Nursing, 22(4), 234-243.
4 Bailey, R. C., & Grenyer, B. F. S. (2013). Burden and support needs of carers of persons with borderline personality disorder: A systematic review. Harvard Review of Psychiatry, 21(5), 248-258.
5 Carotte, E, & Blanchard, M. (2018). Understanding how best to respond to the needs of Australians living with personality disorder. SANE Australia
6 Grenyer, B. F. S., Ng, F. Y. Y., Townsend, M. L., & Rao, S. (2017). Personality disorder: A mental health priority area. Australian and New Zealand Journal of Psychiatry, 51(9), 872-875.
7 Lawn, S., &, & McMahon, J. (2015). Experiences of family carers of people diagnosed with borderline personality disorder. Journal of Psychiatric & Mental Health Nursing, 22(4), 234-243.
8 Bailey, R. C., & Grenyer, B. F. S. (2013). Burden and support needs of carers of persons with borderline personality disorder: A systematic review. Harvard Review of Psychiatry, 21(5), 248-258.
9 Grenyer, B. F. S., Ng, F. Y. Y., Townsend, M. L., & Rao, S. (2017). Personality disorder: A mental health priority area. Australian and New Zealand Journal of Psychiatry, 51(9), 872-875.
10 Beatson,J.,Broadbear, J., Sivakumaran, H., George, K., Kotler, E., Moss, F., Rao, S. (2016). Missed Diagnosis: The emerging crises of BPD in older people. Australian NZ J Psychiatry.1139-1145.
11 Mattar,S,. Khan,F. (2017).Personality Disorders in Older Adults: Diagnosis and Managedment. J Progress in Neurology and Psychiatry Vol 2 April-June.
12. Temes,C.M., Zanarini, M,C., (2018) Psychiatr Clin North America December 41 (4) 665-694.
13. Not known identity.

Other references:

14.Grabowski,D.C., Aschbrenner, K.A., Feng,Z., Mor,V. (2009). Health Affairs May-June 689-700
15. Kitchear, M., Willmott,M., Alamilda,M., Wong,A. (2009). Home and Community Based Services. An Introduction to Olmstead Lawsuits and Olmstead Plans. National Centre for Personal Services UCSF
16. Tyler,P., Reed,G.M., Crawford,M.J., (2015). Classification, Assessment, Prevalence, and Effect of Personality Disorders. Lancet Feb 21 385 (9969) 717-26
17. Report. Consumer and Carer Experiences of Stigma from Mental Health and other Health Professionals (2011) Mental Health Council of Australia. Melbourne. Victoria.

End.