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Submission to the ***Clinical Practice Guidelines for the Management of Borderline Personality Disorder: Public Consultation Draft***

The MHCC thank the NHMRC of providing us with the opportunity to comment on the *Clinical Practice Guidelines for the Management of Borderline Personality Disorder: Public Consultation Draft*. We welcome this work which focuses on improved responses to people with complex mental health presentations and improves outcomes for those affected.

Further to the original NHMRC notification of the development of the Guidelines, MHCC wish again to express our concerns regarding the focus on the development of clinical guidelines for the care of people with a diagnosis of BPD without a more thorough acknowledgement of the prevalence of interpersonal trauma (specifically childhood abuse) in people with a BPD diagnosis. We suggest that the Guidelines refer to the ACE study (Felitti VJ, Anda RF, Nordenberg D, et al. *Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The adverse childhood experiences (ACE) study*. Am J Prev Med 1998;14: 245—58).

### **Diagnosis / aetiology**

- 1.1. In the first instance, we suggest that the title, should rather read *Clinical Practice Guidelines for the care of people with Borderline Personality Disorder*, with the focus on 'care' and 'people' rather than 'management' and 'disorder'.
- 1.2. MHCC propose that the diagnosis of BPD be reconsidered in the light of long established research evidence supporting that assessment, treatment and care be offered within the theoretical perspective and practice framework of trauma informed care and practice (TICP). It is important for people presenting with a complex range of symptoms and behaviours, not to be viewed through the narrow focus of a BPD diagnosis (DSM criteria) or channelled through a treatment process entirely based on that diagnosis.
- 1.3. Item 5.3.2 (p.73) prioritises a lengthy diagnostic process rather than talking with the person i.e. the taking of a history. We believe that diagnostic tools / questionnaires can be extremely alienating and that after a crisis (when tools are often used). This post crisis time in particular provides an opportunity for the 'clinician' to engage in a genuinely therapeutic way. It provides a window to understand a person's difficulties, distress and other symptoms and intervene appropriately rather than risk the possible re-traumatisation from a questionnaire type process.
- 1.4. Item 5.1.3 (p.70) states that "a diagnosis should be communicated when confident it is correct." Our position is that 'symptoms' or more appropriately 'presentations' need to be understood in light of the consumer's lived experience and that naming a diagnosis is generally less than useful. What is more, it is clear from the case notes of people with BPD and consumer stories that the diagnosis of BPD is generally one

of many that they may have received over time, and may carry concurrently. In particular this diagnosis is often used in a pejorative way, and one that has been stigmatising and regularly resulted in discriminatory practices. The release of the Guidelines will not necessarily change these practices.

With the advent of e-health records, it is even more important that consumers be provided the necessary psycho-education including from a trauma informed perspective. Such an approach will enable them to be supported, rather than be labelled and so minimise the risk of stigmatisation and re-victimisation.

- 1.5. Whilst the DSM and/or the ICD as shown in tables 1.1 and 1.2 (p.34) describe the presentation of a group of people with a range of affects and behaviours, we question the framing of interventions based on diagnostic frames alone. We would rather recommend interventions based on an understanding of what happened to a person to have affected them so profoundly. Extensive research has shown that a medicalised response to people impacted by trauma with an emphasis on symptoms, clinical assessment and diagnosis alone limits both perspective and outcomes. We propose that a more holistic approach be adopted. That is one that takes into account the co-existing problems, and that understands people in the context of their compounded presentation, especially given that recognition and integration of trauma is fundamental to the recovery process.

## **Research/ models**

- 2.1. Despite the extensive review of research evidence undertaken in preparation of these Guidelines, there appear to be some serious gaps in the material included. Most of the evidence is gathered from international sources. The Australian context with particular reference to Aboriginal people with a BPD diagnosis is not evident. The guidelines use the ADAPTE process, searching for guidelines related to the treatment and management of borderline personality disorder which revealed two guidelines, one developed by the American Psychiatric Association (APA), and another in the United Kingdom by the National Institute for Health and Clinical Excellence (NICE). The Guidelines chose the NICE guideline which systematically reviewed the literature and “performed favourably” when assessed with the AGREE instrument. Therefore, the Guideline funder agreed to adapt the NICE guideline. Nevertheless, we suggest this provided a narrow focus excluding some extremely important evidence relating to people presenting with the consequences of childhood trauma with a diagnosis of BPD.
- 2.2. For example, section 6.1 Psychological Therapies for BPD lists a range of models and 6.1.2.2 mentions in passing that other models such as the Conversational Model are advocated and practiced. However such models have not been included in the evaluation or guidelines. This is of particular concern since the research provided by Professor Russel Meares and his followers presents a strong evidence base for remarkable outcomes. We suggest that a number of research studies available from the website below are considered for inclusion in the Guidelines:  
[http://www.psychevisual.com/Video\\_by\\_Russell\\_Meares\\_on\\_Defining\\_The\\_Conversational\\_Model.html](http://www.psychevisual.com/Video_by_Russell_Meares_on_Defining_The_Conversational_Model.html)  
The Conversational Model is a model of psychotherapy suitable for treating personality disorder. This model is built around the nature of self and trauma systems with its theoretical basis in experiential, neurophysiological, developmental and linguistic data.
- 2.3. Likewise, there is little reference to the important work of International trauma experts such as Babette Rothchild, Bessel van de Kolk and John Briere, which inform the

latest thinking in the field of trauma. We refer to the specific comments outlined in Dr Richard Benjamin's submission to the NHMRC draft Guidelines, which clearly outlines the deficits in the proposed Guidelines and with which we are in total agreement.

- 2.4. Similarly, Judith Herman's ground-breaking work on the understanding and treatment of trauma has not been included, despite its relevance. Reference to her work concerning Complex PTSD to describe the symptoms of long term trauma, is particularly applicable to adult survivors of childhood sexual abuse most commonly diagnosed with BPD. *Trauma and Recovery: From Domestic Abuse to Political Terror* ((Herman, J. Pandora: 1998).
- 2.5. Item 2.3 expresses the view that empirical research concerning psychodynamic therapy is "limited because they are hard to standardise." In our opinion this is not so. There are many studies that provide evidence around the efficacy of psychodynamic therapy with positive outcomes being particularly related to the quality of the therapeutic relationship. Such studies include those conducted by Shedler, J. The Efficacy of Psychodynamic Psychotherapy. University of Colorado Denver School of Medicine; American Psychologist, Vol. 65. No.2. & Leichsenring, F, & Rabung, S. Effectiveness of Long-term Psychodynamic Psychotherapy: A Meta-analysis. JAMA. 2008; 300 (13):1551-1565.
- 2.6. We propose the core principle that all treatment and care is trauma-informed. Item 3 p. 49 deals with the general principles for treatment and care of people with BPD, referring to the process of therapy as a journey, and describes many of the difficulties consumers may have in engaging with therapists and ending treatment; the model proposes a structured, time-limited treatment plan generally for 3 months. We suggest that this is unrealistic, with ongoing therapy often being needed for recovery. Since the recommendation in the Guidelines points to DBT, in its purist form as advocated by Marsha Linehan a DBT program should run for 2 years to provide the outcomes necessary in terms of distress tolerance and skills acquisition (1993; 1998).
- 2.7. Item 6.1.2 (p.81) describes the various psychological treatments which have been evaluated. Once again we emphasise the gaps in models reviewed including that of Narrative Therapy. This therapy has been used in clinical settings with people with a diagnosis of BPD. There is some new work being undertaken concerning the efficacy of narrative exposure therapy compared with "treatment as usual" in the treatment of patients with complex traumatic disease (borderline personality disorder (BPD) and posttraumatic stress disorder (PTSD)) as assessed by structured clinical interviews, which is well worth investigating. Evidence already exists concerning positive outcomes for survivors of childhood abuse using this model (Pascual JC, Malagón A, Córcoles D, Ginés JM, Soler J, García-Ribera C, et al. *Immigrants and borderline personality disorder at a psychiatric emergency service*. Br J Psychiatry 2008; 193: 471– 6.
- 2.8. It is clear from the evaluation of models (Item 6.1.1 p.75) that there is 'no one size fits all' model, e.g. DBT is not effective in reducing self-harm (6.7 p.98). Despite this, a number of models are evaluated which have only some evidence of efficacy, and yet psychodynamic therapy is excluded due to the perception of being hard to standardise. This would not appear to be a comprehensive presentation of the evidence.
- 2.9. The Summary of BPD Interventions (tables 6.5-6.9 pp.93-102) provides very useful evaluations across numerous outcome domains. However, it is difficult to assess the

overall performance of the models in the following discussion 6.3.2 (p.103). Perhaps a chart might assist services in considering the best training and models to utilise. The recommendation that DBT is the best comprehensively effective model on the basis of its overall performance is understood. Nevertheless, it is clear from consumer evidence that where a person has had the financial means to access long-term psychotherapy (complex trauma/ relational models) this has been what has provided the best outcomes and in many cases been life-saving.

### **Settings/ role delineation**

- 3.1. We welcome the recommendation in the Guidelines that people with BPD should not be diverted to specialist BPD services, but that they should be cared for across a diversity of mental health settings. Further, we would like to stress the importance of community managed services in this regard.
- 3.2. The Guidelines refer to the particular healthcare settings in which the Guidelines apply (1.6 p. 36). We stress the importance of recognising the diversity of the mental health services which are available. These Guidelines need to acknowledge the range of mental health professionals who work in the community managed sector e.g. social workers, counsellors, and psychotherapists. Many have extensive experience in domestic violence/sexual assault services and counselling and are well placed to work with clients with a diagnosis of BPD. Many consumers may prefer to access services via community-based services without clinical referral and their choices should be supported. In this way consumers may experience less stigmatisation and discrimination.
- 3.3. Trauma-informed programs and services internationally represent the 'new generation' of transformed mental health and human services organisations and programs which serve people with histories of violence and trauma. It has been clearly shown that recovery is possible when a strengths-based model is used rather than the deficits based model based on diagnosis. These guidelines do not reflect a strengths-based approach but rather perpetuate the view of people with BPD are difficult to work with. From the point of view of mental health workers, the value and rewards in working with this group of people needs to be acknowledged in the Guidelines.
- 3.4. Item 2.2.3 (p.46) refers to consumer defined treatment goals and suggests that "people with BPD should be involved in identifying their own treatment goals and management plans." We suggest that under a model of recovery orientated practice that consumer directed goals around recovery are a key principle, and that self-determination is supported wherever possible bearing in mind the different obligations under states mental health legislation. The treatment goals in 2.2.1 (p.46) which focus on behaviours and emotional regulation should also include addressing all impacts of complex trauma, including grief and loss and psychosocial problems. This is alluded to in paragraph 3 p.48 which refers to the "adoption of behavioural criteria to measure BPD pathology and the effects of treatment may cause significant interim effects to be overlooked and not understood." However, this more holistic approach is not addressed in the Guidelines.
- 3.5. Item 3.2 (p.49) refers to adult survivors of childhood sexual abuse who have BPD having special needs. No explanation of those needs is included nor assisted by the general principles in table 3.1 in a way that adequately expresses the approach needed in working with adult survivors.

- 3.6. Item 3.4 (p.51) suggests that people with BPD “are sensitive to feeling rejected and abandoned.” In our view this minimises the degree to which people with BPD experience feelings of abandonment which are frequently at the extreme end of the spectrum. It may take a very long time for consumers with complex trauma to build the trust and rapport necessary to undertake therapeutic work. In the first instance, treatment should be tailored to meet individual needs, as well as be available for as long as necessary to facilitate and maintain safety. This is particularly important to ensure that consumers do not disengage from services altogether because of feelings of abandonment.

### **Assessment/ safety**

- 4.1. The Guidelines do not highlight the importance of the relationship towards recovery, irrespective of the model. The importance of the relationship between therapist and consumer and the length of time needed to establish safety and trust in order to secure positive outcomes are crucial. Borderline presentations generally occur on a background of severe relational trauma. Such trauma can often only be addressed through long-term work which addresses attachment issues.
- 4.2. The guidelines focus on structured interview and techniques that secure a diagnosis rather than assessing the concept of ‘self’ and the impact of trauma on current issues. Without exploring the impacts of trauma on self it is difficult for consumers to understand themselves, their relationships to others, to the world or their life experiences. The more a client can understand what has happened to them the greater the possibility for them to make sense of their feelings and behaviours. With that in mind, we suggest that a three month intervention is very limited and likely to be less than effective if not re-traumatising.
- 4.3. Further to this, referral to a psychologist via the number of sessions now available under Better Access through Medicare is but a short term ‘band-aid’. Premature termination of clients who can no longer access the service due to lack of funds, is likely to trigger severe abandonment issues. Survivors attest to the benefits of building trust through a long-term secure relationship with a therapist towards recovery. Whilst expensive, long-term benefits in-terms of reduction in self-harming behaviours, need for crisis interventions and hospitalisation and the repercussions of poor emotional regulation are far more substantial in human and economic cost.

### **Adolescent/ family issues**

- 5.1. Item 1.5 refers to the target population for the Guidelines which include adolescents 12-18 years. We express concern regarding establishing a diagnosis in young people, and especially a diagnosis of BPD and the possible long-term outcomes for people stigmatised from early youth with such a diagnostic label.
- 5.2. Whilst acknowledging the importance of the sentiments expressed in Item 3.8 (p.62) related to family and carer involvement, especially in relation to young people we suggest that attention is paid to an awareness of the repercussions of family dysfunction. This particularly pertains to issues concerning power and control, secrecy and grooming that may have occurred during an abusive childhood as well as issues concerning memory or lack of memory of abuse histories particularly when the trauma occurred in a pre-verbal context.
- 5.3. Adolescents in particular may not be in a position to express preferences regarding family involvement. In cases in which there is suspicion of abuse within a family context, service providers should be cautious about advocating strongly for their

involvement. See last paragraph on p.62 stating that “services should continue to support and collaborate with families and carers, even if consent has not been given.”

### **Neurodevelopment/ pharmacotherapy**

- 6.1. The study conducted by Widom, et al., (2009) referred to (p.64) suggests that “physical abuse and neglect, but not sexual abuse predicted BPD.” We would argue that a substantial review of the literature suggests otherwise.
- 6.2. Noting item 2.1.3 (p.46) on the aetiology of BPD and the “potential role of trauma in abnormal neurodevelopment” we suggest that the Guidelines fail to provide the necessary emphasis on this critical aspect.
- 6.3. Item 4.1.2.3 (p.66) concerning neurobiological research is extremely scant. There is a lot of research which provides substantial evidence of clear and consistent explanations regarding developmental pathways to BPD but it has not been concluded. The extensive work of Louis Cozolino, 2002. *The Neuroscience of Psychotherapy: Building and Rebuilding the Human Brain*; and *The Neuroscience of Human Relationships: Attachment and the Developing Social Brain* (2006) provide evidence concerning these matters and would be useful inclusions in the understanding of brain development in response to complex trauma and of BPD symptoms.
- 6.4. Likewise the “non-specific factors” described in item 4.1.2.5 (p.67) concerning adverse experiences during early childhood as “a risk of a range of mental health problems and mental illnesses,” could do well to be described in detail particularly related to the work of John Bowlby, 1988, *A secure base: Parent-child attachment and healthy human development*.
- 6.5. Item 6.2 (p.84) provides a summary of evidence on pharmacotherapy for BPD. We recommend that there is substantial evidence particularly concerning the use of anti-psychotic medications that needs to be reviewed. We refer to Livesley, J. 2012. *Moving beyond Specialised Therapies for BPD: The Importance of Integrated Domain-Focused Treatment* and the references cited in his paper for further information. Summaries such as this fail to address the unique nature of individuals who present for help at mental health services.
- 6.6. The table concerning recommendations: pharmacotherapy (Item 6.2.3) in R.12 states that “medicines should not be used as primary therapy for BPD, because they do not change the nature and course of the disorder.” Whilst acknowledging that medication may be necessary as an adjunct to psychological therapy, it is important for the Guidelines to provide guidance to staff in the criminal justice system where for many inmates presenting with ‘challenging behaviours’ this may have been the only treatment utilised.

### **Other comments**

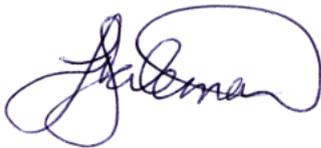
- 7.1. We fully understand the difficulties concerning the cost of providing long-term interventions for people with complex needs with a diagnosis of BPD in the public mental health system. However, we suggest that the cost to the individual, families and the community is much greater if not addressed in a way that will prevent the cycling in and out of mental health services, emergency admissions and interactions with the criminal justice system. The costs of unrecognised and untreated complex trauma are enormous in terms of not only reduced quality of life, life expectancy and

lost productivity, but in significant increases in the utilisation of medical, correctional, social, and mental health services. In 2007 alone, the cost of child abuse to the Australian community is conservatively estimated to be at least \$10.7 billion (Report by Access Economics, *The Cost of Child Abuse in Australia*, Australian Childhood Foundation & Child Abuse Prevention Research Australia at Monash University, 2008).

- 8.1. As a penultimate comment we suggest that despite the eminence of the advisory organising committee (1.7.1 p.36) that there is little evidence of consultation outside of the group. We consider that it is a real omission that consultations with a wide range of professionals who work with trauma survivors were not included in the development of the Guidelines.
- 9.1. Finally an alphabetical bibliography would be most useful, as it is hard to find authors from the reference endnotes.

MHCC thanks the NHMRC for their interest in our comments and expresses its willingness to provide any further information and be consulted in the future in relation to this initiative.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Jenna Bateman', with a large, stylized flourish at the end.

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