

## THE SOCIAL AND ECONOMIC BENEFITS OF IMPROVING MENTAL HEALTH.

Submission prepared by the Australian BPD Foundation for the

Productivity Commission into Mental Health April 2019

### INTRODUCTION

The Australian Borderline Personality Disorder (BPD) Foundation is pleased that the Commission is considering the role of mental health in supporting economic participation in enhancing Australia's productivity and economic growth.

Our Not For Profit Foundation was established a decade ago to work towards more effective and evidence based treatment and support services for those living with BPD and to promote the voices of those, their carers and clinicians who support them.

We look forward to this opportunity to contribute to the Commission's deliberations by highlighting the issues of those living with BPD many of whom live with other co-morbidities, their carers, friends and others who support them.

As well recognised by the Commission, the incidence of mental illness in our community and the opportunity costs of not allocating sufficient resources to tackle this. The issues paper states that *"Almost half of all Australian adults have met the diagnostic criteria for an anxiety, mood or substance use disorder at some point in their lives, and around 20% will meet the criteria in a given year (ABS 2008)"*. We find it concerning that this figure of 20% does not appear to include many of the complex and severe mental illnesses such as personality disorders and schizophrenia.

The fact that only 8 percent of total Government resources is directed to mental health expenditure and if you include personality disorders and schizophrenia well over 20% of Australians experience mental illness in any one year means that so many with a mental illness are not provided with timely and appropriate supports and treatments to aid in prevention, recovery and their capacity to lead a life worth living. This is starkly evident with those living with BPD.

### WHAT IS BPD

- BPD is a common mental illness 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-harming behaviours<sup>1</sup>.
- BPD commonly manifests in adolescence or young adulthood, although the symptoms may have been present and undiagnosed or misdiagnosed since childhood. Thus, it impacts on those on the cusp of their productive lives

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<sup>1</sup> American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th edition, Text Revision (DSM-V-TR). Washington DC: American Psychiatric Association; 2013

- Personality Disorders affects up to 6% of the population<sup>2</sup> and borderline personality (BPD) affects at least 1%. These are complex mental illnesses which frequently present with other psychiatric comorbidities including substance abuse, eating disorders, depression, anxiety, and bipolar affective disorder<sup>3</sup>.
- Approximately 10% of people with BPD will die by suicide<sup>4</sup>.
- 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 mental health crisis have a personality disorder, while 25–43% of adult inpatients and 23% of adult outpatients in mental health facilities meet the criteria for BPD<sup>5</sup>.
- The incidence of BPD seen in parents who come to the attention of Child Protection Services is approx. 30%
- The incidence of BPD within forensic services is estimated to be 20% and within aged care 10% of patients in inpatient units, residential care services and nursing homes have significant clinical issues related to a personality disorder<sup>5</sup>.
- The incidence of BPD in regional, rural and remote areas of Australia is difficult to quantify, unless it is manifested in an extreme way, because of minimal or non-existent services, the stigma and discrimination attached to the diagnosis, the general under provision of specialist services in these locations and the reluctance to seek help by those at risk.
- The incidence of BPD in Australia's First Nation peoples residing in rural and remote sites is doubly concerning because of the disadvantage they endure in their everyday lives.
- The poorer physical health status of those with BPD lead to more utilisation of general medical services, pharmaceutical services and to longevity less than a comparable age cohort.
- high rates of gender and sexual diversity in individuals with bpd. A study by Frias et al<sup>6</sup>(2016) concluded sexual diversity related to BPD to be independent of identity disturbance and this cohort experiences the burden of double discrimination from society<sup>7</sup> and mental health clinicians<sup>8</sup>

### In summary:

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2 Tyrer, P., Mulder, R., Crawford, M., Newton-Howes, G. I. L. E. S., Simonsen, E., Ndeti, D., & Barrett, B. (2010). Personality disorder: a new global perspective. *World Psychiatry*, 9(1), 56-60.

3 Quirk SE, Berk M, Chanen AM, et al. Population prevalence of personality disorder and associations with physical health comorbidities and health care service utilization: A review. *Pers Disord* 2016; 7: 136–46.

4 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.

<sup>5</sup> [Missed diagnosis: The emerging crisis with Borderline Personality Disorder in older people.](#)

J Beatson, J Broadbear, H Sivakumaran, F Moss, E Kotler, and S Rao. *Australian and New Zealand Journal of Psychiatry*. Dec 2016;50(12):1139-1145.

<sup>6</sup> Frias, A., Palma, C., Farriols, N., & Gonzalez, L. (2016). Sexuality-related issues in borderline personality disorder: A comprehensive review. *Personality and Mental Health*, 10, 216-231. doi: 10.1002/pmh.1330

<sup>7</sup> World Health Organisation. (2016). FAQ on Health and Sexual Diversity: The Basics. Retrieved October 6 2017 from <http://www.who.int/gender-equity-rights/news/20160517-faq-on-health-and-sexual-diversity.pdf>

<sup>8</sup> Shelton, K., & Delgado-Romero, E. A. (2013). Sexual orientation microaggressions: The experience of lesbian, gay, bisexual, and queer clients in psychotherapy. *Psychology of Sexual Orientation and Gender Diversity*, 1(S), 59–70. <http://dx.doi.org/10.1037/2329-0382.1.S.59>

Those diagnosed with BPD are among those with the highest usage of mental health services, drug and alcohol services, emergency departments, intensive care units, housing, shelters and the justice system<sup>9</sup>. Some population cohorts endure more adversity and lack of treatment and support from clinicians because of where they live, how they live and the lack of support and a caring community. They have severe and continuing disability with a poor quality of life and for them, and their families face many adversities. People diagnosed with BPD experience prejudice and discrimination in mental health services, general health services, from other professional groups, and in some parts of the general community. These groups often compare the behaviours of people with BPD with other mental illnesses, saying that their problems are not 'real' or a 'serious' mental illness and that their state of distress or disability is not sufficiently severe to warrant access to treatment within the mental health services. Many people diagnosed with BPD say that they are ignored and blamed for their illness<sup>10</sup>. These attitudes further compound their sense of shame, lack of self-worth and their experiences of discrimination.

The impact of BPD on the wellbeing of consumers and carers is severe.<sup>11</sup>

- Consumers live with constant and intrusive suicidal thoughts. They often find deliberate self-harm to be the most effective way to manage their emotional distress, pain and shame. Although this often brings short-term relief, it frequently has real and severe long-term consequences both for their mental health and physical well-being. It has further consequences for their relationships with families, carers and healthcare providers;
- Carers frequently live with constant anxiety, lack of support and information to appropriately support their family member or friend's suicidality/self-harming and minimise the impact on their own physical and mental health.<sup>12</sup> Often the family dynamics become dysfunctional adding to the distress, anger and chaos experienced by all. The concept of a whole of family support and training system to support them is lacking and so the carer and the family members may develop vicarious trauma themselves.

In reality, it is not only the mental illness aspects of having BPD that impacts on the immediate circle of those living with BPD. It encompasses the full spectrum of a daily life and living for all. The impact is both personal and financial. These impacts in turn have far reaching consequences to the person's

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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 <https://www.yourhealthinmind.org/getmedia/e4a256bf-e2b8-4870-8ee5-54fd0a1d3acc/Borderline-personality-disorder-YHIM.pdf.aspx?ext=.pdf>

11 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.

12 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.

12 Carotte, E., & Blanchard, M. (2018). Understanding how best to respond to the needs of Australians living with personality disorder. *SANE Australia*.

life time productivity and the broader economy. This is clearly shown in the Impact Statements from a sample of those who live with BPD. See Appendices 1-6 included at the end of this submission.

### **The far-reaching effects of mental illness on the productive life of an individual**

Mental illness adversely influences the ability of a person to have a capacity to lead a productive and satisfactory life of their choosing. It also influences the quality of living on a range of people beyond the individual affected. As the Commission has alluded to we suggest an appropriate metaphor to describe this effect is to consider the ripples in a pond when a stone is dropped into the water. The effects of the ripples are most keenly felt – and more readily identified – closest to the point of impact. However, these effects radiate outwards far beyond the point of impact and often become harder to quantify. Nevertheless, the Impact Statements (appendices 1-6) provide a snapshot of this.

In regard to BPD, the majority of the social emotional and financial impact of BPD is felt by the person with BPD, where the impact can range from absolute and enduring, to mild and sporadic. In addition, very often, close family members (in particular parents, children, spouses and siblings) also experience a significant impact with a similar range of severity. Broader family members, friends, work colleagues and health professionals are also impacted to varying degrees. Issues already identified by the Commission including a lower probability of being employed, absenteeism, higher utilisation of mental and general health services, decreased life expectancy of 20 years are all relevant when considering the overall impact of BPD on a person's capacity to contribute to the Australian economic productivity.

Over the lifespan of a person with BPD their ability, unless diagnosed and treated consistent with the evidence based guidelines developed in 2012 by the NHMRC<sup>13</sup>, to maintain steady employment and provide for a level of financial security, superannuation nest egg and to meet life's exigencies is greatly diminished. They are frequently totally reliant on the welfare system (or the financial support of family and close friends) are without home ownership, and resources to manage their declining years. Their housing viability is precarious with a risk of homelessness, particularly when residing in the private sector and because of a limited supply of public sector housing stock.

Put simply, it is much more difficult and in some cases impossible to lead a full and productive life when the person is un- or misdiagnosed (exposing the individual to unnecessary treatments and services), either because there are no available services, the services provided are insufficient to meet the demand or some services discriminate, based on diagnosis, against people with BPD ; the person cannot gain or maintain a job because of regimented employment conditions; they live with that fear of homelessness, and the family ties have broken down irrevocably.

### **The costs of BPD to the economy**

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13 <https://nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality-disorder>



The paucity of research on the financial ramifications for those living with BPD and their carers means that it is difficult to quantify. There is some research into other mental health conditions, but they cannot be easily extrapolated into a BPD case study.

Australian research<sup>14</sup> undertaken in 2017 reported, across a number of studies, a mean cost saving of treating BPD with evidence-based psychotherapy was USD \$2,987.82 per patient per year. AUD\$4000/yr. A further mean weighted reduction of USD \$1,551.37 per person per year was found compared to “treatment as usual”

Long term follow up studies show us that the most common outcome for people with BPD is remission and recovery with 60% achieving recovery at 10years. With evidence based treatments up to 80% will achieve remission in 1-2 years.

One Australian research dealt with youth suicide<sup>15</sup>. The reference is included here because of the high rate of youth suicides who also have been diagnosed with BPD. One caveat, it did not include the incidence of attempted suicides requiring hospitalisation. So, this study’s costs are an under representation.

As the Commission will already be aware, suicide is the leading cause of death among Australians between 15 and 24 years of age and a recent study estimated the economic cost of youth suicide (15–24 years old) for Australia using 2014 as a reference year measured the total economic costs of 307 youth suicides in Australia was estimated at \$22 billion a year with the average cost per youth suicide valued at \$2,884,426 (including tangible costs and indirect costs (average loss of 62 life years and close to 62 years of productive capacity).

Spectrum and the Victorian Coronial Prevention unit conducted a collaborative study of BPD related suicides in Victoria for the period 2009-2013 and reported an average of one BPD suicide per week in Victoria (246 deaths) and 98% had contact with mental health services one year prior<sup>16</sup>.

A study<sup>17</sup> by Spectrum the Personality Disorder Service for Victoria has reported 1123 BPD presentations to Eastern Health emergency departments during the year May 2015-April 2016. 700 of the BPD presentations were unique individuals (38% were repeat visits). (Eastern Health provides hospital services to the eastern suburbs of Melbourne).

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<sup>14</sup> Meuldijk D, McCarthy A, Bourke ME, Grenyer BFS (2017) The value of psychological treatment for borderline personality disorder: Systematic review and cost offset analysis of economic evaluations. PLoS ONE, 12(3): e0171592

<sup>15</sup> Kinchin, I., Doran, CM. The Cost of Youth Suicide in Australia (2018) International J Environmental Research Public Health. April 15 (4) 672.

<sup>16</sup> Rao, S and Broadbear et al – Personal communication

<sup>17</sup> Broadbear et al (unpublished) Personal communication

Despite the fact that personality disorders account for 10% of all suicides in Victoria it remains a hugely neglected area within mental health and receives only a fraction of the budget allocated for suicide prevention.

Another study<sup>18</sup>, this one from The Netherlands estimated the direct BPD related costs of 88 persons in an outpatient setting and found the lost opportunity costs disturbingly high.

Other costs fall under the headings of:

- Morbidity (other physical health costs)
- Private hospital costs
- Private Health Insurance Costs (for some)
- Forensic psychiatric institutions costs
- Disablement costs
- Disability costs
- GP costs (includes non-bulk billing costs)
- Medication costs
- Social services costs (Disability payments/Unemployment benefit payments/Rental Assistance and other assistance payments/Age pensions and similar)
- Out of Pocket medical expenses and/or consequences of their lifestyle
- Occupational loss costs
- Informal and formal care costs

There are also the intangible costs to the individual and families as already raised such as:

- The loss of family cohesion and sense of belonging.
- The costs of feeling stigmatised and less worthy than other people which is amplified by the lack of access and treatment from many health professionals in the mental health and general health sectors and there is no joy in their life, just fear, misery and a sense of abandonment.

It is in today's remit for Governments to start lessening this reality.

*Firstly*, they could support having a National Policy for BPD and an action plan to address this mental illness that impacts on so many young lives.

*Secondly*, they could endorse and promulgate the Clinical Practice Guidelines which were developed in 2012 and they have dormant since that year. Associated with that there could be a restriction on Medicare Payments on clinicians who operate outside these guidelines without a valid reason for doing so.

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<sup>18</sup> Van Asselt, A.D.I., Dirksen, C.D., Arntz, A., Severens, J.L. The Costs of BPD: Societal Costs of Illness in BPD patients. (2007). European Psychiatry. October 22, 354-361. The Netherlands.

*Thirdly*, they could increase the Medicare benefits for psychology services from 10 sessions per year to 40 sessions per annum to maximise the treatment gains able to be achieved through a recognised psychotherapy program to those with BPD<sup>19</sup>.

*Fourthly*, and no less importantly, they could have the NHMRC commission targeted research into the evaluation of BPD treatment regimens as well as the economic costs and benefits of them.

*Fifthly and Sixthly* Governments could, as mentioned before:

Provide an increase in general funding for mental health services and directed to the BPD agenda coupled with pre-agreed output targets and KPIs backed by a stronger commitment from government to support those affected with this condition. Just tipping more monies into the mental health bucket may have some benefits but a designated and targeted program backed by hard data emerging from the action goals set would result in stronger and earlier results.

Have a community wide awareness communication program which in effect promulgates the concept that developing BPD has no boundaries and does not discriminate between the rich and the poor and that with early diagnosis, appropriate treatment and support the prognosis for people with BPD is positive.<sup>20</sup>

Personality disorders are not effectively treated with medications.<sup>21</sup> The most effective treatment for people with personality disorders is psychological treatments with an emphasis on psychoeducation and life skill training. There is no 'quick fix'. The medicalisation of the health care system biases the use of pharmaceutical therapies to treat mental health conditions. These treatments can be effective for depression and anxiety, but there is little evidence to support their effectiveness for treating personality disorders. Ineffective pharmaceutical treatment can result in poorer outcomes (e.g. increased sense of hopelessness) and higher risk of suicide in people with personality disorders.

### **A strategy for increasing productivity in the workplace by addressing mental health issues**

There is no doubt that in Australia work gives meaning to life. It provides a sense of self-worth, of achievement, of belonging and purpose.

Employers want reliable employees who stay with their employers and 'pull their weight' while those employees with BPD want a sensitive employer who operates a caring

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<sup>19</sup> <https://nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality-disorder>

<sup>20</sup> Ng FYY, Bourke ME, Grenyer BFS (2016) Recovery from Borderline Personality Disorder: A Systematic Review of the Perspectives of Consumers, Clinicians, Family and Carers. PLoS ONE 11(8): e0160515. <https://doi.org/10.1371/journal.pone.0160515>

<sup>21</sup> Chanen AM, Thompson KN. Prescribing and borderline personality disorder. Aust Prescr. 2016 ;39(2):49-53

workplace. The views of other employees towards their colleague who has BPD is an important consideration also in defining the culture and ethos of a workplace. So changing the workplace is a complex societal issue which cannot be undertaken by fiat.

A key issue which is hard to quantify is unreported discrimination in the workplace or a lack of understanding amongst employers towards those affected by mental illness. This is particularly an issue for family member carers of those afflicted by BPD, where a lack of understanding of BPD and mental illness in general and its effects on carers, combined with the lower “discernibility” of such effects can have a compounding impact on productivity. Whereas, an individual afflicted by mental illness may be able to provide an employer with medical evidence of a formal diagnosis in order to access sick leave entitlements, family member carers are often unable to “prove” their suffering and the challenges they face.

Regarding providing easier access to personal leave for mental health purposes, often those with BPD, whether directly or indirectly, find it difficult to obtain leave from work for mental health reasons without feeling stigmatised. The impacts of BPD are not often discernible to others, in the way that say having the flu is, and therefore employers are more likely to question employees regarding absences. Making it easier for those affected by BPD and mental illness in general to access leave entitlements without having to feel stigmatised prioritises self-care, which is one of the most important ways for effectively managing mental health.

Also, employers should concentrate on the workplace culture, respect employees for the contribution they can make, being aware about mental health issues in general and BPD in particular because it is a disorder of the young person who has less work experience and understanding of a positive work environment, to provide leadership in setting the standards of all employees. This includes having a Code of Conduct to cover Communication standards, Discrimination standards Workplace Health and Safety requirements including the Mental Health Safety for all staff and Employee Assistance options. Employers need to ensure that effective and transparent Human Resource Management policies are in place so that employees with a mental illness and also carers are clear about their right and privileges to take personal leave. In this this day and age of blended families and kinship groups, personal and Bereavement Leave should stretch to allow leave for non-blood family members.

To best address these issues, we feel the Commission should consider a two-part strategy:

1. A targeted education campaign for employers concerning the impacts of mental illness of their staff and/or family members carers; in addition to the benefits of investing in a mentally healthy workplace.



For instance, a study undertaken by PwC and Beyond Blue in 2014<sup>22</sup> found that for every \$1 a workplace spent on making their workplace healthier, they recouped \$2.30 in productivity gained over the long term. Spreading the awareness of such findings would offer employers better insight into the importance of investing in mentally healthy workplaces and would in turn lead to increased productivity.

2. Legislative change to:

- a. provide for easier access, for all employees, to use annual or personal leave entitlements for mental health purposes; and
- b. place a requirement for employers to consider workplace mental health – including considering the impacts on carers – on par with workplace physical health and safety.

With regards to legislative change to place workplace mental health on equal footing as workplace physical health and safety, a survey conducted by TNS Social Research<sup>23</sup> in partnership with Beyond Blue in 2014 found that while 76% of employees surveyed believed their workplace was physically safe, only 52% found it to be mentally healthy. This would suggest that creating mentally healthy workplaces is under-prioritised by employers, to the detriment of their employees and overall productivity. As highlighted above, a healthier workplace leads to significant productivity gains over the long term.

**A greater investment in mental health in the workplace will deliver net benefits to productivity**

The Commission's own estimates show that approximately 4.1 million Australians suffered from mental illness in the 12 months to 31 March 2018, which equates to over 16% of the population. Despite this, as outlined above, less than 8% of Australia's total government health expenditure is directed towards mental health services. In our view, this represents a gross underinvestment. It relegates the majority of those with a mental illness into a role of a second class citizen because they cannot work and so be a productive member of the workforce. It results in family members shouldering a greater responsibility for paying for and/or providing care and support (treatment, housing, basics of living) to those experiencing mental illness. So having far reaching negative impacts to the economic productivity of the nation.

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<sup>22</sup> PwC and BeyondBlue (March 2014), "Creating a mentally healthy workplace – return on investment analysis". Accessed online from [https://www.headsup.org.au/docs/default-source/resources/beyondblue\\_workplaceroi\\_finalreport\\_may-2014.pdf](https://www.headsup.org.au/docs/default-source/resources/beyondblue_workplaceroi_finalreport_may-2014.pdf)

<sup>23</sup> TNS Social Research and BeyondBlue (2014), "State of Workplace Mental Health in Australia". Accessed online from <https://www.headsup.org.au/docs/default-source/resources/bl1270-report---tns-the-state-of-mental-health-in-australian-workplaces-hr.pdf?sfvrsn=8>



The Australian BPD Foundation is of the firm belief that increasing spending on mental health care will provide a net productivity benefit to the country and such an increase therefore should be considered a necessary investment into Australia's economic future.

For BPD, directing resources towards treating mental illness early in the illness with appropriate evidence-based psychotherapy delivered by mental health professionals with appropriate skills and training as well as providing psychoeducation and support to families and carers minimise many of the negative impacts to a person's productive life before they occur. Directing resources by having effective mental health promotion as part of the community's health literacy and a responsive, accessible integrated clinical treatment pathways for people with BPD Australia wide is far more efficacious than continuing the present fragmented state described in this submission.

In conclusion, the Australian BPD Foundation opines that the time has passed for the continuation of the adverse life consequences including not being able to live a mental healthy life and one where they and their carers experience extreme disadvantage and are weighed down daily. This is both an economic and moral argument, one that hopefully will be in part resolved in the recommendations arising from this Productivity Commission's deliberations.



## IMPACT STATEMENT – PRODUCTIVITY COMMISSION - LIVED EXPERIENCE 1

My BPD journey began when I was around 15. Self-harming, sudden and unexplained outbursts of anger and rage, disassociation and problems with relationships and social situations. Although I was bright, I struggled at times at school, due to depression, lack of motivation, difficulty concentrating and struggles with friendships and peers. I started drinking at this age, stealing alcohol from my parents' wine cellar, I think in a vain effort to try to regulate my emotions, and had my first drug overdose on Paracetamol. Thankfully I threw that up at the time, as now I know that a Paracetamol overdose can actually slowly kill you through liver failure.

My journey continued throughout my adult life. It was insidious and subtle, always lurking in the background, waiting to pounce or infiltrate my life when situations arose that I found difficult to handle, or even just everyday functioning. When I was in my early 20s I began to experience anxiety and agoraphobia. Depression was a constant battle. Ongoing feelings of emptiness, loneliness and isolation plagued me almost daily and affected so many aspects of my life. Things that people take for granted such as family, relationships, friends, work and even planning a holiday or going shopping were an ongoing struggle for me. I continued to self harm until my late 20s. I recall turning up for work in long sleeves on a hot day, or wearing a wrist brace, constantly having to invent stories about RSI and “feeling the cold” to cover up my superficial, self-inflicted cuts and burns.

The mental health system and “the system” in general let me down enormously throughout the remainder of my adult life. I will attempt to simplify my experiences for the sake of space and time. At those times when I was acutely unwell, and experiencing severe emotional dysregulation and depression, I was handcuffed by police as well as had a police woman throw a bottle of water over me whilst laughing with her colleagues in the back of a police van, shackled and restrained by hospital staff and mental health workers

and drugged against my will (I was once given a drug that I had a pre-existing allergy to...when I tried to tell the psychiatric liaison staff member this she told me to be quiet and gave it to me anyway. This woman is lucky she still has her registration and job as I was too unwell at the time to take the matter further).

The icing on the cake was in the last four years. I had in total three suicide attempts. I recall my first attempt, the paramedic came to my house, burst into my bedroom where I was lying on the bed, semi conscious, and immediately started to rifle through my drawers, bed, belongings and person, I believe searching for evidence of what I had taken (I had had a polypharmacy overdose). When she eventually found the empty packets, she looked at me as though I was scum, threw the empty packets on the floor and proceeded to force me to walk to the ambulance trolley. At this point I recall collapsing. My second attempt I recall being semi conscious in the back of the ambulance, and overhearing a male paramedic say there was a person potentially having a heart attack near to my house and they should be attending to them as they had “a real emergency”. My last suicide attempt, almost two years ago to the day, was the most serious one. I ended up in intensive care on a ventilator for two days and apparently almost died. The upshot was, I was discharged home the day after being taken off the ventilator, to an empty house, with 3-day (yes, 3-day) follow up from the CAT Team. Unfortunately these experiences are often the case for many people with BPD who find themselves in the public health system, often through sheer ignorance. This is combined with a negative culture of blame and punishment that exists within the system, and a general lack of care and empathy for extremely ill individuals.



## IMPACT STATEMENT – PRODUCTIVITY COMMISSION - LIVED EXPERIENCE 2

If you met me now you wouldn't know that I had Borderline Personality Disorder. I don't even fit the guidelines for diagnosis anymore. However, if you had met me from between the ages of 10 and 27, you would have seen that I was a very unwell person.

When I was a small child, I started to develop what I now know was extreme anxiety, manifested very strongly in physical symptoms – migraines, vomiting, insomnia. My childhood environment was chaotic – my dad had his own (undiagnosed) mental health problems, and would often come home from work in a rage, screaming, throwing things, verbally and physically abusing us. My mum was so caught up in managing him that she had no time for my feelings or problems – everything was an inconvenience. Despite all of this, I managed to get by. I finished high school with a high score, and was accepted into university. When I began Uni, I couldn't manage my problems anymore.

I had very high hopes for myself. To escape my toxic home, I wanted to have an excellent career that I could support myself with. While studying at Uni, I fell apart. I had severe episodes of depression – I couldn't function, I slept all day. I went to the GP and was put on an antidepressant, and sent to a Psychologist. We talked a lot about my life and my childhood, and the way I felt, but it didn't help much. After taking a leave of absence from Uni and then decreasing to part-time study, I graduated with a degree. This is when my behaviour got out of control. I started my first full-time job, and my sense of identity was non-existent. I began smoking cigarettes heavily, using painkillers and benzodiazepines to manage anxiety and physical symptoms; engaging in risky and dangerous sexual behaviour, and over-spending. Eventually I was sent on to a psychiatrist who diagnosed me with Bipolar II Disorder. I was started on a mood-stabiliser, which made me feel terrible.

At the end of my first working year I was not coping, and quit my job. I took a small overdose of benzodiazepines and ended up in a Psychiatric hospital, where my diagnosis of Bipolar II Disorder was reinforced; I was discharged on more medication. Now unemployed and with no ability to work, but a strong desire to, my life became a constant turmoil of getting a new job, lasting two weeks, and then collapsing in a heap. I spent most days sleeping and binge eating. My inability to maintain romantic relationships, the loss of previously strong friendships and an inability to make new ones, as well as my family's frustration with my condition caused a loneliness I almost can't bear to remember. Self-harm began to take a place in my life in the form of what I call 'mini-overdoses'; I was in and out of psychiatric hospitals. Medical professionals were sometimes kind and sympathetic; other times, very open that they felt I was attention-seeking and causing my own problems. Sometimes my anxiety was so severe that I could not stand or sit – the only time the intense dizziness was abated was if I was lying down. I despaired constantly over my lack of career success and what I felt was a life being wasted.

At one stage, I was seeing a psychiatrist who had me on around eight different medications to cover any possible psychiatric diagnosis. I was a walking zombie. I had done some research online and felt that my symptoms seemed to align with BPD – she told me this could not be true, as I was a kind person, and those people had no empathy, were manipulative, and could not be treated. Shortly after this, sick of all the medication's side effects, as well as complete lack of efficacy, I stopped everything cold-turkey. I became violently ill, and for the first time cut myself deep enough to need

to go to the ED and have stitches. This time, I was admitted under a new Psychiatrist who told me gently that he thought I had BPD. I thought my life was now truly hopeless.

Roughly the next two years were incredibly difficult. I still believed so strongly that the 'right' mix of medication would make me better, despite being told that it really won't help BPD all that much, and the clear evidence that it had not. I began doing a DBT course, and that was the beginning of me truly understanding BPD, and the way my mind worked – why it jumped to places that other people's minds didn't seem to go to. The self-loathing, the flashbacks of trauma, the lashing out to take the horrible feelings away from myself because they were unbearable. It was mirrored back to me in other members of the group, and after two courses and roughly a year, I had a good understanding of my condition, and my behaviour had begun to change. I still had horrific anxiety, and it got so bad that I was again hospitalised and treated with ECT, which was a very difficult experience. I still was unsuccessful in maintaining steady work, even though I constantly tried; I estimate at this point in my life I have had at least 20 – 25 jobs.

Eventually I realised there were things I could only talk about with a female psychiatrist, and by some stroke of luck, I found a psychiatrist who seemed to truly understand trauma and BPD, and most importantly, empathise with it. She helped me see how a lot of the things I had blamed myself for, and internalised, were not my fault, and that I grew up in an abusive household. She believed, as did many of the therapists I worked with during the DBT course, that BPD was wholly treatable and that I had hope – and slowly I began to as well.

I'm now 32 and married to a wonderful person. I have a professional job I am proud of, and I have been able to rebuild some friendships that went by the wayside during my hardest years. I take a small amount of medication which helps manage the anxiety that I still – and may always – live with. I have travelled and achieved things I never thought I would. I honestly thought by this stage I would have suicided, or still been in the state I was. But I'm not; I live a life with happiness and purpose, most importantly, I finally love and accept myself, which always seemed like the most unobtainable goal. Even though I feel like I "lost" over ten years of my life to this illness, I know that I am lucky to be where I am at my age. It breaks my heart to know that other people are going through what I did, with that feeling of hopelessness so intense that it drives you to destroy yourself. Reduction in stigma, and thus early intervention, is the key. I dare any mental health professional to look at me and say that recovery from BPD is hopeless. Understanding, compassion and correct treatment is the key to people recovering earlier, and losing less of their life – and most importantly, staying alive.



## IMPACT STATEMENT - PRODUCTIVITY COMMISSION - LIVED EXPERIENCE 3

I was first diagnosed with Borderline Personality Disorder (BPD) in the year of 2007. I was fresh out of high school, and I was told this would be 'the year of my life'. Unfortunately, this was the year I first attempted to end my life. Having no recollection of ever hearing the term 'Borderline', I was a lost teenager trying to come to terms with living with an untreated, excruciatingly painful, draining and stigmatising disorder.

The impact it has had on my life has been instrumental in my recovery now. However, this 'road to recovery' nearly came at a cost- losing my life on many occasions. I was quite late into being led to dialectical behavioural therapy (the leading therapy that manages a BPD diagnosis), so the thirteen years of being in the mental health system has not been simple to navigate, to say the least.

Majority of my transition to adult hood was me trying to navigate an illness that had very little accessible treatment and very little understanding of the complications that came with the illness. Majority of my years were spent in isolation, suicidal states and reoccurring self-harming episodes. These cycles would occur depending on the stability of my life. Due to not having access to DBT (or ever being introduced to that early intervention), these cycles would tear at the safety nets I tried so desperately to keep around me.

While searching for treatment, my financial stability was often minimal. I was living off disability payments on and off for a large period of this time in my life. However, caused more distressed as this was also not always easy to access. I spent a lot of my adulthood in psychiatric facilities, being heavily medicated. I spent a lot of time in fear for my life as I did not have any guidance in how to self-manage my BPD diagnosis.

When BPD is left untreated, it is quite difficult to keep jobs, build on relationships, work towards a future when you don't foresee one. Financially, navigating BPD has left me often relying on income from family and close friends. I felt a lot of shame as during this time of my life, people around me could not quite understand why I didn't have stability when it came to income and standing on my own two feet.

The time that it took to eventually be led to life saving treatment was thirteen years. Thirteen years I was hospitalised thirty times. Thirteen years I believed I was going to never make it out alive. Thirteen years I have been subjected to discrimination and stigma.

I eventually discovered a space where I could voice my illness to help and educate others. Speaking out was instrumental to leading me to the right treatments such as Dialectical Behavioural Therapy (even though I originally had to wait 6-12 months to access this). Still, time was of the essence and I thrived in this intensive treatment. DBT eventually lead me to become a peer support worker. Thirteen years it took me to create a career. It took a lot of my high school peers 4-7 years to finish their degrees, find stability and lead what society feels is a 'normal' life. I spent 4-7 years trying to figure out how to stay alive.

I can happily say I am the most stable I have ever been. I have a fiancé, a wonderful role in peer support and advocacy work. However, I spent a long time feeling a pain I wouldn't wish upon any human being.

I hope this letter can help the BPD space move forward and can help people lead a life worth living. I hope this letter can buy some valuable time to avoid the pain I had to experience. I am a great example of how recovery can be achieved if the right tools are in place.

BPD Advocate and Peer Support Worker



## IMPACT STATEMENT - PRODUCTIVITY COMMISSION – CARER 1

I write this document in order to contribute information to your study and help you to understand to extent of costs in terms of income, living standards, social engagement and connectedness to the broader group around those with poor mental health.

E was not diagnosed until she turned 18, but we knew she was suffering since around the age of 11-12. It has been a long and arduous road for E, and her father and I. The journey's impact on E has been enormous, as it has been on me, as her parent/carer - my relationships, work and finances, family, and more recently my care of E's little boy G.

Despite the emotional cost of E's mental illness, and all the feelings involved in our story, I will endeavour to keep this document as concise and factual as I can so that it may be of use to you in your information gathering.

I work full time and have been in the same position within the same amazing NFP for the last 6.5 years. I love my job and I know that I am well regarded. As well as stable employment it has also been a huge relief to go there at the beginning of each day, just to escape the chaos that seems to surround my daughter's world and that sucks all that love her, into it.

I have often wanted to expand myself in another role within my employment, to take up the opportunity to obtain study leave, and grow as a person and contributor to this organisation. I was offered a role, working with a varied group of people I admire, to take on more responsibility, and to push myself, as well as earn more money. I refused this offer and have let countless opportunities pass me by since. I think back and reassess all the time - could I have done it, was it just me stopping me, was I overreacting by not thinking I had the capacity to take on additional workload, responsibilities etc. the simple answer is no. I couldn't do it in the past and still can't. I am not master of my own destiny as we all aspire to be. Hospital/dr/specialist appointments, suicide watch, self education around mental illness and accompanying drug use and just the many times when I had to be wholly present to cuddle and hold, to endlessly walk around the block talking with my girl to keep her safe and grounded, not wanting her to self harm or turn to the illicit drugs that numb her internal pain.

These and my now 4 year old grandson (son of E, who has been in my sole care since 3.5 months) are the same reasons I gave up my volunteer position in the Emergency Department of Box Hill Hospital after 3 years and also gave up attempts to volunteer in a small capacity for the Australian Borderline Foundation National Conference organising committee.

These are the reasons I neglected my own health and self care. Why, when going through my own rigorous Cancer treatment, doctors decided to keep me hospitalised longer to ensure I got the chance to recuperate that I would not have been given at home with my daughter. And why I was never able to attend any of the wonderful support groups available. It's why I can't attend any of the support groups for carers of mental health or kinship care. I was either bombarded by distressed or abusive phone calls, didn't know who would be at my home when I got there, or what state my beautiful girl would be in, or more recently I'm just too damn tired and depleted.

I am a young at heart and fit as a fiddle (these days as I get closer to the conclusion of active treatment) 54 year-old. I have things I want to do, I have things i need to do (including putting aside and growing funds to support me in retirement). I want to have friends, I want to learn, I love to DIY around my home, to read the paper, to travel, to volunteer, to take on

more at work and contribute to an organisation I truly believe in.... to have the opportunity to be a fulfilled and productive person.

And I want this for my family as well. I want them to laugh and learn, to have healthy relationships, to have a strong moral and ethical code, a connectedness to community (both local and global) and be generous of spirit. We as a country need to be promoting a healthy, inclusive and **happy** community, including those without a mental health concern and well as those with, in the solution. We need to think outside the box to create incidental change and not limit approach to professional 9-5 expensive, all too often tried and tired methods.

Thankyou for asking for examples of lived experience and giving carers the opportunity to change the world (for their treasured family members with mental illness, and for those that live it beside them).



## IMPACT STATEMENT - PRODUCTIVITY COMMISSION - CARER 2

### The Social and Economic Benefits of Improving Mental Health

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#### In scope for this inquiry – Personality Disorders

##### Focus

- Suicide prevention
- Measures that could improve the integration and continuity of support for particular groups, such as people with severe, persistent and complex mental illness, and which could better take into account the episodic nature of some mental illnesses.

##### Assessment components

- Consequences of mental health
- Effectiveness and cost of current programs and supports
- Gaps in current programs and supports available
- Likely effectiveness of alternative programs and supports

#### **‘An appropriate stitch in time saves plenty when it comes to BPD’**

Many people with a personality disorder are inadequately supported in Australia’s current mental health system. Not only is there great human distress here (for themselves and those around them) but this is costing Australian health services unnecessary expense. Lack of training and support for clinicians, and limited services means issues are not addressed – and fester to become entrenched mental ill health, and often end up with physical health problems as well.

The people living with mental illness withdraw from participating socially and economically, carers and family members may also withdraw from the workforce to support them, In addition, many clinicians and workers become demoralised in a system that is overburdened and insensitive to the actual needs of their clients. The system no longer seems ‘person-centred’, rather it appears to be about the KPI’s.

#### **My background**

My daughter was 28 when she passed away 2 years ago from complications directly related to her Borderline Personality Disorder (BPD) diagnosis. I will tell you more about the failings of mental health systems for her later in this letter.

BPD has a **genetic** component - her father also has BPD.

The overall picture is one of so much lost hope and sadness. Her father and I met in our teens, married at 21, bought a house and 8-9 years later had two children. We were both employed, intelligent and future oriented, subdividing our block and building an investment home. Unknown to us at the time, his BPD was triggered by feelings of abandonment due to my attention on the children, and my Librarianship studies at University. We separated,

twice, then divorced. He attempted suicide (more abandonment) which led to his diagnosis. He was working at British Aerospace at the time. From two independent people, with two properties, we both ended up on Centrelink benefits (DSP for him, and for me it was Single Parenting Payment, Carer Payment, then Newstart after my daughter passed away). We no longer own the houses (lost to the financial settlement and substance abuse to further bury feelings associated with BPD.) We both live in our separate Housing Trust houses.

I have recently re-entered the workforce full-time – at the age of 58. He has never returned to work and my daughter never worked. My son - with an IQ of 136 at 6yo - has been so traumatised by what he saw and heard, that he has only managed one part-time job in the past.

This illness has the potential to be very damaging for many people if it is not taken seriously, and not treated early. The coping strategies become entrenched, and life ends up being so much more than all the soap operas you can imagine. And so much that we could have contributed to society has also been lost.

When my children's father was finally diagnosed the psychiatrist didn't even explain BPD to us, he thought it was a hopeless diagnosis. Their father was not offered therapy, only medications. We were offered no strategies, and no hope. **Education and training is still needed for health professionals in the area of personality disorders.**

Many years later when our daughter started showing signs of BPD I asked **CAMHS** to treat her with therapies tailored for people with BPD and was told that was not possible, as treatment cannot be given without a diagnosis, and as she was under 18 that was not possible. Thank goodness our mental health system has come a long way since then. She also received no therapy, only medications to subdue her self-harming was offered to her by Streetlink (youth homeless medical service in Adelaide). This started her dependence on substances.

My daughter had a long history of contact with **SA Mental Health**, initially as a 12 year old through Child & Adolescent services, and later as a teenager presenting repeatedly by ambulance with drug/alcohol or as a 'walk-in' to ED Emergency Departments for self-harming behaviours.

She also had consistent contact with **DASSA**, but the cycling between SA Mental Health and Drug & Alcohol services was inadequate and damaging at best. (Neither wanted to take her on, unskilled? understaffed?) **We need services to collaborate** - rather than the continual referring to each other, and the non-admission that neither service can support clients with a dual-diagnosis.

Due to her mental illness and self-medication with prescription and illicit drugs, she had ongoing concerns around **accommodation** and ended up living in on the streets. A few years later, after a detox in a private clinic, she moved to an SRF Supported Residential Facility (not really suited for people with BPD) and a Boarding House in Elizabeth (too little care, and the move meant workers could no longer visit her in shared accommodation. She had to catch 3 buses to get to their office, hard for anyone, let alone people struggling with

mental illness). After a visit to ED, she was referred to a 'CRC' Community Rehabilitation Centre for mental health (Wondakka). Due to inadequate understanding of her illness, and conflicting principles with DASSA, she was evicted in June 2015 to homelessness – again. So much hope was dashed, right there. It took so many years for her to get to that point, only to have inadequate services abandon her once again.

Our family believes her diagnosis was the reason she was denied access to many services that could have supported her to recovery. The consequence of not addressing her needs ended up costing the SA public in terms of the expense of other services that were funded by the SA and Australian Governments and which ended up picking up the pieces for us -

- Medicare (weekly GP visits & Mental Health Care Plans)
- SA Ambulance
- Hospital – ED presentations and admissions
- SA Community Mental Health
- DASSA (Drug & Alcohol Services SA)
- NGO's (Non Government Organisations) –support workers for her
- Carers SA - respite for me
- PIR (Partners in Recovery)

And how was I? Life was very lonely. I felt isolated. My relationship dissolved, he couldn't take the drama and chaos any more. My son did not want to come home because of the intensity. He felt guilty for having a life and doesn't want to share with her what he is doing. So many people around the person with BPD feel the ripples of the disorder.

I have been advocating for people living with BPD and their families and carers for some years now. I have a short list of some services I think would really help:

### **CONTRIBUTING COMPONENTS TO IMPROVING MENTAL HEALTH AND WELLBEING**

- REAL collaboration between Mental health & Substance abuse services
- Day Centres  
Self-determined, activity places to spend time, learn skills, stigma free.
  - <https://thehavenproject.org.uk/>
  - [https://www.researchgate.net/publication/304250389\\_Recovery\\_and\\_Borderline\\_Personality\\_Disorder\\_A\\_Description\\_of\\_the\\_Innovative\\_Open\\_Borders\\_Program](https://www.researchgate.net/publication/304250389_Recovery_and_Borderline_Personality_Disorder_A_Description_of_the_Innovative_Open_Borders_Program)
- Accommodation  
Residential mental health services, which provide overnight specialised mental health care in a domestic-like environment (p11 in Issues Paper)  
SRF's in SA are more suited to people with intellectual disabilities. People with mental illness experience periodic of being unwell. They do not need to be treated as if they are not capable or intelligent.

As part of the stepped system of care – consider when people are exited from CRC's it could be helpful to offer the option of shared accommodation. I wonder if everyone

wants to live alone...instead of going into their own Housing Trust home, perhaps people could be given the option of being housed WITH others? Group homes, with staff who visit daily?

## **STRUCTURAL WEAKNESSES IN HEALTHCARE**

- **Funding**

When funding expires, projects end, and workers move on. This is really hard for people with BPD because they place their trust, open up themselves to start doing the necessary work of looking at themselves, and then the worker leaves. This feels like abandonment for someone with BPD.

- Mental Health ED's separate from medical ED's
- Walk-In mental health clinics – 24hr
  - <https://static1.squarespace.com/static/5b6a7f7e71069901ea5ef1eb/t/5bbd68cdec212dcf29072aea/1539139794585/Safe+Haven+pres.pdf>
  - <http://www.northbrisbane.pirinitiative.com.au/wp-content/uploads/2014/02/Safe-Space-Final-project-report-2017.pdf>
  - [https://www.researchgate.net/publication/233724355\\_Community\\_alternative\\_s\\_to\\_acute\\_inpatient\\_care\\_for\\_severe\\_psychiatric\\_patients](https://www.researchgate.net/publication/233724355_Community_alternative_s_to_acute_inpatient_care_for_severe_psychiatric_patients)
- Service like Headspace for people 25-40
- Aged Mental Health Care for people over 65
- 10 Mental Health sessions through Medicare is not enough.  
For people with complex mental health, at least the option to have 40 sessions per year should be able to be accessed.



## IMPACT STATEMENT - PRODUCTIVITY COMMISSION - CARER 3

### The Costs

1. Of enormous concern to us is Sexual Abuse Support Services for Children that Disclose Peer Familial Sexual Abuse needs reform based on our experiences in the system that have prolonged our suffering. We feel betrayed by the current system in place that does not view the issue of peer sexual abuse from the **innocent** child's and family's perspective. We are isolated and alone in bringing this issue to the fore. We remain in the mental health system as we grapple with the silence and secrecy, stigma and shame and try to access promptly the correct treatment for our daughter as she develops her adult personality. **This is at the root of her and our family's dysfunction also putting her younger sister at risk of mental wellbeing problems.**

The clinicians and myriad of experts and professionals I visited over the course of nearly five years (before diagnosis of emerging traits of BPD) did not take my concerns seriously as her Mother and seemed completely flummoxed despite knowing my daughter had been sexually abused by her cousin and my own family history (my sister was diagnosed with schizophrenia in the 1970s). They failed to disclose the strong link between sexual abuse and the likely development of Borderline Personality Disorder. We were not alerted at any stage to this proven strong scientific link. We were discharged from SECASA as being effectively healed; However, there was serious neurological damage caused during the time of rapid brain development and our daughter suffered as she kept the secret of peer sexual abuse secret. We should have been told what to look out for. And treatment needs to be prompt to stop this illness in its tracks whilst the child is developing their adult personality.

My daughters behaviour improved temporarily after been dismissed by SECASA in terms of she no longer blamed herself for what had happened to her, yet as she hit the teenage years it was clear she was experiencing a crisis. Self-harm, running away, emotional and physical abuse, promiscuity, disordered eating, suicide ideation and depression, anxiety and angry outbursts and school refusal were daily behaviours over a period of years. We were a family in crisis. This was not 'normal adolescent behaviour'.

There is a growing body of scientific evidence that there is a very strong link between mental health and adverse childhood events and in particular sexual abuse. **This should have been a red flag to services that my daughter was in a high-risk category yet it took seven years to get an eventual diagnosis and handle on her behaviour in spite of my**

**persistence and perseverance and at an enormous cost to my own mental health.**

Our daughter sustained neurological damage at a key time in her development. Her innocence and childhood was taken away from her. She was the victim of a criminal act regardless of the age of the offender and whether he is culpable or not. The crime of '*sexual penetration of a child under 16*' is what has now been reported to the police, only as of last month (February 2019). The law does not state that the act of rape is age specific. No action has been taken as this child (our nephew) is also a victim and not culpable under the law. However, the effect on our daughter of this violation is as if it was performed by an adult. Had this same act been committed by an adult who was culpable the current sentencing laws here in Victoria are fifteen years imprisonment according to my research. Most importantly our daughter might have received a very clear message **she did nothing wrong** instead of what has transpired in this tragic case of two children - both victims, but one child completely innocent, necessitating completely different responses from both sets of parents, the wider family and clinicians and especially specialized sexual health services, to ensure both children are given the required support to prevent long lasting damage to them **and** to avoid putting other children at risk and perhaps to even catch a perpetrator who may be responsible for the offending child acting out what he was subjected to, or witnessed either first hand or by looking at pornography online.

This **same** response to both children is a huge flaw in the system and keeps the more innocent child's carers/parents family locked in a victim cycle of seeking acknowledgement and support when a criminal offence has occurred regardless of culpability. Those who have the courage to bring this difficult subject out into the light need support but the crime is being denied, minimized, trivialized by the offender and his family and indeed the wider family and society. In our case it was put down to curiosity or normal childhood exploration. It was not. Far from it.

**2. Of further concern is the specialized services are acting for both child victims so use language that negates the more innocent child's experience.** SECASA told us to refer to the event as 'inappropriate sexualized behaviour' or 'harmful sexual behaviours'. This downplaying of the seriousness of the act and same response is extremely damaging to the more innocent child and serves to protect the offending child first and foremost. This only serves to solidify in the more innocent child's mind that she was somehow to blame. It is difficult for a child to make sense of what has happened to them. Use of this language is not upholding the human rights of the more innocent child. In protecting the offending child, they are further victimizing the more innocent child particularly when the act committed on

my daughter is defined under law 'as sexual penetration of a child under 16'. And it occurs within a family setting which should be a source of support when trauma happens and not the cause of further trauma because people minimize it and dismiss it because of the use of this minimizing language. This makes it easy for friends and family to turn a blind eye and they too are coercing by not referring to it as what it is - the serious crime of sexual abuse. Family and clinicians need to know they have a responsibility to speak up on behalf of the violated child too. They need to be educated about this. The language can be different for both children without minimizing one child's experience and adding to the message that they did something wrong. They did not. The other child did.

The terms 'inappropriate sexualized behaviour' and 'harmful sexualized behaviour' minimizes the severity and does nothing to acknowledge the link to the trauma and possible long-term impact of the non-culpable child's actions on the non-offending child. This was not a case of normal developmentally appropriate childhood curiosity or playing 'Doctors and Nurses' or 'I'll show you mine if you show me yours'. The act performed on my daughter 'oral rape' is classified as sexual assault in Victorian Law. Her cousins told her not to tell anyone. The effect on my daughter is the same as if it was performed by an adult. It is peer sexual abuse and there are serious long-term mental health effects clearly documented. We need to call it what it is. It is disempowering and counterproductive for the more innocent victim and can add to suffering and lack of support and access to appropriate diagnosis and mental health treatments at a crucial time when the brain is developing. This needs to be addressed immediately and with the purpose of preventing further trauma to victims and secondary victims.

**3. To this day we have had no feedback that the perpetrator victim had the necessary intervention to make family gatherings safe let alone any apology or acknowledgment he is aware of the seriousness of his childhood actions.**

We cannot re-enter the wider family as it is an unsafe environment when **we do not have access to the knowledge as to why this child acted as he did due to privacy issues**. There is nothing forthcoming from his parents to us or indeed via SECASA. We have been left in complete and utter isolation not knowing if this other offending child is at risk or has indeed continued to offend with other children. Has he had the appropriate support and intervention? There are also other young children in the family who may be at risk. The moral burden that falls on us should we ever choose to re-enter and participate in the wider family is to be care-takers to other children which is not fair on us. We do not know (we suspect there is) if there is another predator within the family that would account for the



offending boys' actions. We do not want to be part of the silence that breeds this crime. We cannot 'move on' or 'bury it' as we have been advised by family members we have confided in as our daughter has suffered severe psychological distress that needs ongoing specialized treatment.

Clearly the services attempt to protect and support both children without acknowledging one child is completely innocent and has been the victim of a heinous crime and often incurs lifelong psychological damage in the same way child victims of adult perpetrators do. There may be an argument from the perpetrators point of view to refer to it as 'harmful sexual behaviour' but from the non-consenting child victim's point of view who asked this child to STOP from their point of view they have been a victim of a criminal act and heinous crime.

**There is a massive distinction on how both child victims and their families should be supported and responded too to avoid mental health crisis and the ripple effect of this silent crime in our communities and how it perpetuates due to the secrecy.**

4.. **We were advised not to report this 'incident' to the police.** We had no intention of charging this child, our nephew who is also a victim in the eyes of the law as he was under 10. However, he committed a serious violent crime against another child. If a seven-year-old set fire to a house that is a crime. He may not be culpable but it is a crime. Clearly the offending child is also a victim. The message we received was 'He does not deserve to have this on record **as if she does**'. Where does that leave my husband and myself What happens if he abuses someone else. Where is the footprint to protect other children and indeed the child himself who is obviously in crisis if he is re-offending? What happens to this offending child if his behaviour goes unchecked? Where is the accountability that he knows the seriousness of his actions and that he won't re-offend? The inference is 'boys will be boys'. Or he was 'curious'. This curiosity destroyed my daughter's childhood. Words as such 'he deserves to get on with his life which implies she does not'. She almost killed herself. She was in crisis. This might ruin his life without acknowledging it has already ruined my daughter's childhood. My daughter did not recover from the neurological damage that happened during the time she help the secret. Clinicians used minimizing language making her us doubt the gravity of what she had endured.

**The non-offending innocent child has been the victim of a criminal offence. A criminal offence was committed but the person cannot be held criminally responsible because he was under 10 at the time. It must be made mandatory to report it especially as we as parents of the violated child deserve to know if it is a safe environment to re-enter and**



**that the issue has been dealt with openly and the child has had the appropriate intervention and is safe too.**

I have taken it upon myself to get this justice through an application on her behalf to Victims of Crime which is currently in progress.

**THE COST OF THE ACT OF FAMILY PEER CHILDHOOD SEXUAL ASSAULT ON OUR DAUGHTER (Primary Victim), and to her IMMEDIATE FAMILY (Mother, Father, 2 siblings and the wider COMMUNITY).**

**Costs - Financial, Social, Emotional, Physical Health & Vocational and Spiritual**

1. Counselling Sessions at SECASA for X (17 Sessions to date charge at \$130 per session)
2. Counselling Sessions at SECASA for X's parents (20 sessions to date charge at \$130 per session)
3. Counselling Sessions (8) approx. to date. Mental Health Plan (X's Mother)
4. Private Psychologist for X's Mother since X's behaviour became problematic at aged 7 (10 years off and on with average of once every three months over that time -approx. 40 sessions).
5. One year psychiatric registrar appointments - X's Mother (52 sessions)
6. Ongoing Fortnightly Counselling for X at CYMHS over a period of 3 - 4 years
7. Ongoing Monthly Counselling for X's parents at CYMHS over a period of 2 years.
8. Current Fortnightly Headspace Appointments for X's Mother and X
9. Crisis Management Counselling Family Sessions as required
10. Family Counselling Sessions (6) approx. at CYMHS over a period of 4 years.
11. Visits to Emergency Department Hospitals x 3 with X
12. Numerous visits and engagement with School Welfare Counsellors (primary and secondary school for all children), GP visits for mental health plans etcetera, Occupational Therapists, Psychologists, Psychiatrists both before the diagnosis and to confirm diagnosis and to manage diagnosis.
13. Police Called to House on three Occasions due to violent incidents (Mordialloc Police Station)
14. Police engaged when daughter ran away (Sandringham Police Station)
15. Car Accident whilst X's Mum was on the way to the ED in Hospital while X was disregulated and violent whilst I was driving.
16. Speeding Fine during a violent incident where X became enraged and I failed to observe we were in a school zone. (Moorabbin) Traffic Infringement Notices (I had to stop the

car suddenly for X's safety in a no standing zone as she opened the door to jump out whilst the car was moving)

17. Daughter jumped out of moving car. (Safety risk to her and others)
  18. Daughter jumped out in front of a car. (Safety risk to her and others)
  19. Younger sister (aged 10) traumatized by X's outbursts and distressed and threatened to kill Police called to house to intervene.
  20. Loss of trust and relationship by X of her Mother. Verbal and emotional abuse of X to her Mother.
  21. X's Mother Unable to return to Paid workforce as in Carer Role for my daughter.
  22. X's Father currently not working in paid employment as he supports his daughter and me in her recovery and transitions to a more flexible arrangement where he can be at hand to help out.
  23. Victims of Crime Application in Progress (Since November 2017). Engagement with Windermere Services and allocation of a Case Worker to assist me in my VOCAT claim. Ongoing Engagement with Victims of Crime Lawyer appointed by Windermere, face to face meetings, phone calls, emails, document gathering and research to support my application on behalf of my daughter and my other applications on behalf of my husband and myself as secondary victims.
  24. Detailed submission to Royal Commission into Mental Health Terms of Reference Consultation
  25. Application and ultimately a rejection of support from NDIS to allow my daughter to receive private DBT treatment which has been recommended by her treating psychiatrist at CYMHS at the time. (It has been advised not to have her in group sessions as she may be influenced negatively by others who are further along the BPD path). So far, I mainly have managed to contain the more severe behaviours associated with BPD. However, without this early intervention and prevention treatment now I fear for my daughter's future health.
  26. Submission and complication of reports and subsequent rejection of Application for Carer Payment and Carer Allowance from Centrelink. (February 2019)
  27. Family Connections Course — An 8-week evening course of two hours for both my husband and I run by Volunteers.
  28. Bouverie Centre, Brunswick - Weekend Course 'Building Resilience for BPD Families' attended by my husband and I to learn about BPD and develop coping skills
  29. Loss of friends and family and completely isolated from family as a result of taking a stand.
  30. Loss of the family life and close relationships we were entitled to lead but which was destroyed by this this violation.
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31. Parentline - Regular telephone support line used by me at times of crisis.
32. Lifeline - Regular support line used by my daughter and me at times of crisis.
33. WIRE - Referral and support when marriage hit difficulties. Financial and Separation advice sought.
34. Launch Housing - Housing support sought as marriage broke down temporarily under strain of daughters behaviour.
35. Member of online Facebook Forums for Mothers whose children have been sexually abused and also Parents of Children with BPD for support. (There is no group for Mothers whose children are the more innocent victims in peer sexual abuse **and** who have gone on to develop emerging traits of BPD that I know of in Australia online of face to face)
36. Numerous Trips to GP re physical ailments of my daughter - stomach problem, Irritable Bowel Syndrome, Cystitis, Sleep disturbances, Anxiety, Depression, Anger, Eating behaviours, regular blood tests for food sensitivities and intolerances
37. Family Conflict - Decrease and cancellation of holidays, social activities, withdrawal from friends, increase in family arguments. Crisis within our family unit. My daughter's school refusal and inability to perform duties to usual standard of peers - self-care, organization skills, assignments, not independent, not able to get a part time job. Post-traumatic stress. Having to drive her to school every day to make sure she goes. Prepare food and pay for home help as I try to parent my other children and provide support in the absence of any family help whatsoever and in fact family toxicity to do with the sexual abuse. We have not been able to 'turn to family' in our distress as family and their reactions have been the cause of our suffering.
38. Loss of time in school and extra support required. Teachers having to make allowances. Term meeting with Vice-Principal and Student Support Manager involving her treating clinicians as well.
39. Expensive extracurricular singing lessons to give her success in one area.
40. Loss of income from not working. Both parents. Loss of opportunity to write and publish two books which I have now missed the deadline for.
41. Loss of fees and deposits from events my daughter has pulled out of at the last minute and subjects she has not finished for example VET Music Production at Sandringham College and a World Challenge Trip to Nepal through the school.
42. Expensive holistic therapies - meditation, mindfulness, yoga, gym memberships, private singing tuition.
43. My advocacy work - writing for BPD Newsletter, attending meetings, webinars, submission to Royal Commission on Mental Health, Filing and liaising with Police with regard to them accepting a reporting of this crime, this submission to Mental Health

Productivity Commission, Attending and speaking at BPD Conference in Brisbane in Carer Role (self-financed)

44. Foregoing and reducing trips to visit my family and dependent Mother (now dying) and Sister overseas as unable to leave my daughter for long periods due to her special needs.

## Background

We are a family of five residing in Melbourne, Victoria - two parents and three children (now in their teens) who have been engaged with the Victorian mental health system as a highly complex needs family over the past 10 years. As parents, our main goal is our daughter's full recovery and to leave 'the system' and become a 'normal' functioning happy family as we were, prior to our middle daughter when she was 9 years old, disclosing family peer sexual abuse (child on child sexual abuse). The violation she suffered by her cousin was 'sexual penetration of a child under 16'. I was an extremely vigilant mother at all times. It simply never crossed my mind that my daughter would be sexually abused by another child let alone her cousin in the care of a trusted adult, her Aunt.

Our daughters behaviour deteriorated markedly from about aged 7 and I sought help from many sources, alas to no avail. Finally, at aged 14 we received the long-awaited diagnosis of 'Emerging Traits of Borderline Personality Disorder. Things improved at that point though our lives are changed forever and still filled with the trauma and the ripple effects of familial peer sexual abuse. The sexual abuse she disclosed had occurred when she was aged 7, at the home of her cousin, a boy, under the supervision of his Mother (my husband's sister). He was four months older than our daughter at the time. We learned over the following years it was not an isolated incident. After the initial disclosure we informed both parents (separately) of our nephew, of our daughters disclosure and to this day, almost seven years later neither the child or either parent (separated) has ever contacted us to acknowledge, explain and/or re-assure us as to why our nephew may have acted this way, which further adds to the burden of concern we carry in around safety in particular.

Our daughter was the **innocent** victim in peer sexual abuse. There is little acknowledgement societally, legally or within our wider family of her suffering. She deserves the same rights as any other child in Australia to safety and security which have been denied to her as a result of this crime regardless of the age of the perpetrator child victim. **She deserves the same resources to assist in her recovery as any other victim of crime.**



I am a migrant, away from my own family and trusted support network. I suffer as a secondary victim, as does my husband having lost his family over this incident. They refuse to acknowledge and deal effectively with the violation by one child of another openly. This has cast a dark shadow over our lives and in particular over our young daughter's character and affected how we live our lives without the support and security of the wider family network who are aware that our daughter was sexually abused by her cousin. She or we were not supported by the wider family in dealing with the gravity of what had occurred and in fact we have become as if we were the bad guys. Our other two daughters have missed out as well on a normal childhood partaking in milestones, traditions and rituals within the wider family as it is an unsafe environment for our children when the crime remains unacknowledged. This is not an environment that promotes good mental health.

Over this period of years, I became a carer to my middle daughter as well as a parent to my other two children, trying to minimize damage to them. I had no 'village' of support. No family to rely on. I could not return to paid work as planned. My marriage was strained and broke down temporarily. My daughter was physically and emotionally abusive to me and I was advised by a Police Sergeant to take out an intervention order against her. My youngest daughter was particularly vulnerable to her older sister's outbursts and behavioural issues. My eldest daughter was studying for Year 12 at the height of the family trauma. She is now at University and coping well though I am not sure if there has been any residual damage there. I fear there has. **The impact on siblings must be considered.**

Justice McLellan in the Royal Commission into Institutionalized Responses to Sexual Abuse has said 'the number of children being abused in family settings far exceeds those abused in institutions'. In our lived experience this act of peer sexual abuse within the family has caused devastation to our family and a heavy reliance on Government support services and treatments to help us recover. Had the sexual abuse occurred in an institutionalized setting, there may have at the very least been acknowledgement and some form of justice and accountability which I imagine would go a long way in healing and validation of a victim's suffering. It may have restored our daughter's mental health or even prevented the onset of BPD traits. Our daughter has been denied any form of acknowledgement or justice and suffers greatly because of this.

It is our firm belief based on what we have experienced that the current medical (and legal system) fails the innocent child and their carers when a child is courageous enough to disclose sexual abuse. We were not given the correct advice by specialized sexual abuse



services, which prolonged our suffering and has kept us 'in the system' . It has irrevocably damaged us as a family from having to navigate a system that in our experience has little understanding of the effects of peer sexual abuse in a family setting on the innocent non-offending child victim as opposed to the offending child victim.

Our daughter's diagnosis came via the emergency department of our local hospital after years of being engaged with professional clinicians at CYMHS and SECASA and appointments with a myriad of other professionals, who knew her background story. This caused so much additional suffering that could have been avoided I firmly believe. I was repeatedly told by my daughter's clinicians that her behaviours were 'normal adolescent behaviour' or by my GP that it is only 'a mother daughter dynamic/personality clash'. I was dismissed and demeaned in the system and not taken seriously, the one person who had my daughter and entire family's best interests at heart and did not have the same degree of attachment to my husband's side of the family. Clearly these professionals, and there were many were all ill-qualified or worse ignorant of the link between childhood sexual abuse and long-term adverse mental health effects. One clinician even suggested the answer for me was to find a job and everything would settle down. I constantly felt the attention shifting to me when I clearly and accurately explained my daughter's distress and escalating behaviours. I did not feel the same loyalty that my husband did to his family where the abuse had occurred and that added to our family conflict as we approached things differently. I wanted answers whereby he was been pressurized by other family members 'to bury it' and 'to move' on. The spotlight and blame went on me which caused further distress, distraction and delay in forming the correct diagnosis at a time when my daughter should have been monitored closely for the onset of serious mental health problems. My husband at that time before diagnosis was not as supportive as I would have liked. He was in deep grief over what had happened his child at the hands of his nephew and under his sister's supervision.

Our 'success' over the last ten years has come at enormous cost to each of us. We measure our success below:

1. Our daughter, **a child had the courage and trusted someone enough to disclose peer sexual abuse** in a family setting. The fact that our daughter (or any child) had the courage to disclose sexual abuse as a child to a trusted adult gave us the opportunity to stop any further abuse by the offending child of her or her siblings. That is only what we could control. We have no idea if he abused any other family member.



2. We have kept our daughter alive when she planned to die. Our daughter has never been hospitalized nor has she ever been in residential care or fostered out because we could not cope IN SPITE of the massive trauma and disruption and cost to our and her siblings' lives. She has been physically and verbally violent with me in particular and blames me for not protecting her (as she recorded in her Victims of Crime Impact Statement). My husband and I are the main care-takers 24/7, deep in the trenches, on the frontline warding off the consequences of her cousin's actions over the past nearly 10 years which often manifested in self-sabotaging behaviours. I am the Mother with a finger in the hole of the dam warding off the onset of this serious personality disorder which often co-exists with other mood disorders and diagnosis if left unchecked. And we have contained the onset of this illness to some degree (as noted by CYMHS in December 2018 who acknowledged the progress being made). **Early detection and prevention is key.**
3. Our daughter has to date not taken any medication for depression and anxiety (as we toughed it out whilst we waited for the correct diagnosis over years of trauma). We believe she eventually got the right diagnosis which might have not been the case had she been treated for symptoms of anxiety and depression or an eating disorder first and foremost if she had not disclosed sexual abuse. This is due to our tenacity. We are seeking treatment of the root of the issue - neurological damage sustained as a result of the trauma of sexual abuse as opposed to treating the symptoms. We also heavily researched and relied on holistic therapies as well as the medical model whilst seeking answers to her life threatening behaviours. We went to the root of the problem. The sexual abuse she suffered and her vulnerability as a highly sensitive and trusting and kind nature may have made it easier for her to be preyed on. She was told not to tell anyone.
4. We have consistently provided a safe and loving environment for her and upheld her human rights as a child for safety and security and protection from sexual abuse in spite of this being threatened by the wider family. We have played to her many strengths to give her a sense of success in her life to overcome her trauma. It is an ongoing journey as we still to this day seek to access the right treatment for her promptly - private DBT therapy which is extremely expensive.

