

Foundations for Change

**Borderline Personality Disorder
– Consumers’ and Carers’ Experiences of Care**

Summary Report



Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

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Introduction

This Summary Report draws together the findings of two Australian national online surveys conducted in 2011 by the Private Mental Health Consumer Carer Network (Network), about the experiences of mental health consumers with diagnoses of Borderline Personality Disorder (BPD) and of their family members and carers. The data from these surveys has been reported in two separate primary reports, *FOUNDATIONS FOR CHANGE: PART 1- CONSUMERS: Experiences of CONSUMERS with the Diagnosis of Borderline Personality Disorder (BPD)* and *FOUNDATIONS FOR CHANGE: PART 2- CARERS: Experiences of CARERS supporting someone with the Diagnosis of Borderline Personality Disorder (BPD)*.

Participation in the BPD consumer and carer surveys was open to any consumer who identified themselves as having a diagnosis of BPD or any carer who identified themselves as being a person whose family member had a diagnosis of BPD and were those that responded to an invitation to participate distributed in the first instance to 20 mental health service organisations and 29 consumer and carer networks across Australia, including clinical mental health service systems and community and non-government organisations with a request for on-forwarding to consumers and carers. The surveys were widely publicised and delivered online via 'SurveyMonkey' across Australia. The surveys were conducted between 27th May and 30th June 2011. It should be noted therefore that since the survey respondents were not a random sample from a population based sampling frame of BPD consumers, and were instead self-selected by virtue of choosing to participate in the survey, the extent to which the conclusions drawn from the survey are representative of the wider BPD population depends on the extent to which response bias may have existed. Similarly, many consumers that did participate were also selective of which questions they would answer, particularly later in the survey.

It is rare in the literature of mental health research to find studies from the perspectives of people with this debilitating condition, and from their family members. There is a lack of information about what a diagnosis of BPD means for people, the treatment they may, or may not have received, their perceptions of barriers to care, and the quality of services they receive. There has been prior research about Australian mental health consumers of diverse diagnoses, with samples containing substantial numbers of respondents with BPD. For example, in a study of consumers' and carers' perceptions of stigma conducted by the Mental Health Council of Australia (MHCA, 2011) (12%; n=49) of the consumer respondents had a BPD diagnosis. Though uncommon, studies have also examined the attitudes of mental health *staff* towards consumers with BPD diagnoses. Deans and Meocevic (2006), for example, found that the majority of the 65 mental health nurses they surveyed felt patients with BPD diagnoses to be manipulative; the authors expressed concern about how high levels of staff negativity affected consumers. It is far more common, particularly in the last two decades, to find research about various forms of individual and group psychotherapies and treatment protocols. This growth of research about BPD treatment is partly because traditional approaches have been described as "woefully inadequate" (Linehan, 1993, p. 3), together with an

acknowledgment that people with this diagnosis who seek help account for a substantial number of inpatient and outpatient services used.

These two surveys: Experiences of Consumers with the Diagnosis of Borderline Personality Disorder, and Experiences of Carers Supporting Someone with a Diagnosis of Borderline Personality Disorder, are unique, therefore, in redressing a gap in the research literature. The surveys also represent the first to be undertaken across Australia by a consumer and carer organisation seeking the views of consumers with BPD, and of carers about their experience of care. The important information and insights described below will contribute to the broader need of improving treatment and services for consumers and families who experience BPD.

It is important to preface this Summary Report by adding a methodological caveat: caution should be exercised in our interpretation of the quantitative and qualitative data from our national surveys. Whilst 161 consumers and 128 carers entered the survey instruments, 153 and 121 respectively proceeded to complete the survey questions. Of these, not all completed the full surveys and not all respondents completed all applicable questions. In addition these numbers represent a very small¹ sample of people affected by the diagnosis of Borderline Personality Disorder in Australia. Nevertheless the information gathered offers a compelling description of what it means to live with a diagnosis of BPD, to care for someone with this difficult condition, and of the experience of seeking mental health care services.

Purpose of the BPD Consumer and Carer Summary Report

The aim of this Summary Report document is to distil the main themes from both BPD consumer and carer surveys. The findings are accompanied by some reflection on social context as a form of preliminary discussion and analysis.

Borderline Personality Disorder – A Brief Background

Borderline Personality Disorder is considered to be the major form of personality disorder, both the most common and most serious (Chanen et al, 2007). People with the diagnosis of BPD are among those with the highest levels of unmet need in Australian mental health services. It is conservatively estimated at a 2% population prevalence rate, that BPD affects over 440,000 Australians. SANE Australia suggests that between two and five per cent of the population is affected by BPD at some stage of their lives, so the number may in fact be higher (SANE, 2011). It is common in clinical practice, occurring in at least 10% of outpatients and 20% of inpatients. It is associated with high levels of additional mental health problems (such as depression and drug and alcohol use) and severe and continuing disability across a broad range of domains of interpersonal and social

¹ 2% of the current Australian population of 22, 328, 800 is 446, 576, a very conservative population prevalence estimate for BPD. 2% prevalence estimates (Swartz et al, 1990) have been challenged in recent community studies e.g. Grant et al, 2008, which postulate 5-6% population prevalence.

functioning, poor quality of life, high usage of mental health and general health resources, and high mortality. The suicide rate for this disorder is estimated at 10%, the same as for schizophrenia (Paris, 2002; PMHCCN 2011). Most people (74%) diagnosed with BPD have at least one co-occurring Axis II disorder (Barrachina et al, 2011), and strong co-morbidity with Axis I conditions such as serious depressive episodes, and bipolar II disorder (Stone, 2006), making accurate assessment of prevalence difficult.

A diagnosis of BPD is contested territory at a number of levels. The use of the adjective “borderline” to describe a large sub-set of people with personality disorders (PD), the use of the term “PD” as a derogatory label and the definition of BPD itself have been subjects of ongoing dispute. The disorder has only recently been formally recognised as a discrete diagnosis and considered a mental health service responsibility to treat.

Though people with mental illness often experience stigma, consumers with a diagnosis of BPD have endured not only societal stigma but also exclusion and disapproval from within mental health services. For some mental health service staff the issues and needs of people with diagnoses of BPD seem chronic and unrelenting, and their emotional pain unassuageable. People with BPD diagnoses who are refused care or derided for needlessly taking up valuable resources are further traumatised. At the same time, because difficulty with relationships of trust is at the core of the experience of BPD, service providers need high level skills and training to effectively engage with these consumers. The evidence base for treatment efficacy has been relatively poor until quite recently. There is controversy about the use of medication, and the evidence for a physiological component of the condition is as yet in the early stages of research. It is not surprising therefore, in an environment of treatment uncertainty and negative experience of services that consumers and their families continue to struggle to access effective assistance.

Survey findings

The Summary below is not intended to cover the results of all survey questions asked of the respondents. The objective is to provide a précis of the major findings and broad themes.

Demographic Data for Consumers and Carers

Demographic data showed that the consumers and carers who participated in the surveys were from all Australian states and territories, though the participation rate was relatively higher in South Australia (SA), Victoria and Western Australia (WA), possibly due to more effective network dissemination of the survey in these states.

Most respondents lived in metropolitan areas with 61% of consumers (n=92 of 151) and 62% of carers (n=75 of 121) living in capital cities. There were, however, a higher proportion of subjects from consumers and carers living in regional towns and remote areas, when compared to the distribution of the national population. Assuming that the distribution of people with BPD is similar to the geographic distribution of the Australian population, this could indicate differences in levels of perceived support and isolation between urban and rural survey participants, prompting those in rural areas to speak out more about their circumstances.

Many more women than men responded to the surveys. Of the consumers who recorded their gender (n=147) 88% (n=129) were women and 12% (n=18) were men. This does not reflect the national gender mix of 51% females and 49% males in the overall Australian population (ABS, 2011), but may reflect the higher rates of BPD diagnosis given to women, despite the prevalence of BPD being similar for both genders in the general population (Grant et al, 2008; Lenzeweger et al, 2007; Torgersen, Kringlen and Cramer, 2001). Women with BPD diagnoses may also participate in surveys at higher rates than men, suggesting the need for alternative methods to access the views of men with BPD. This needs to be taken into account when performing any future population weighted survey in order that male and female responses are representative of the Australian BPD population. Of the carers 80% were women (n=91) compared to men (20%; n=23). This is also very different to the national gender mix, possibly reflecting higher rates of women in carer roles or the possibility that women were more likely to respond than men.

Two thirds of consumers were aged between 25-49 years. This suggests that BPD affects the people in this sample across the lifespan, but particularly those in the prime working decades. Almost half of consumer respondents were single (46%; n=68) and 39% (n=58) were in a spouse or partner relationship. A higher proportion of people with BPD diagnoses in this study sample therefore were single, compared to their counterparts in the general population. However, this does not mean that a higher proportion of the BPD population is single compared to the Australian population, since we do not know if the study sample is representative of the Australian BPD population.

In the broader Australian community, studies focusing on family and relationship configuration indicate that the proportion of people without partners increased overall, between 1986 and 2006 (Qu and Weston, 2012). People are more likely to be partnered after 30 years of age. In 2006, for example, 60% of Australian males and 48% of females aged 25-29 years were living without a partner, but the proportion for both males and females aged 35-49 was just over 30% (Birrell, Rapson and Hourigan, 2004). Approximately 40% of Australians described themselves as not married in the 2006 Australian Bureau of Statistics Census, 6% less than the BPD sample, with alternative categories being married or in a de facto relationship (ABS, 2006). It is impossible to ascertain the precise proportion of those people, however, who may be unmarried but still consider themselves partnered. Consumer respondents came from diverse cultural backgrounds. Almost 5% (n=7) were of Aboriginal or Torres Strait Islander (ATSI) descent, higher than the proportion of these people in the general population (2.5%; ABS, 2006).

Almost half the carer respondents were in the 50-65 year age group (42%; n=50) with the next highest group being in the 40-49 year age group (26%; n=31), suggesting these carers had experienced many years of living with a young adult with a diagnosis of BPD. Many carers (49%; n=72) had children who were not currently in their care, reflecting the older age of this sample. Of the carer respondents, 61.5% (n=72) were married, and most (76.5%; n=78) were the parents of a daughter with BPD. Being in a carer role in this sample of people did not always mean having a biological or familial connection to consumers. Of the 103 respondents who indicated their relationship to consumers, only 30% (n=31) were parents or guardians. Almost a quarter of carers (24%; n=23) were in relationships other than those defined by the survey, for example, foster parent, aunt, concerned community worker, daughter, mother-in-law, even clinicians who considered themselves in professional carer roles. There were no survey questions to further elucidate these relationships, though it is reasonable to assume they may have occurred in the absence of other family supports.

The data suggests that men with BPD are treated differently, and also view treatment differently, compared to women with BPD. Men appeared to have different patterns of help-seeking from the various health professionals compared to females; and differences in their rating of that health professional's helpfulness in assisting them to understand their feelings, and in managing their mental health. This finding may have implications for the previously observed national differences in suicide rates between males and females, (overwhelmingly a male phenomenon at eight men to two women, AISRAP, 2011) and response to suicidal behaviour by health professionals. The findings may indicate the need to approach the treatment of BPD in men in a different way to the approach used for women, and further exploration of these issues is warranted.

Issues of Borderline Personality Disorder Diagnosis

The contested nature of a BPD diagnosis has been briefly alluded to above. Psychiatrists have been reluctant to make a BPD diagnosis, perhaps with beneficent intent, fearing the labeling and stigma that may ensue for their patients. The corollary of this is that consumers may have received

treatment in the past without a diagnosis of BPD being candidly acknowledged. This phenomenon is undergoing change as the diagnosis gains more clinical “legitimacy.” Recently the National Institute for Clinical Excellence (NICE) in Health guidelines have advocated a more transparent, collaborative approach with consumers regarding their diagnosis (NICE, 2009).

Consumers were asked how long ago they had received their BPD diagnosis. Of 105 respondents, the largest proportion of consumers (42%) had received a BPD diagnosis between one and five years previously, and the second largest (27%) between six and 10 years previously. Of the 109 respondents who indicated length of time in treatment, 20% had been in treatment for less than a year, 27% for one to three years, 28% for three to nine years, and 27% had been in treatment for more than nine years. Comparing these figures with the time since diagnosis, it was apparent that many people had been in treatment for longer than the time since diagnosis, confirming the above theory that some clinicians treat patients for BPD without openly discussing it with them. Carers responded to the length of time since diagnosis question very similarly to consumers, with the largest proportion (approx. 26%) stating longer than 10 years ago, the second largest (approx. 24%) responding between one and three years ago, and the third largest groups at approx. 19%, being between three to five and five to 10 years ago respectively.

Many consumers found the diagnosis of BPD difficult to understand. Consumer respondents may also have experienced confusion about whether their diagnosis was considered primary or an “other mental health diagnosis” (secondary). Almost three quarters (71.5%) of 123 consumer respondents noted BPD as their primary diagnosis. When asked whether they had any other mental health diagnoses, 117 consumers responded and of those 64% indicated BPD; this figure does not align with that of the primary diagnosis, and is possibly a function of the structure of the question. The second and third most commonly reported comorbid diagnoses were anxiety disorder (55%) and post-traumatic stress disorder (PTSD) (41%).

It is very concerning that of the 119 that responded to whether medical practitioners had explained a BPD diagnosis to them, 38% of consumers reported that no health professional had explained the diagnosis, and 19% stated that the diagnosis had been explained, but that they had not understood it. This was also the case for carers, with 62% of 93 reporting that medical professionals had not explained to them what a diagnosis of BPD meant. Only one third of carers (32%, n=30) noted a BPD diagnosis being explained to them and that they also understood the explanation. Given the complexity of the nature of BPD for consumers and carers, carer management of crises, and the pivotal role carers play in negotiating services for their family members, this finding reinforces the urgent need to look far more closely at the manner in which we provide psycho-education to consumers and their families.

Early Signs of Borderline Personality Disorder

It is difficult for clinicians to establish BPD diagnoses in children and adolescents, who may experience a range of behavioural disturbances and mood changes not considered markers of

mental disturbance at the time. Nevertheless many of this sample's carers identified early problems with their children. Nineteen carers completed questions about their perceptions of early signs of BPD in the person they cared for. Of these carers, 58% identified sensitivity as the main sign during infancy or toddlerhood, along with moodiness (42%), excessive separation anxiety (42%) and social delay (37%). During childhood, of 19 carer responses, sensitivity rated highly (63%), along with difficulty making friends (62%), school refusal or truancy (53%) and being a victim of bullying (47%). These findings may have multiple implications for how parents and schools respond to a child's behaviour. During adolescence (n=19), anger was the most prominent issues that carers reported noticing (68%), followed by moodiness (63%), impulsivity (58%), body image issues (52%), and sensitivity (53%). Further issues in adolescence noted amongst 16 carers were; difficulty making friends (62.5%), followed by promiscuity (56%) and verbally abusive outbursts (50%). Sexual abuse was noted by carers across each developmental domain: in infancy and toddlerhood (16%), in childhood (47.5%), and adolescence (39%).

Carers sought an evaluation of their child's problems (n=17 responders) mainly as a result of concern about behaviour problems (71%) and mood disturbances (59%). This therefore paints a picture of a young person rapidly losing control of their mental health and well-being, and parents increasingly being affected by multiple issues beyond that expected of childhood and adolescence, yet with descriptions of minimal outside recognition or support.

Experience of Mental Health Services

The data from the surveys from both the consumer and carer view seems to indicate that BPD is a diagnosis for which consumers and carers feel strongly that they cannot access appropriate or sufficient services. Consumers and carers were asked a number of questions about receiving support from mental health services. Even taking potential responder bias into account, and allowing for the fact that these are a very small sample of 153 consumers from an estimated national cohort of approximately² 446, 576 (or 2% of the general population), the study participant's responses paint a very bleak picture of how service providers appear to offer treatment to people with BPD diagnoses. The findings contribute evidence to the notion that the treatment and care of people with diagnoses of BPD presents a substantial gap in health service delivery in Australia.

Survey respondents believed having a diagnosis of BPD resulted in discrimination, being actively excluded from services, and being treated poorly. They were asked to what extent a number of issues of service provision caused them anxiety. The two most highly rated consumer concerns were not being taken seriously (70.5%, n=79 of 112) and discrimination because of the BPD diagnosis (57%, n=64 of 112), followed by not feeling respected (54%, n=60 of 112). This finding is very concerning, if not unsurprising, given the prior research cited above (Deans and Meocevic, 2006),

² See above Footnote 1. 2% of the current Australian population of 22, 328, 800, is a very conservative population prevalence estimate for BPD. 2% prevalence estimates (Swartz et al, 1990) have been challenged in recent community studies e.g. Grant et al, 2008, which postulate 5-6% population prevalence.

and the evolution of BPD considered clinically as a mental illness rather than merely the most common disorder in the category of PDs.

Both consumers and carers were asked how helpful a range of service options had been in the management of BPD, rated across a five point scale ranging from 1 'very unhelpful' to 5 'very helpful'. The 109 consumers that responded to these questions indicated that forms of psychotherapy, including both 'long-term psychotherapy' and 'dialectical behaviour therapy' were among the most helpful interventions. However, over half (52%) of the consumers said that they had not been able to access psychotherapeutic services, most noting problems with waiting lists, financial barriers, services being too far away, or having their concerns dismissed as not important or severe enough. Other services, including community support groups such as art therapy and friendship groups were also identified as helpful. Importantly, education and information about BPD and the identification of early warning signs were identified as being helpful, supporting the comments above about the pressing need for more comprehensive psycho-education. This indicates that consumers with BPD diagnoses appreciate a combination of highly skilled psychotherapy and information, combined with the socially embedded context of community supports, not unlike the mix of strategies proposed for most people with mental health diagnoses.

Consistent support was the most valued aspect perceived by both consumers and carers to contribute to recovery. A little over half of consumers and carers reported accessing support from mental health professionals for longer than 10 years, reflecting the older age of the carer cohort and suggesting long-term mental health experiences. Nevertheless carers in this sample clearly identified a lack of support and services, drawing a picture of ongoing isolation in their carer role. Alarmingly over half the carers of the 78 who responded stated that their lack of support options (51%) when needed, being unable themselves to access existing support (47%), and services not available in their area (43%), as very challenging aspects of their carer experience. Only one third of carers reported that they had accessed carer support groups. This is of great concern given the severity of issues faced by these carers. Though it may somewhat reflect the difficulties carers of people with mental illness face in accessing any support groups, it may also suggest that specific support groups should be better targeted for carers of people with BPD diagnoses.

Consumers and carers of these surveys both felt their concerns were dismissed by health professionals as not important or severe enough. Experiences of exclusion, discrimination and disrespect perpetuate high levels of anxiety for both consumers and carers. **This is the case despite most consumers indicating high motivation to seek support.** The question this subsequently poses is: Does having a diagnosis of BPD predispose people to higher rates of stigma and discrimination than if they had another mental health diagnosis, or are they common experiences of anyone with a severe and complex mental health condition? In the MHCA study reported above, 29% of consumers reported that their treating health professional had shunned them, but this figure rose to 57% for consumers with BPD. (MHCA, 2011). This finding suggests that at the very least, people with BPD diagnoses are more likely to report experiencing discriminatory behaviour. Stigma regarding mental illness is a complex phenomenon described as perceived, experienced and or directed towards the

self, so called self-stigma (Brohan et al, 2010). Women with BPD have been found, for example, to show higher rates of self-stigma than women with social phobia (Rusch et al, 2006), perhaps associated with low self-esteem, the labelling experienced at frequent hospital presentations and visible self-harm scarring. The findings of these BPD surveys and anecdotal accounts of active discrimination when people attempt to access services require further exploration and scrutiny to fully answer the question posed above. While acknowledging that people with BPD diagnoses are often challenging for staff working in the area, these findings flag the need for ongoing education of mental health staff, and indeed any medical staff, including those working in the emergency departments of general hospitals.

The importance of a skilled GP in mental health issues is critical for both BPD consumers and carers. It is unclear, however, how many GPs are, or feel they are, sufficiently skilled in treating BPD patients despite the targeted training resources available to them (Lubman et al, 2011). Consumers and carers were asked about their GP's role in supporting them. The responses were mixed, with GP support obviously important to consumers and falling short of being adequate for carers. It is heartening that over half the consumers (50.5%, n=54 of 107) reported that their GP had been supportive, though 29% (n=31 of 107) rated their GP contact as neutral or unsupportive. Alarming 20.6% (n=22) of consumers stated they had not received GP support, though it is unclear whether this meant they accessed a GP and subsequently received no support, or whether this group of people did not have a GP actively engaged in their care. When asked about perceived helpfulness of services, only 17% of consumers stated their GP was helpful, and 15% that he or she was very helpful.

Whilst the majority of carers (71%) reported that a GP supported the person they cared for with a diagnosis of BPD, it is concerning to find that, of the 72 carer respondents to questions asked specifically about GP support, over half (51.4%) reported that their GP had not supported them as a carer. Of the 72, 76.1% (n=54) also reported that their GP does not provide them with personal counseling for issues related to being a carer. However, almost half (48.5%) stated that the GP had not referred them to other community supports, perhaps indicating a lack of available community supports or a lack of GP knowledge of them. Despite this apparent gap in providing support to carers, GP's referred most consumers consistently to psychologists. This may have particular implications for consumers being referred to and accessing the Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative, with the reduction from 18 to 10 sessions available per annum, initially as of 1st November, 2011 extended to 1st January, 2013. This may have the negative consequence of increasing carer burden. These findings are also relevant to the further training of GP's, particularly the need to raise their understanding and recognition of their role in providing support and counseling for carers and family members of BPD patients.

People with BPD diagnoses go, or are frequently sent by mental health workers to hospital emergency departments (EDs) in crisis and are not infrequently unable to be admitted. Many consumers and carers of these surveys reported that requests for hospitalization were refused on

the basis of their concerns not being perceived as serious enough, not being taken seriously, or a lack of beds as the main reason for refusal even though carers asked for the person they care for to be hospitalized following serious suicide attempts. This had a marked impact on consumers who reported that this refusal made them feel alone and isolated, frustrated and angry, anxious, suicidal and depressed. Of 29 consumers that attended public hospitals, most cited feelings of suicide (93%) and feelings of self-harm (93%), the related feeling of being unsafe (89%) and depressed (69%) as the main reasons for requesting hospital admission. Both consumers and carers reported EDs as their first “port of call,” with most carers perceiving the Emergency Department being their only option. Of 16 carers who provided detailed information about hospital admissions, two thirds cited waiting times for the person they cared for to be seen for medical assistance exceeded four hours. This seems excessive when for 90% of patients, being treated by a doctor or nurse in emergency departments, treatment commences on average within 114 minutes of presentation, that is, less than two hours (AIHW, 2011). These data may support consumer and carer reports that ED staff treat people with BPD diagnoses differently from others, or reflect a lack of ED resources or skilled mental health staff for managing people with any mental illness, including BPD consumers. It also indicates that emergency staff requires a greater understanding of BPD, and greater empathy for people accessing EDs for medical assistance regarding self-harm and suicide attempts.

It is extremely disappointing to note that almost half the of 37 carers of people with BPD who used public hospitals (49%) reported never having been involved in consumer admissions, and only five per cent indicated involvement in the assessment process. Small numbers of carers reported being involved in the treatment process, ongoing management, and decisions about the process of the person’s discharge from hospital. This indicates a lack of engagement with carers by mental health professionals. Four of 23 carer responses to this question indicated that they had been admitted into hospital themselves for issues relating to their mental health or the burden of caring for someone diagnosed with BPD, reflecting the stressful nature of being in the carer role, and reinforcing the need for professional support for carers.

Fifty consumers reported having been hospitalised for BPD in the public sector, with their length of stay ranging between 24 hours and 32 weeks. When hospitalised, a majority of 53 consumers (64.5%) with BPD were detained under mental health legislation. Almost three quarters of 40 carers (72.5%) reported that the consumer they were carers for had experienced involuntary admission, suggesting that they were a distinct and large sub-set of the BPD carer population. Several of the 40 carers (7.5%) reported that consumers’ admission was sometimes only for 24 hours, reflecting potentially different review processes by different psychiatrists within 24 hours of the authorised health practitioner generating the original admission, after which people may be discharged. This seems to support reports from consumers and carers that mental health services discharge people with BPD after short stay admissions.

There were demonstrated differences in BPD consumers’ experience of care in public mental health services from those consumers who had been admitted to private hospitals (N=46, 64% of the

sample). Consumers of the private sector appeared to receive fewer hospitalisations but had a longer length of stay. When requesting hospital admission, public sector consumers rated feeling suicidal, feelings of self-harm and feeling unsafe at a higher rate than those from the private sector. Similarly, when asked about the level of impact on their mental health state when hospital admission was refused, public sector consumers rated feeling angry, frustrated, alone and isolated at a higher rate than private sector consumers.

Despite the general tenor of experience appearing to be more positive in the private sector, when consumers were unable to be admitted to a private hospital (in the private sector admission is usually determined by their treating psychiatrist), equal numbers reported being told their condition was not severe enough to warrant hospitalisation as in the public sector. This raises the very sensitive and complex clinical debate about whether and to what extent hospitalisation is effective for people living with BPD (Bateman and Fonagy, 1999; Paris, 2004; Verhaeghe and Bracke, 2008). This subject has its own vast literature beyond the scope of this Summary Report. Most consumers and carers would reasonably construe some form of hospitalisation in the wake of a serious suicide attempt to be life-saving in the immediate and acute situation, but we have no empirical evidence about its efficacy for people with BPD in the longer term.

Issues of Suicide, Suicide Attempts and Ideation

From our sample it would appear that a diagnosis of BPD has a marked effect on both consumers and carers who live with the impact of constant suicidal thoughts as well as self-harming behaviours. Most alarmingly, 86% of 97 consumers reported making serious suicide attempts and most (99%) reported serious self-harm attempts requiring direct medical attention and intervention. Consumers with BPD reported constantly living with feelings of suicide, self-harm, feeling unsafe, experiencing depression and anxiety as well as reporting their life of chaos. Many consumers expressed negative experiences of receiving care and described this as a lack of understanding, knowledge and skills demonstrated by health professionals.

Mental health consumers and carers are constantly urged to be aware of early warning signs of the illness becoming worse, and to have a relapse or crisis plan in place in case it is needed. Over half the 65 carers in our sample (55%) reported that no mental health professional had helped them understand early warning signs or when the person they cared for might be more at risk of suicide or self-harm. Similarly almost three quarters of carers, an alarming 73.4% of 64 carers reported that they had not received a crisis plan for the person they cared for.

Health Professionals, Treatment and Community Supports

Consumers and carers were asked their views of the various health professionals working with them. Health practitioners were viewed differently by consumers and carers. Most consumers saw either psychiatrists or psychologists for their BPD. Psychiatrists and psychologists were rated highly by consumers in terms of understanding their feelings, responsiveness in a crisis, and understanding

and managing their mental health. Carers also reported that psychologists were supportive of them as carers. Long term support from the same health professional was rated by consumers as the most useful in assisting their recovery, with GPs cited by consumers as particularly responsive in a crisis.

Very few consumers were taking no medications for their BPD, with most being prescribed anti-depressants, anti-psychotics, anti-anxiety medications, or combinations of these. The majority of the 122 respondents to these survey questions were taking anti-depressants for their mental health issues (69%), 42% were taking an anti-psychotic medication, 29% were taking an anti-anxiety medication, 17% reported taking no medications, and only 1.6% did not know what medication they were taking. However qualitative responses from 11 consumers who did not know their medication, and who provided the medication names indicated that most were taking a combination of anti-psychotic medications and anti-depressants. It is unclear whether health practitioners were using medications to treat BPD or co-occurring conditions such as depression, psychosis, PTSD or anxiety.

Community supports such as shelters, gambling or drug and alcohol services were perceived by carers as neither very helpful nor very *unhelpful* for the person they care for. This was surprising given the needs of people with BPD and the high rates of homelessness and lack of family and friendship supports among this population.

Discussion

Mental health clinicians internationally are in a process of re-appraising the efficacy of treatment for people with BPD diagnoses, a condition often considered too difficult, chronic and intractable to treat effectively. Though it is acknowledged there are many other consumers with severe, complex and chronic mental illness whose treatment is equally deserving of research attention, people with BPD may be singular in having attracted discrimination from both the wider community and from some mental health professionals themselves. It is difficult to gauge where service provision can be improved without knowing how people with BPD diagnoses and their families traverse the mental health services landscape. The findings of these online surveys of consumers with diagnoses of BPD, and their carers and family members, reveal important information about how they live daily with this difficult mental illness: how they experience a diverse range of mental health services, what assists and what detract in their efforts to seek care.

In conclusion, this survey of the views of consumers with BPD and carers of people with BPD has shown that there are many problems with the current care provided to people with a BPD diagnosis in Australia. This has been demonstrated across all aspects of care and has been confirmed both by consumers and carers. We hope that the findings of these surveys will help inform better care for people with a BPD diagnosis and better support for carers. We hope that the findings of these surveys and the information derived from them will assist in our combined efforts to respectfully provide consumers and carers with accessible, practical, affordable, long-term and above all, evidence-based services with positive outcomes for people who live with diagnoses of BPD.

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Acronyms

AMA	Australian Medical Association
APA	American Psychiatric Association
ASPD	Anti-Social Personality Disorder
BPD	Borderline Personality Disorder
CBT	Cognitive Behaviour Therapy
CDMS	Centralised Data Management Service
CSA	Childhood Sexual Abuse
CVT	Comprehensive Validation Theory
DBT	Dialectical Behaviour Therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Emergency Department
ICD-10	International Classification of Diseases – 10 th Edition
ITP	Interpersonal Therapy
MACT	Manual Assisted Cognitive Behaviour Therapy
MBT	Mentalization-based Therapy
MBCT	Mindfulness-Based Cognitive Therapy
MHCA	Mental Health Council of Australia
NESARC	National Epidemiologic Survey on Alcohol and Related Conditions
Network	Private Mental Health Consumer Carer Network (Australia)
NICE	National Institute for Health and Clinical Excellence
NCS-R	National Comorbidity Survey Replication
NSW	New South Wales
NZ	New Zealand
ONS	Office of National Statistics (UK)
PMHA	Private Mental Health Alliance
PMHCCN	Private Mental Health Consumer Carer Network (Australia)
PTSD	Post Traumatic Stress Disorder

