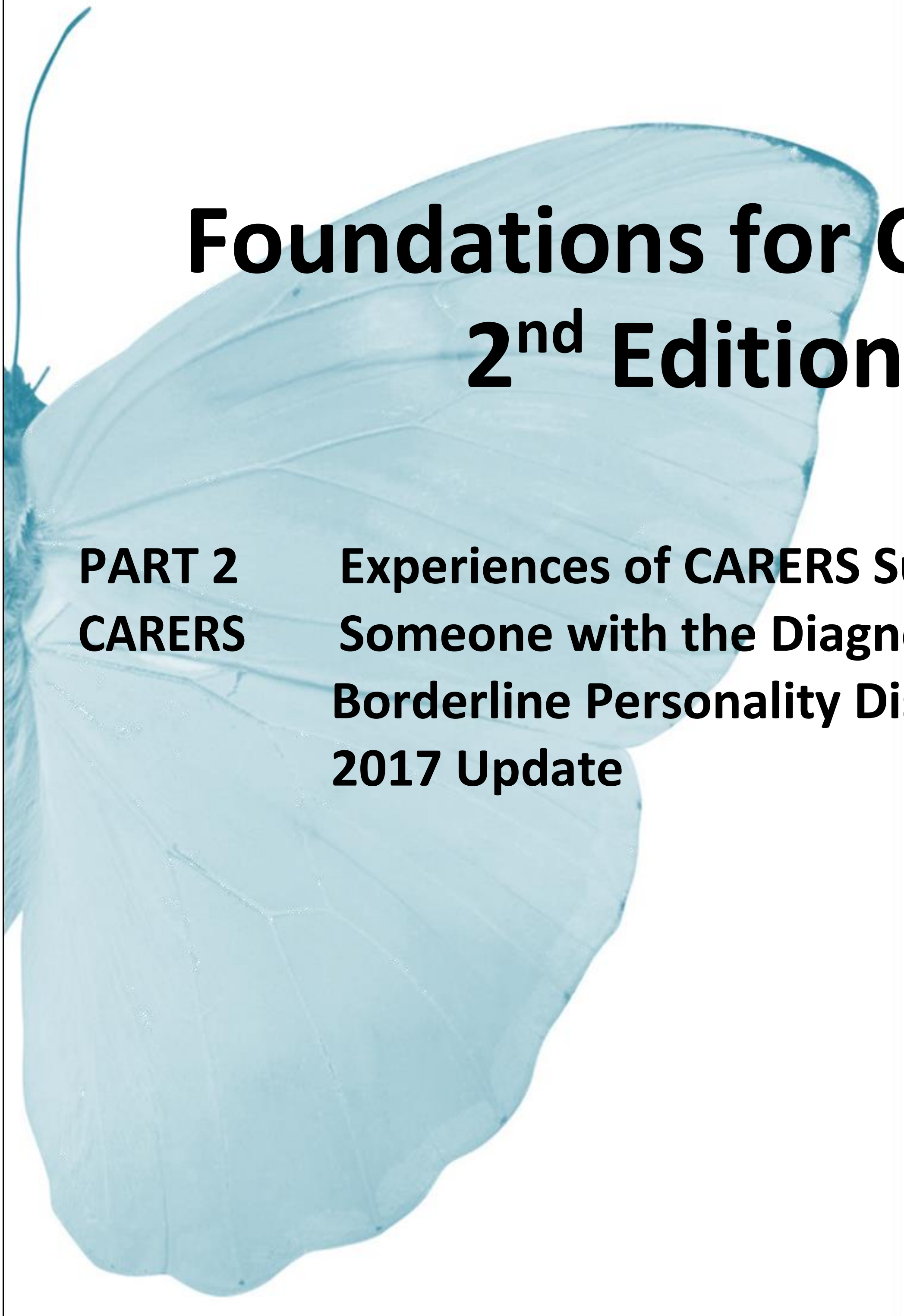

Foundations for Change
2nd Edition

PART 2 CARERS
Experiences of CARERS Supporting Someone with the Diagnosis of Borderline Personality Disorder (BPD): 2017 Update

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

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This is an Independent Report of the Data from a National Survey Undertaken by the Private Mental Health Consumer Carer Network (Australia) Limited

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Contents

Acronyms

ACT	Australian Capital Territory
BPD	Borderline Personality Disorder
CBT	Cognitive Behaviour Therapy
DBT	Dialectical BehaviourTherapy
ED	Emergency Department
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
NZ	NewZealand
PTSD	Post Traumatic Stress Disorder
QOL	Quality of Life
SA	South Australia
TAS	Tasmania
VIC	Victoria
WA	Western Australia

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Experiences of Carers Supporting Someone with the Diagnosis of Borderline Personal Disorder

Executive Summary

This report provides analysis of the results of survey that was originally conducted in 2011 and repeated in 2017. This work was undertaken in order to compare and determine any changes in the healthcare experiences of informal carers of consumers with BPD over time, given greater awareness of BPD within mental health and primary care service systems since the first survey was undertaken, and the release of the National Health and Medical Research (NHMRC) Guidelines for the Treatment of BPD at the beginning of 2013; almost 5 years ago. A companion survey was also conducted with people with BPD, and results of this repeat survey are provided in a separate report.

One-hundred and sixty-eight carers of people with a diagnosis of BPD entered the survey site. Of these, 168 (100%) proceeded to answer survey questions, with 46 carers (27.38%) completing all questions, and 122 (72.61%) being selective in which questions they responded to. This represents a lower overall number of responses in 2017 compared with the original survey in 2011 in which 121 of 128 carers (95.0%) proceeded to answer survey questions, with 61 carers (50.4%) completing all questions, and 60 (49.6%) being selective in which questions they responded to.

As per the 2011 survey, participation in the current survey was open to any informal carers of a person who identified as having a diagnosis of BPD. The invitation to participate was distributed to mental health service organisations and 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 survey was widely publicised and delivered online via 'Survey Monkey' across Australia, and was conducted between 1st June, 2017 and 21st July 2017 (51 days). The 2011 survey was open for 35 days. Like, the original survey, it should be noted therefore that 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 therefore depends on the extent to which response bias may have existed. Similarly, many consumers that did participate were also selective of the questions they answered, particularly later in the survey.

The questions posed to respondents in the 2011 and 2017 surveys were essentially the same. A small number of revisions and additions were made to the 2017 survey to reflect the current Australian context and to address oversights from the original survey. For example, a third option of 'other' was added to 'gender' to capture any LGBTI individuals.

Summary of Results:

Survey responses were received from carers in each region of Australia.The distribution of the responses in each state was similar to the distribution of the national population.

More than two thirds of survey respondents lived in Capital cities (68.9%, n=115) with 28.7% (n=48) living in regional towns and 2.4% (n=4) in remote towns in Australia. This reflects the national population pattern for Australia.

Most respondents were female (84.8%, n=140) compared to males (15.2%, n=25). This does not reflect the national gender mix of 51% females and 49% males in the overall Australian population.

Almost half of respondents were in the 50-64 years age group (48.8%, n=82) with the next highest concentration of carers in the 40-49 year age group (23.8%, n=40). Smaller figures were reported in other age groups. That is, the survey sample si predominantly those in the prime working decades from 40-64 years.

Almost two thirds were in a spouse/partner relationship (61.9%, n=104), 20.8% (n=35) were separated or divorced, and 14.3% (n=24) were single. These results suggest that people caring for a person with BPD are more likely to be in a spouse/partner relationship compared with their age matched counterparts in the general population. According to the 2017 survey, those who were single perceived their access to supports as more challenging (p=0.03); whereas there was no significant difference found in 2011.

Only 1.8% (n=3) of respondents were of Aboriginal or Torres Strait Islander Descent. Forty-two respondents were born outside of Australia and came from a range of countries. Most had been in Australia for 10 years or more, and few spoke a language other than English at home.

Almost half of respondents were a parent or guardian (48.8%, n=79); another 20.4% (n=33) were a spouse/partner. The person cared for was more likely to be female (76.5%, n=124) than male (22.2%, n=36), and also more likely to be single (55.9%, n=90) followed by a having a spouse/partner (32.9%, n=53), or separated/divorced (9.3%, n=15).

More than two thirds of respondents (76.5%, n=114) reported the cared for person's primary diagnosis was BPD. Anxiety disorder was mentioned as the prominent comorbid diagnosis (64.3%, n=83) followed by post-traumatic stress disorder (PTSD) (31%, n=40). There was a significant increase in PTSD (31% vs 20%, p<0.001) and in obsessive compulsive disorder (OCD) (21.7% vs 10%, p=0.02) in 2017 compared to 2011. There was a significant increase in 2017 in BPD diagnosis 'within the last year' (15.9% vs 6.2%, p=0.02) and a non-significant but noticeable decrease in diagnosis in 'longer than 10 years ago' (17.2% vs 26.8%).

In most cases, a psychiatrist was the first to make a diagnosis of BPD (66.9%, n=99), with psychologists (16.2%, n=24) and GPs (8.1%, n=12) making the first diagnosis in far fewer cases. The number of psychiatrists who diagnosed BPD in 2017 was significantly lower than that of 2011 (80.5%, n=70, p=0.02). Eleven carers did not know who made the diagnosis. Of concern, 74.5% (n=111) of carers reported that the medical professionals who diagnosed BPD did not explain to them as a carer what BPD means. This number was significantly higher than the 2011 survey (62.4%, n=58, p=0.04). Only 14.7% (n=22) of carers had the diagnoses explained to them and also understood the explanation given; this number was significantly lower than the 2011 survey (32.3%, n=30, p=0.001).

29.7% (n=35) of respondents reported that the person had either not been admitted to hospital or that it had been more than 18 months since their last admission; significantly lower than the 2011 survey (52.3%, n=34, p=0.002). Conversely, 33.9% (n=40) of carers reported the person's admission in the past 3 months, which was significantly higher than the 2011 survey (20%, n=13, p=0.04).

Almost two thirds reported the person taking anti-depressants for their mental health issues (64.58%, n=93), 38.89% (n=56) were taking an anti-psychotic medication, 34.72% (n=50) were taking an anti-anxiety medication, and 18.06% (n=26) reported them taking no medications, compared with 22.3% (n=21) in 2011. Similar rates of not knowing what medication the person was taking were reported in each survey period they were taking (5.3%, n=3 in 2011 and versus 9.03%, n=13 in 2017, p<0.001).

The most common unusual/concerning behaviour or sign of future problems with mental health that carers noticed about the consumer during infancy or toddlerhood was sensitivity (72.7%, n=24 of the 33 carers). Moodiness (21.2%, n=7), excessive separation anxiety (42.4%, n=8) and social delay (27.3%, n=9) were also highlighted. Compared to the 2011 survey, there was a significant increase in reported sensitivity and a decrease in other reported issues. During childhood, sensitivity rated highly (66.7%, n=26), along with being a victim of bullying (56.4%, n=22), difficulty making friends (51.3%, n=20), and body image issues (46.2%, n=18). Compared to the 2011 survey, there was a significant decrease in a range of reported issues. During the person's adolescence, sensitivity (72.7% vs 52.6%) and body image issues (72.7% vs 52.6%) were the most prominent issues that carers reported noticing; both significantly higher than 2011 results. Moreover, emptiness, anorexia, bulimia and hallucinations were also statistically higher. Comparing, samples from the two survey periods, it appears that, from carers' perspective, health service providers, and teachers to a lesser degree, are continuing to fail to recognize and act on parents' concerns for these children. Once an evaluation of their child was undertaken by a professional, 56.1% (n=23 out of 41) of carers reported that therapy was the main treatment, followed by medication (53.66%, n=22), and hospitalisation (24.39%, n=10); similar to 2011 survey results.

Carers continued to experience many challenges in their carer role, with a lack of support options available to them as the most commonly cited challenge (48.87%, n=42). Carer support groups, education and information, counselling for them as carers, and mental health professional support were noted as helpful; though no support types were rated as 'very helpful' overall. Similar to 2011 survey, being unable to access supports when needed (54.1%, n=73) and not being taken seriously (54.1%, n=73) rated high on the list of barriers experienced by carers. Further statistical analysis did not show any significant differences between 2011 and 2017 survey responses; that is, both samples experienced high levels of problems with accessing support for their carer roles.

Of the full range of issues that may cause anxiety for the person they care for as challenging, lack of long-term consistent support (67.48%, n=83), not being taken seriously (67.48%, n=83), and long waiting lists/times to see mental health professionals (60.16%, n=74) were overwhelmingly and most frequently rated as being very challenging. There was a significant increase in 2017 in the response rate of not being taken seriously (44.1% vs 67.48%, p<0.001).

Regarding which mental health services had been helpful/supportive for the person cared for, psychotherapy was rated highest as either helpful or very helpful (36.07%, n=44) compared with other services. Mental health services support for identifying early warning signs, developing a crisis plan, education and information about BPD, and hospital admissions stood out as very unhelpful. Mental health service input to developing a crisis plan was now more unhelpful (29.03% vs 10%, p=0.002). There was a significant increase in the rating of mental healt support groups as being helpful (16.26% vs 4.3%, p=0.004). While CBT was reported to be either helpful or very helpful in 2011, DBT was preferred in 2017; CBT was reported less in 2017 as 'very helpul' (6.5% vs 15.9%, p=0.04).

Psychologists were seen as the key contributors in patients' recovery across both survey periods.

However, the percentage of respondents that affirmed the contribution of each type of health professional support was quite low.

51.61% (n=64) said that their GP had not supported them as a carer; very similar to 2011 survey results. Of these, 79.03% (n=98) also reported that their GP does not provide them with personal counselling for issues related to being a carer (76.1% in 2011). However, 69.67% (n=85 of 122) reported that a GP has supported the person they care for in terms of issues related to BPD. Referral to carer support services or mental health professionals was reported as mixed. Of concern, almost half of carers (55.56%, n=65 of 117) reported that their GP had not referred them to other supports. This figure was slightly higher than the 2011 survey (48.5%, n=32 of 66) but was not significant. Compared to 2011, GP support had significantly increased in 2017 across all variables except for those who had private hospital admissions- metropolitan (50% vs 69.6%, p=0.03), rural (46.7% vs 69.8%, p=0.04) and 'no private hospital admissions' (34.8% vs 62.9%, p=0.03), suggesting that greater equity of GP experience was now apparent, particularly for rural populations and for those who had no private hospital admissions.

Rates of public and private hospital use were similar across both survey periods: 39.3% (n=48) said the person they cared for uses only public, 8.2% (n=10) use only private, 23.0% (n=28) use mostly public and some private, and 27.0% (n=33) use mostly private and some public hospital services.

Compared to the 2011 survey, the only significant difference in public hospital use was observed in those who had not been admitted during the past three years (23.1%, n=9, p=0.001). Carers reported that the cared for person's longest stay in hospital for mental health issues ranged from three or more weeks (28.13%, n=18), two weeks (15.63%, n=10), or one week or less (53.13%, n=34), representing a significant decrease in the hospital length of three weeks or more since 2011 (52.5%, n=21, p=0.003) and a significant increase in length of one week or less (27.5%, n=13, p=0.003). Overall, hospital treatment for BPD continues to be highly variable.

Reports of involuntary hospital admissions were similar across the survey periods (in 2017 64.06%, n=41 'yes' compared with72.5%, n=29 in 2011). For public hospital users, 34.48% (n=20) of 58 carers reported that they had never been involved with the decision-making for these admissions; significantly lower than the 2011 survey (48.6%, n=18, p=0.03). However, respondents' involvement (n=14) significantly increased in the patients' assessment process (24.14% vs 5.4%, p<0.001).

52.38% (n=33) carers reported that they had experienced times when they had asked for the person they cared for to be admitted to hospital but had been refused; similar to 2011 experiences. Of note, 17.24% (n=5 from a small total of 29 carers) said that a psychiatrist refused the admission, which was significantly lower than that results reported in 2011 (31.3%, n=5, p=0.02). Also, a third of the carer respondents (31.03%, n=9) did not know who refused the person's admission to hospital. Similar experiences were reported in the consumer survey, with results suggesting that communication quality about the reasons for non-admission has declined for both consumers and carers since the previous survey in 2011. Further comments about how they as a carer felt and what the impact was of the refusal to admit the person to hospital included overwhelming feelings of helpless, hopeless, being highly distressed, terrified that their loved one would suicide, angry and frustrated.

The main reasons for seeking hospitalization were directly as a result of suicidal behaviours of the person (80.0%, n=28) and self-harm behaviours (74.29%, n=26); similar to 2011 and non-significant change. However, in 2017, there was a significant increase in the following issues: 'out of control' (71.41% vs

45.5%, p<0.001), 'life in chaos' (54.3% vs 36.4%, p=0.01), 'depression' (74.3% vs 50%, p<0.001) and 'anxiety' (62.9% vs 40.9%, p=0.001).

Responses from carers about the number of admissions of the person to private hospitals in the past three years compared to public hospitals over the same period were similar. The longest stay in private hospital was reported by 76.32% (n=29 of 38 reponses) of carers as three or more weeks, with very low responses across the other shorter admission lengths. This last cohort (3+ weeks) showed significantly higher rate in 2017 than that of 2011 (61.1%, n=11, p=0.02).

Carer respondents reported that the person they cared for saw a range of mental health professionals for issues related to their BPD, with most reporting psychiatrists (77.12%, n=91) and psychologists (77.12%, n=91) as the two main professional groups. In 2017, there was a significant increase in use of psychologists (77.12% vs 59.20%, p=0.006), compared with 2011.

Of those who reported that the person with BPD did access mental health professional support, 29.73% (n=33) stated that they had done so for 5-10 years, and 28.83% (n=32) for more than 10 years. The later response rate was significantly lower than the 2011 survey (45.3%, n=29 of 64, p=0.02).

The extent to which mental health professionals had supported carers for issues related to caring for a person diagnosed with BPD (n=110) varied across the spectrum of 'very supportive' to 'not supportive'. Of note, GPs were rated as 'supportive' (34.91%, n=37 of 106) and 'very supportive' (17.92%, n=19 of 106). It would seem that GPs are an important source of support for carers. On the contrary, 32.65% (n=32 of 98) of carers reported that psychiatrists were 'not supportive'. Psychologists were stated as more supportive than ratings of that profession from the 2011 survey (14.8%, n=8, p=0.01).

Carers' responses to questions about whether mental health professionals had helped them to understand how to help manage the person's early warning signs and risk of suicide or self-harm also showed large gaps: 78.18% (n=86 of 110) reported that mental health professionals had not helped them to understand these issues. This represented a significant increase since the 2011 survey; i.e. more mental health professionals had not helped carers to understand these issues (78.18% vs 55.4%, p=0.001). In addition, most respondents (82.73%, n=91 of 110) had not received a crisis plan from mental health service providers for the person they care for.

105 carers responded to the question asking if the person they care for had ever attempted to end their life, to which 76.19% of respondents said 'yes' (n=80), 10.48% said 'no' (n=11) and 13.33% (n=14) said they didn't know. These results were similar to the 2011 survey (76.3% 'yes', 15.2% 'no', and 8.5% 'don't know'). The length of time that mental health professionals took to respond to the person cared for in a crisis varied: the same day (21.82%, n=24), within 2 days (22.73%, n=25), between 2 days-1 week (21.82%, n=24), longer than a week (8.18%, n=9), did not response (9.09%, n=10), and did not know (16.36%, n=18). Upon collapsing results, 44.55% (n=49) reported a response from mental health professionals within two days and 55.45% (n=61) reported a response of longer than this, including not at all. No significant difference was observed between 2017 and 2011 surveys (33.3%, n=21 and 66.7%, n=42 respectively), suggesting that response times to consumers in crisis, as reported by carers, have not improved since 2011.

As distinct from the term 'crisis', reported response time when the person self-harmed or attempted suicide were similar: 55.55% (n=45) receiving support the same day or within 1-2 days (non-significant vs 44.55%), with 38.3% (n=18) reporting a response of longer than this, including not at all (vs 55.45%, p=0.01). When compared to 2011 results, both of these reponses were significantly different (38.3%, n=18, p=0.01, and 61.7%, n=29, p=0.001 respectively). In particular, the 2017 survey showed significant improvements in the same day response (35.8% vs 21.3%, p=0.01) and in those who did not get a response compared to the 2011 survey (2.5% vs 23.4%, p<0.001). These results suggest that response times to consumers' self-harm and suicide attempts, have improved significantly since 2011.

However, when asked what the longest time was that it took to get support for the person cared for after requesting it, a higher proportion of carers than consumers (p=0.004 in 2011) reported that they did not get a response (p=0.64). This suggests that services are making different judgements about need and crisis when assessing information provided by the carer versus the consumer with BPD.

In response to a crisis, GPs (60.19%) were more commonly rated as`very responsive' or 'responsive' by carers (n=62 of 103) compared to other professionals, and psychiatrists were noted as 'not responsive' (30.61%) (n=30 of 98) by a greater number of carers than any other profession.The results were very similar to results from the 2011 survey.

Across the two survey time periods, carers' ratings of the person seeking help from psychiatrists and mental health workers following self-harm appeared to increase. However, consumers' reported the opposite: in 2017, fewer sought help from their GP (38.86%, n=89) compared with 2011 survey respondents (48.3%, n=42); and fewer 2017 survey respondents sought help from a psychiatrist (31%, n=71 compared with 37.3%, n=31 in 2011). Of concern, the proportion of people not seeking any support from health professionals, as reported by both carers and consumers, appears to have increased (Carers: 39.30%, n=90 for 2017 compared with 32.5%, n=27 for 2011).

Carers were slightly less likely to seek help for themselves from psychiatrists (11.63%, n=10) and more likely to seek help from staff at the hospital emergency department (27.91%, n=24). Both figures were slightly lower than the 2011 survey (15.9%, n=7 and 29.5%, n=13 of 44 respectively) but did not show any significant difference. Of great concern, 40.70% of carers (n=35) did not seek any help for themselves, which was significantly higher than that of 2011 result (27.3%, n=12, p=0.03).

Similar to the consumers who they care for, only 4.8% (n=3 of 62) of carers in the 2017 survey reported that they did not get a response to their requests for help when the person was suicidal or self-harming. Compared to 2011 survey results, this was a significant difference (35.9%, n=14 of 39, p<0.001), suggesting clear improvement in services' response to carers' requests for help. If these figures are collapsed, 41.93% (n=26 of 62) of carers got support within 2 days but 46.77% (n=29) had to wait 2 days or more and more than half of these did not get any response; there was a significant improvement in the later variable since 2011 (66.7%, n=26, p=0.002).

Carers overwhelmingly reported medical attention following suicide attempt and self-harming by the person involved hospital emergency department contact (90.7%, n= 49 of 54, compared to 86.7%, n=26 in 2011, p=0.56) with the remainder attending a GP (22.22%, n=12). These results did not show any significant differences. In 75.0% of cases (n=42), carers reported that the person they cared for was referred to a mental health professional as a result of the self-harming at these times. The remainder were not; the result was almost the same as the 2011 survey (76.5%, n=26).

Carer respondents (n=114) had few positive comments to make about other community support services. Similar to earlier responses, their response patterns suggested that they neither found them very helpful nor very unhelpful. Perceptions of gambling support as not applicable has significantly decreased in 2017 (87.5%, n=98 of 112 respondents) compared with 2011 survey results (96.8%, n=60 of 62, p=0.02).

Context for the 2017 Survey

This report provides an update on the experiences and needs of Australian consumers with a diagnosis of Borderline Personality Disorder (BPD), derived from a survey conducted in 2017. It also provides a comparison of results from a similar survey conducted in 2011. The consumer survey has an accompanying family/carer survey (Part 2), also conducted in 2011 and again in 2017.

The purpose of the original 2011 surveys was to better understand the needs of consumers with BPD diagnoses and of their family members and carers, what supports were most helpful and what barriers there were to accessing help in the current mental health system. The purpose of repeating these surveys in 2017 was to determine whether any improvements in these experiences has occurred, given greater awareness of BPD within Australia's mental health and primary care service systems, and the release of the National Health and Medical Research (NHMRC) Guidelines for the Treatment of BPD in late 2012. The NHMRC BPD Guidelines include evidence-based recommendations (EBR), consensus-based recommendations (CBR) and practice points (PP). Key recommendations are summarised in the following table:

Table 1: Key Recommendations from the NHMRC Guidelines for the Treatment of BPD

Key Recommendation	Type
Health professionals at all levels of the healthcare system and within each type of service setting should: acknowledge that BPD treatment is a legitimate use of healthcare services be able to recognise BPD presentations be aware of general principles of care for people with BPD and specific effective BPD treatments provide appropriate care (including non-specific mental health management, specific treatments for BPD and treatment for co-occurring mental illness) according to their level of training and skill refer the person to a specialised BPD service or other services as indicated undertake continuing professional development to maintain and enhance their skills	CBR
People with BPD should be provided with structured psychological therapies that are specifically designed for BPD, and conducted by one or more adequately trained and supervised health professionals.	EBR (B) #
Medicines should not be used as primary therapy for BPD, because they have only modest and inconsistent effects, and do not change the nature and course of the disorder.	EBR (B)
The majority of a person's treatment for BPD should be provided by community-based mental health services (public and private).	CBR
Adolescents with BPD should be referred to structured psychological therapies that are specifically designed for this age group. Where unavailable they should be referred to youth mental health services.	PP
Health professionals should inform people with BPD about the range of BPD-specific structured psychological therapies that are available and, if more than one suitable option is available, offer the person a choice.	CBR
Health professionals should refer families, partners and carers of people with BPD to support services and/or psychoeducation programs on BPD, where available.	CBR
Health professionals should consider assessment for BPD (or referral for psychiatric assessment) for people (including those aged 12–18 years) with any of the following: frequent suicidal or self-harming behaviour marked emotional instability multiple co-occurring psychiatric conditions non-response to established treatments for current psychiatric symptoms a high level of functional impairment.	PP (adults) CBR (adolescents)

B - Body of evidence can be trusted to guide practice in most situations

More specifically, the guidelines include the following further detail related to the care of people with BPD and in their communication with the person's family/carers:

"After making the diagnosis, health professionals should tell people with BPD that they have this illness, explain the symptoms, talk about how the person's own experience would fit this diagnosis, emphasise that it is not their fault, and carefully explain that effective treatments are available. Some health professionals believe it is better not to tell a person they have BPD (particularly if the person is younger than 18 years old), mainly because some parts of the health system and society have discriminated against people with BPD and increased their suffering. However, telling the person the diagnosis can help them understand what they have been experiencing and might help ensure they receive effective treatment" (p.1).

"Admissions to hospitals or other inpatient facilities should not be used as a standard treatment for BPD and should generally only be used as short-term stays to deal with a crisis when someone with BPD is at risk of suicide or serious self-harm. Hospital stays should be short, and aim to achieve specific goals that the person and their doctors have agreed on. Health professionals should generally not arrange long-term hospital stays for people with BPD. If a person with BPD needs to visit an emergency department because they have harmed themselves or cannot cope with their feelings, staff should arrange mental health treatment to begin while the person's medical needs are being dealt with. Emergency department staff should attend to self-inflicted injuries professionally and compassionately" (p.2).

"Having BPD should never be used as a reason to refuse health care to a person" (p.3).

"For all people with BPD, a tailored management plan should be developed in collaboration with them. The person's family, partner or carer should be involved in developing the management plan, if this is in the person's interests and they have given consent for others to be involved….
Health professionals should acknowledge and respect their [family/carers'] contribution. Health professionals should, with the person's consent, involve families, partners and carers of people with BPD when developing a crisis plan. However, some people with BPD prefer not to involve others….Health professionals should help families, partners and carers of people with BPD by giving them clear, reliable information about BPD, arranging contact with any support services that are available (such as carer-led programs that educate families/carers on BPD and respite services) giving them information about how to deal with suicide attempts or self-harm behaviour, advising them about the most helpful ways to interact with the person with BPD, and offering referral to family counseling" (p.3).

The 2011 surveys reported that many of these above recommended practices and care options were not provided to people with BPD or their family/carers. Given that the national BPD guidelines were released almost 5 years ago, it is time to see how the situation has changed. In particular, we were interested in comparing survey results to answer the following broad questions:

- Has the level of discrimination towards people with BPD changed?
- Has transparency of the BPD diagnosis and education about what it means improved?
- Has medication use changed?
- Has GP support changed?
- Are there any changes across public and private hospital systems?
- Have there been any changes to urban and rural experiences?
- Has service responsiveness changed? (ED, mental health services, disciplines)
- Has the service response to self-harm changed?
- Has family/carer support changed?
- Has health professional responsiveness to family/carers changed?
- Has response to family/carer involvement changed?

Survey Method

The surveys were developed as online tools open to any Australian mental health consumer with a diagnosis of BPD, or any carer or family member of consumers with a diagnosis of BPD.

The survey instrument and questions were devised in the first instance by the Network Independent Chair, and then reviewed by consumer, carer and academic researcher stakeholders. Piloting the Australian BPD surveys was not undertaken.

Participation in the BPD consumer survey was open to any consumer who identified themselves as having a diagnosis of BPD and were those that responded to an invitation to participate distributed in the first instance to mental health service organisations and 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 1st June and 21st July 2017. 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. Therefore, 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.

Statistical Analysis

The data are presented predominantly as descriptive statistics. Univariate analysis using the Statistical analysis was performed using either the "SurveyMonkey" cross-tabulation function within the online survey or SPSS statistical software version 23. Comparisons of survey proportions with known population percentages were compared using a one-sample test of proportions. Chi-square tests of association were performed in order to identify relationships between categorical variables.Cramer's V effect size was also used to assess effect size.This statistic ranges from 0 to an upper limit of 1 where conventional criteria are 0.10=small, 0.30= medium, and 0.50 =strong.Two independent sample test of proportions was used to compare the data between 2011 and 2017 survey. Same test was used to compare the results between carers and consumers. The statistic helps facilitate a meaningful interpretation of the strength of any relationship.The level of statistical significance was chosen as $p<0.05$. Although a large number of hypotheses were tested, we did not adjust for the number of comparisons performed. Rather,we have left the p-values as they stand and interpreted the findings cautiously.The readers hould be aware of this when reading the report.Confidence intervals for proportions are not presented since the results were not designed to estimate the views of the total Australian BPD population,but instead represent the views of those individuals with BPD and carers of individuals with BPD that responded to the survey.

Results

Survey response rate

There were 168 carers who took part in the online survey, however it is impossible to ascertain just how many carers the survey was on-forwarded to.This precludes the estimate of the response rate as well as obtaining details of who did not respond,i.e.age, geographic location etc. One-hundred and sixty-eight carers of people with a diagnosis of BPD entered the survey site. Of these, 168 (100%) proceeded to answer survey questions, with 46 carers (27.38%) completing all questions, and 122 (72.61%) being selective in which questions they responded to. This represents a lower overall number of responses in 2017 compared with the original survey in 2011 in which 121 of 128 carers (95.0%) proceeded to answer survey questions, with 61 carers (50.4%) completing all questions, and 60 (49.6%) being selective in which questions they responded to.

Demographic Details

State and Territory Location

All 167 carers indicated the state or territory in which they lived. Survey responses were received from carers in each region of Australia.The distribution of the responses in each state was similar to the distribution of the national population. The higher response rates in SA, Victoria and WA may reflect more effective network dissemination of the survey through those states or may simply reflect the large sampling variation due to the relatively small number of participants in each State (see Table 2).

Table 2: Response Count by State or Territory (n=167)

Australian State/Territory	Total Population	Percentage of total population	Survey response count	Percentage of survey population	P-value for difference in proportion[a]
NewSouthWales	7, 797, 800	31.98%	28	16.8%	0.09
Victoria	6, 244, 200	25.61%	37	22.2%	0.63
Queensland	4, 883, 700	20.03%	12	7.2%	0.27
WesternAustralia	2, 567, 800	10.54%	10	6.0%	0.64
SouthAustralia	1, 717, 000	7.04%	69	41.3%	< 0.0001
Tasmania	519, 100	2.13%	5	3.0%	0.89
AustralianCapitalTerritory	406, 400	1.67%	5	3.0%	0.82
NorthernTerritory	245, 000	1.00%	1	0.6%	0.97
Total	24, 385, 600	100	**167**	100%	

Source of national population data: ABS (2017)3101.0 - Australian Demographic Statistics, Dec 2016. http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0 [a]Based on a one-sample test of proportions.

Location Density

Of the 168 respondents, all except one person provided information on their area of residence. More than two thirds of survey respondents lived in Capital cities (68.9%, n=115) with 28.7% (n=48) living in regional towns and 2.4% (n=4) in remote towns in Australia. According to the ABS (2017), more than two thirds of Australians live in a Capital city and, between Censuses, the number of people living in capital cities grew nearly twice as fast as the number of people living outside of capital cities (10.5% and 5.7% respectively). Our survey results reflect the national population pattern.

Gender

Of the 165 respondents who recorded their gender, most were female (84.8%, n=140) compared to males (15.2%, n=25). This does not reflect the national gender mix of 51% females and 49% males (ABS 2017) in the overall Australian population ($p<0.001$), or more diverse gender identify (Australian Human Rights Commission, 2017). These results may reflect the higher rates of women in carer roles or the possibility that more female carers chose to participate in this survey than male carers.

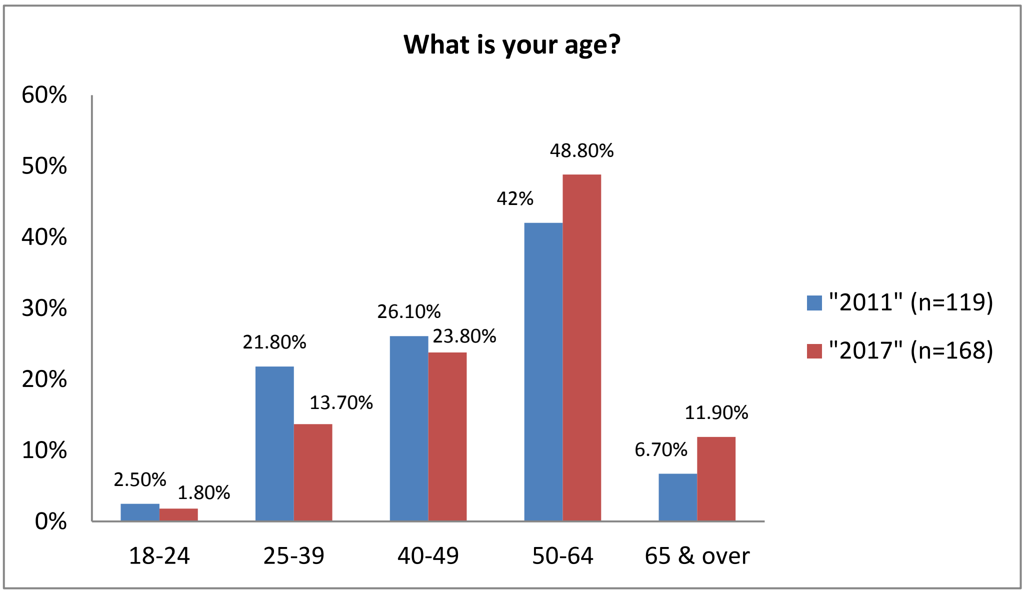
Age

Of the 168 subjects who responded to this question, almost half were in the 50-64 years age group (48.8%, n=82) with the next highest concentration of carers in the 40-49 year age group (23.8%, n=40). Smaller figures were reported in other age groups (Table 3 and Figure 1). These figures were similar to that of 2011 survey. The age range for carers for a person with BPD therefore included the whole adult lifespan but particularly includes those in the prime working decades from 40-64 years.

Table 3: Age of Carers

Age groups	2011 N (%)	2017 N (%)
<18	0 (0)	0 (0)
18-24	3 (2.5)	3 (1.8)
25-39	23 (21.8)	23 (13.7)
40-49	31 (26.1)	40 (23.8)
50-64	50 (42)	82 (48.8)
65 & over	8 (6.7)	20 (11.9)

Figure 1: Age of Carers



Marital status

Of the 168 subjects who responded to this question, almost two thirds were in a spouse/partner relationship (61.9%, n=104), 20.8% (n=35) were separated or divorced, 14.3% (n=24) were single, and none were widowed. These results are very similar to results from the 2011 survey. Given national figures for marital status by age group within the general population, these results suggest that people caring for a person with BPD are more likely to be in a spouse/partner relationship compared with their age matched counterparts in the general population (Hayes, Weston, Qu & Gray, 2011).

We also assessed whether carers who are single may be better or worse off in terms of service support and found that there was a significant association in terms of 'support access' (Table 4). According to the 2017 survey, those who were single perceived their access to supports as more challenging (p=0.03); whereas there was no significant difference found in 2011.

Table 4: Association between carers relationship status with support accessibility and options

	Relationship status		χ^2	***P***	**Effect size**	**Relationship status**		χ^2	***P***	**Effect size**
	2011 (n=76)					**2017 (n=133)**				
	Single	**Spouse/ partner**				**Single**	**Spouse/ partner**			
Support access			2.66	0.264	0.19			7.04	**0.03**	0.23
Very challenging	17 (47.2)	19 (52.8)				30 (48.4)	32 (51.6)			
Challenging	8 (40)	12 (60)				13 (29.5)	31 (70.5)			

Neutral/not challenging/ not applicable	5 (25)	15 (75)				6 (22.2)	21 (77.8)			
Support options			1.07	0.585	0.12			5.18	0.075	0.197
Very challenging	16 (42.1)	22 (57.9)				29 (44.6)	36 (55.4)			
Challenging	9 (45)	11 (55)				15 (35.7)	27 (64.3)			
Neutral/not challenging/ not applicable	5 (29.4)	12 (70.6)				5 (19.2)	21 (80.8)			
Service availability			1.02	0.6	0.12			3.91	0.142	0.173
Very challenging	11 (36.7)	19 (63.3)				21 (46.7)	24 (53.3)			
Challenging	7 (50)	7 (50)				16 (39)	25 (61)			
Neutral/not challenging/ not applicable	10 (34.5)	19 (65.5)				12 (26.7)	33 (73.3)			

*Data are presented as number (percentage)

Aboriginal or Torres Strait Islander Descent

Of the 117 respondents that answered this question, only 1.8% (n=3) were of Aboriginal or Torres Strait Islander Descent and 163 (98.2%) were not. These percentages do not reflect the overall Australian population densities and the perceived wisdom that Aboriginal carers actually makeup a disproportionately higher percentage of those in carer roles for persons with BPD than the non-Aboriginal population (Jenkins & Seith, 2011). This perhaps suggests that a lower proportion of Aboriginal carers participated in the survey than non-Aboriginal carers and that other means of seeking the views of Aboriginal carers need to be explored.

Country of Birth, Years in Australia, and Language Spoken at Home

Forty-two respondents were born outside of Australia and came from a range of countries, predominantly from the UK (n=20), New Zealand (n=4), and the USA (n=2). There was one from each of the following countries: Indonesia, Canada, Holland, Lebanon, Hong Kong, Malta, Portugal, Finland, Italy, Philippines, Myanmar, Singapore, Belgium, Hungary and India. Though small in number, the variety of backgrounds suggests that the survey captured the views of people from diverse cultural backgrounds. Most of these respondents had been in Australia for 10 years or more, except for five (lowest stay 1 year and highest stay was 70 years) and only two spoke a language other than English at home.

Twenty-three carers indicated that the person cared for was also born outside of Australia (New Zealand, UK, Holland, India, Maldives, Myanmar, Phillipines, Portugal, Singapore and Thailand). The length of time that the consumer had lived in Australia ranged from 3 years to 48 years, and none spoke a language other than English at home.

The Journey of Caring for a Person with BPD Diagnosis

Status of the person cared for

Of the 162 respondents who indicated their relationship to the person cared for, almost half of the carers were a parent or guardian (48.8%, n=79). Another 20.4% (n=33) were a spouse/partner. The rest of the carers were siblings, children or friends (25.9%, n=42). Of interest, 4.9% (n=8) indicated that they were other than the survey defined relationships (Parent/guardian, spouse/partner, sibling, or son/daughter). The responses were quite different to that of 2011 survey (30.1%, n=31 carers were a parent or guardian and 24.3% (n=23) had referred to themselves as 'others'. A greater proportion of younger people responded to the 2017 consumer survey; therefore, this shift in the 2017 carer survey may reflect this shift, given that families may have shared communication about the consumer and carer surveys.

From 162 carer responses, the person cared for was more likely to be female (76.5%, n=124) than male (22.2%, n=36). Similar to the 2011 survey results, this is not proportionate to the gender mix of the population (ABS, 2017) or the evidence for the estimated BPD prevalence in the population (Grant et al, 2008). This finding suggests that either many men with BPD do not have carers or that a higher percentage of carers who care for women with BPD answered the survey. The person cared for was more likely to be single (55.9%, n=90) followed by a having a spouse/partner (32.9%, n=53), separated/divorced (9.3%, n=15) or widowed (1.9%, n=3). There was no survey question included in the consumer survey to determine whether the person lived with their carer.Therefore, aspects of the day-to-day contact with the person could not be examined. Of 159 carer responses, only four (2.5%) indicated that the person they cared for was of Aboriginal or Torres Strait Islander descent.

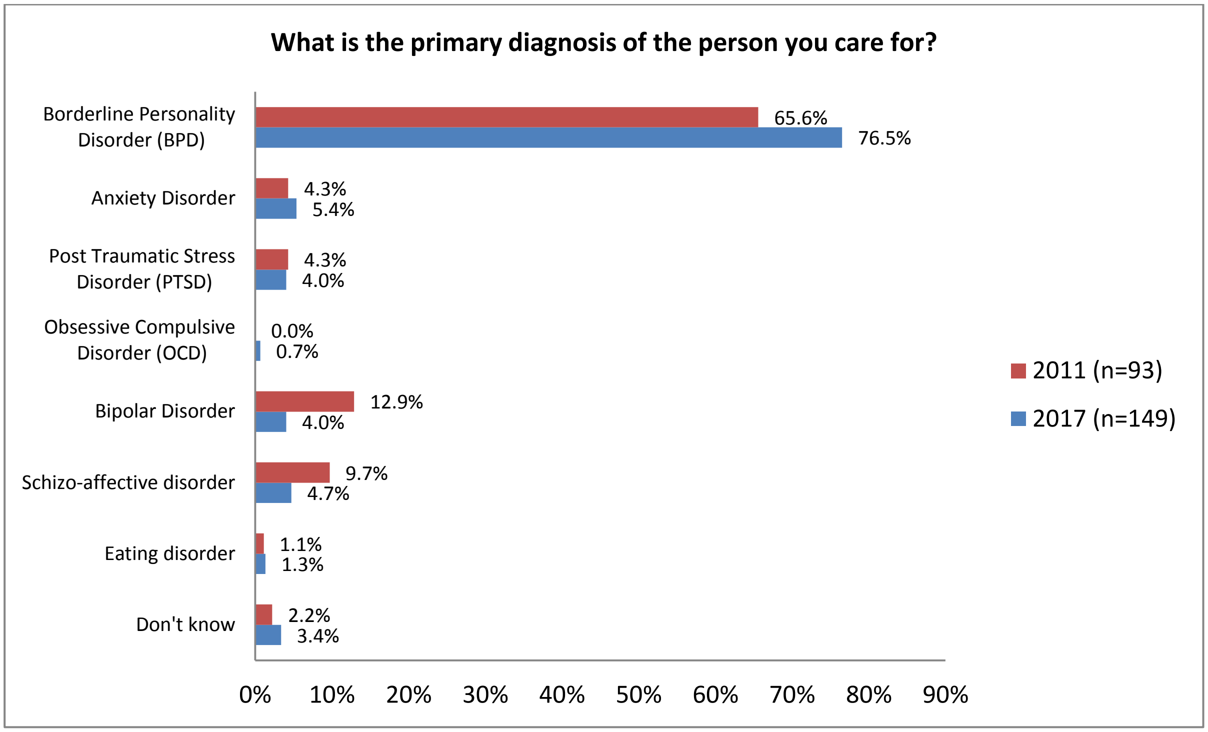
Mental Health Diagnoses

From 149 responses, the primary diagnoses of the persons cared for is shown in Figure 2 and Table 5 below. More than two thirds of respondents (76.5%, n=114) reported a primary diagnosis of BPD, with far fewer indicating other primary diagnoses. This figure was slightly higher than that of the 2011 survey but did not show any significant difference.

Table 5: Primary Diagnosis of the Person Cared For

Primary diagnosis	2011 N (%)	2017 N (%)
Borderline personality disorder	61 (65.6)	114 (76.5)
Anxiety disorder	4 (4.3)	8 (5.4)
Post traumatic stress disorder	4 (4.3)	6 (4.0)
Obsessive compulsive disorder	0 (0.0)	1 (0.7)
Bipolar disorder	12 (12.9)	6 (4.0)
Schizo-affective disorder	9 (9.7)	7 (4.7)
Eating disorder	1 (1.1)	2 (1.3)
Don't know	2 (2.2)	5 (3.4)

Figure 2: Primary Diagnosis of the Person Cared For

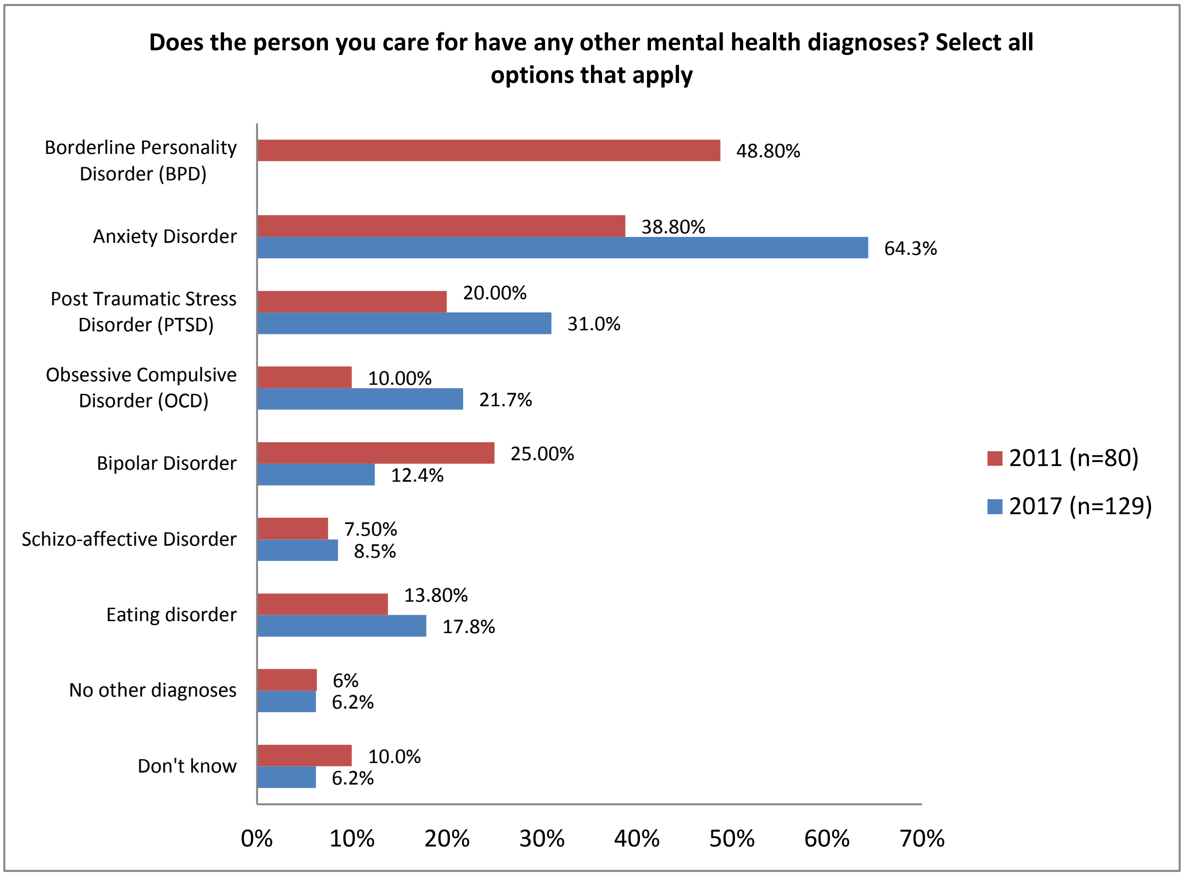


Of the 129 carer respondents to the question about the comorbidity, anxiety disorder was mentioned as the prominent comorbid diagnosis (64.3%, n=83) followed by post-traumatic stress disorder (PTSD) (31%, n=40) (Table 6 and Figure 3). There was a significant increase in PTSD (31% vs 20%, p<0.001) and in obsessive compulsive disorder (OCD) (21.7% vs 10%, p=0.02) in 2017 compared to 2011. However, BPD was not included as an option in the 2017 survey.

Table 6: Comorbid Diagnoses of the Person Cared For

Comorbid diagnoses	2011 N (%)	2017 N (%)
Borderline personality disorder	39 (48.8)	N/A
Anxiety disorder	31.04 (38.8)	83 (64.3)
Post traumatic stress disorder	16 (20.0)	40 (31.0)
Obsessive compulsive disorder	8 (10.0)	28 (21.7)
Bipolar disorder	20 (25.0)	16 (12.4)
Schizo-affective disorder	6 (7.5)	11 (8.5)
Eating disorder	11 (13.8)	23 (17.8)
No other diagnoses	5 (6.0)	8 (6.2)
Don’t know	8 (10.0)	8 (6.2)

Figure 3: Comorbid Diagnoses of the Person Cared For



Although the groups were not matched carer/consumer samples, there were some interesting similarities and differences between their responses to questions about primary and other diagnoses (see Table 7). The 2017 carers' report of the person's primary diagnosis of BPD (76.5%, n=114) was very similar to that reported by consumers 76.18%, n=291). However, in 2011, anxiety disorder (54.7%, n=64 vs 38.8%, n=31; p=0.03) and PTSD (41.0%, n=48 vs 20.0%, n=16; p=0.002) were noticeably higher in the consumers' report of their comorbid diagnoses compared with carers report of these comorbid diagnoses. In 2017, this was a similar pattern, with anxiety disorder reported by 64.3% (n=83) compared with 69.8% (n=222) of consumers, and PTSD reported by 45.28% (n=144) of consumers in 2017, compared with 31% (n=40) of carers in 2011 (p=0.005). This may reflect the range of consumers and carers that responded to the survey but may also possibly reflect the differing understandings of BPD and mental illness generally, and their different experiences of the impacts.

Table 7: Carer & Consumer report of Primary and Comorbid Diagnosis of the Person Cared For

Primary diagnosis	Carer Primay N (%)	Consumer Primary N (%)	Carer Comorbid diagnosis N (%)	Consumer Comorbid diagnosis N (%)	Carer vs Consumer comorbid difference (p value)
Borderline personality disorder	114 (76.5)	291 (76.2)	NA	NA	NA
Anxiety disorder	8 (5.4)	27 (7.1)	83 (64.3)	222 (68.81)	-4.51 (p=0.26)
Post traumatic stress disorder	6 (4.0)	28 (7.3)	40 (31.0)	144 (45.28)	-14.28 (p=0.005)
Obsessive compulsive disorder	1 (0.7)	4 (1.05%)	28 (21.7)	54 (16.98)	4.72 (p=0.24)

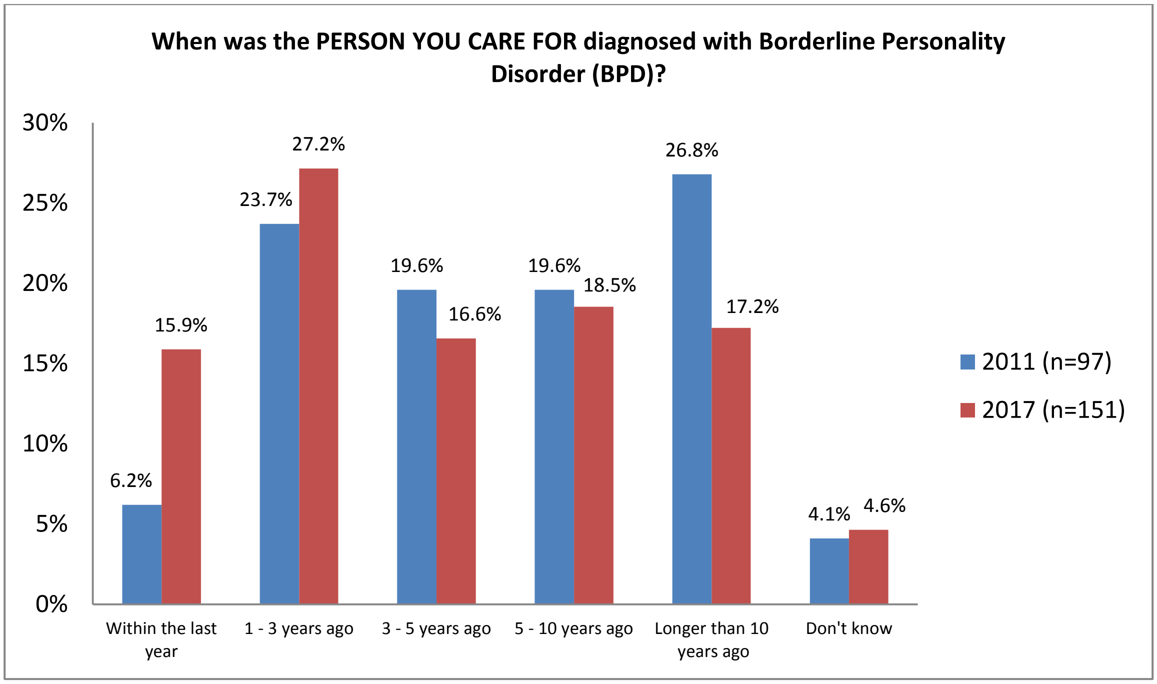
Bipolar disorder	6 (4.0)	30 (7.9)	16 (12.4)	48 (15.09)	-2.69 (p=0.46)
Schizo-affective disorder	7 (4.7)	6 (1.6)	11 (8.5)	NA	NA
Eating disorder	2 (1.3)	NA	23 (17.8)	74 (23.27)	-5.47 (p=0.21)
Depression	NA	22 (5.8)	NA	108 (33.96)	NA
Dissociative Identity Disorder	NA	6 (1.57%)	NA	NA	NA
Autism	NA	2 (0.52%)	NA	NA	NA
Postnatal Depression	NA	1 (0.26%)	NA	NA	NA
Dysthymia	NA	NA	NA	5 (1.57)	NA
Alcoholism/substance Dependence	NA	NA	NA	4 (1.26)	NA
Schizo-AffectiveDisorder	NA	NA	NA	3 (0.94)	NA
Panic Disorder	NA	NA	NA	2 (0.63)	NA
ADHD	NA	NA	NA	2 (0.63)	NA
Other	NC	NC	NC	15 (4.72)	NA
No other diagnoses	NC	NC	8 (6.2)	NC	NA
Don't know	2 (2.2)	NC	8 (6.2)	NC	NA
Total	**149**	**382**	**129**	**318**	

The length of time since the person cared for was diagnosed was variable according to the 151 carers who answered this question, and it reflected a broad range of experience of caring, from those who had been diagnosed within the last year (15.89%, n=24), to those who had been diagnosed more than 10 years ago (17.22%, n=26) (Table 8 and Figure 4). There was a significant increase in 2017 in diagnosis 'within the last year' (15.9% vs 6.2%, p=0.02) and a non-significant but noticeable decrease in diagnosis in 'longer than 10 years ago' (17.2% vs 26.8%).

Table 8: When the Cared for Person was First Diagnosed

Length of diagnosis	**2011** **N (%)**	**2017** **N (%)**
Within the last year	6 (6.2)	24 (15.9)
1-3 years ago	23 (23.7)	41 (27.2)
3-5 years ago	19 (19.6)	25 (16.6)
5-10 years ago	19 (19.6)	28 (18.5)
Longer than 10 years ago	26 (26.8)	26 (17.2)
Don't know	4 (4.1)	7 (4.6)

Figure 4: When the Cared for Person was First Diagnosed



Of carers from the 2017 survey who responded to which health professional made the first diagnosis of BPD for the cared for person (n=148), in most cases, a psychiatrist was the first to make a diagnosis (66.9%, n=99), with psychologists (16.2%, n=24) and GPs (8.1%, n=12) making the first diagnosis in far fewer cases. The number of psychiatrists who diagnosed BPD in 2017 was significantly lower than that of 2011 (80.5%, n=70, p=0.02). Eleven carers did not know who made the diagnosis.

Of concern, of 149 respondents, 74.5% (n=111) of carers reported that the medical professionals who diagnosed BPD did not explain to them as a carer what BPD means. This number was significantly higher than the 2011 survey (62.4%, n=58, p=0.04). A further 5.4% (n=8) had BPD explained but reported that they did not understand the explanation given. That is, only 14.7% (n=22) of carers had the diagnoses explained to them and also understood the explanation given. Of concern, this number was significantly lower than the 2011 survey (32.3%, n=30, p=0.001). Sixty-six carers took the time to make further comments and, similar to the 2011 survey resuls, most emphasized the struggle to get a clear diagnosis and be acknowledged and involved as carers. Of note from the 2017 survey, a small number of carers undertook their own research, usually on the Internet.

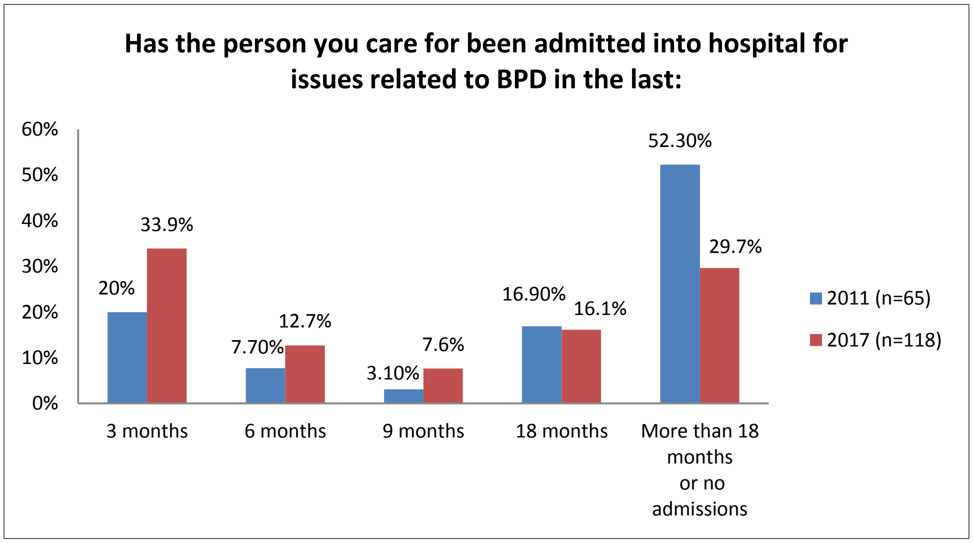
> *"As my daughter is 21yo my husband and I have no legal right to go into the consultation. We never got to speak with the psychiatrist at all. The only contact we had was I wrote a four page letter outlining the past 5yrs, I hope he read the letter."*
>
> *"I had already read about Borderline personality disorder before the diagnosis so I had some background knowledge. Also I am a registered nurse so had some familiarity with this condition."*

Patterns of hospital use, by the person with BPD, were reported by 118 carers, with 29.7% (n=35) reporting that the person had either not been admitted to hospital or that it had been more than 18 months since their last admission (Table 9 and Figure 5). The result was significantly lower than the 2011 survey (52.3%, n=34, p=0.002). Conversely, 33.9% (n=40) of carers reported admission in the past 3 months, which was significantly higher than the 2011 survey (20%, n=13, p=0.04). This may reflect improved early intervention via hospitalization for people with BPD or, as stated earlier, it may relate to the greater proportion of younger people who also responded to the consumer survey.

Table 9: Hospital Admissions for BPD

Hospital admission	2011 N (%)	2017 N (%)
3 months	13 (20.0)	40 (33.9)
6 months	5 (7.7)	15 (12.7)
9 months	2 (3.1)	9 (7.6)
18 months	11 (16.9)	19 (16.1)
More than 18 months or no admission	34 (52.3)	35 (29.7)

Figure 5: Hospital Admissions for BPD



Medication

According to the 144 carers who answered questions about the cared for person's medication, almost two thirds reported them taking anti-depressants for their mental health issues (64.58%, n=93), 38.89% (n=56) were taking an anti-psychotic medication, 34.72% (n=50) were taking an anti-anxiety medication, and 18.06% (n=26) reported them taking no medications, compared with 22.3% (n=21) in 2011. Of note, a greater number of 2017 consumer respondents reported taking no medication (24.06%, n=83, p=0.14). This may suggest that a greater proportion of current carers may think that the person is taking medication when, in fact, they are taking medication. Similar rates of not knowing what medication the person was taking were reported in each survey period they were taking (5.3%, n=3 in 2011 and versus 9.03%, n=13 in 2017, p<0.001). Responses to 'other' from the 24 carer respondents indicated mood stabilizers as the most frequently named medication. The results were similar to 2011 survey and did not show any significant differences. Of the 118 carers who said the person they cared for was taking medication of some type, they provided 199 responses across the available options (anti-depressant, anti-anxiety, anti-psychotic). This indicates that carers were aware of the cared for person taking more than one medication type.

Carers' Reflections on the Consumer's Experiences in Childhood and Adolescence

On reflection, the most common unusual/concerning behaviour or sign of future problems with mental health that carers noticed about the consumer during infancy or toddlerhood was sensitivity which was report by 72.7%

(n=24) of the 33 carers who responded to this question (Table 10). Moodiness (21.2%, n=7), excessive separation anxiety (42.4%, n=8) and social delay (27.3%, n=9) were also highlighted. Compared to the 2011 survey, there was a significant increase in reported sensitivity and a decrease in reported moodiness, picky eating, poor temperament and verbal delay noticed during these developmental periods. These results suggest that carers in the 2017 survey may have been less aware of the range of issues that may indicate future mental health problems but more aware of something being not quite right at a more global level, through increased awareness of concerns about sensitivity, when the cared for person was a young child.

Table 10: Issues Noticed in Infancy and Toddlerhood amongst Carers

Issues	Response Rate		2011 vs 2017 response rate difference (p-value)
	2011 (n=19)	2017 (n=33)	
Sensitivity	**57.9% (11)**	**72.7% (24)**	**+14.8% (p=0.02)**
Excessive separation anxiety	42.1% (8)	42.4% (14)	+0.3% (p=1)
Social delay	36.8% (7)	27.3% (9)	-9.5% (p=0.12)
Inability to be consoled	21.1% (4)	24.2% (8)	+3.1% (p=0.61)
Inability to self-soothe	21.1% (4)	24.2% (8)	+3.1% (p=0.61)
Colic	15.8% (3)	21.2% (7)	+5.4% (p=0.36)
Moodiness	42.1% (8)	21.2% (7)	**-20.9% (p=0.001)**
Sexual abuse (of this child)	15.8% (3)	18.2% (6)	+2.4% (p=0.70)
Picky eating	26.3% (5)	15.2% (5)	**-11.1% (p=0.05)**
Poor temperament	26.3% (5)	15.2% (5)	**-11.1% (p=0.05)**
Cognitive delay	15.8% (3)	15.2% (5)	-0.6% (p=0.84)
Sensory problems	5.3% (1)	12.1% (4)	+6.8% (p=0.07)
Motor delay	15.8% (3)	12.1% (4)	-3.7% (p=0.41)
Verbal delay	26.3% (5)	12.1% (4)	**-14.2% (p=0.011)**
Physical abuse (of this child)	15.8% (3)	9.1% (3)	-6.7% (p=0.13)

Carers also reflected on whether they noticed anything unusual/concerning in the person they cared for during their childhood (n=39) (Table 11). Again, sensitivity rated highly (66.7%, n=26), along with being a victim of bullying (56.4%, n=22), difficulty making friends (51.3%, n=20), and body image issues (46.2%, n=18). Compared to the 2011 survey, there was a significant decrease in the 2017 response rate in school refusal/truancy, moodiness, multiple schools, poor grades, conflict with authority figures, impulsivity, anger, suspension of expulsion and in poor temperament. That is, carers appeared to be more attuned to internally focused concerns in the person's life and less likely to report concerns with potential external manifestations of those problems. However, the findings are based on small number of responses, but if these findings were to be confirmed in a larger study they would have multiple implications for how parents and schools respond.

Of note, body image issues, drug abuse and alcohol abuse were added to the 'Childhood' list given more recent increasing concerns for and awareness of these issue being apparent in pre-adolescents; hence, a comparison with the 2011 survey for these issue was not possible. That there were responses at all to these issues is of considerable concern, given the young age of the persons at the time. In particular, that body image was report of almost half of carers (46.2%, n=18) is of particular concern.

Table 11: Issues Noticed in Childhood amongst Carers

Issues	Response rate 2011 (n=19)	Response rate 2017 (n=39)	2011 vs 2017 response rate difference (p-value)
Sensitivity	**63.2% (12)**	**66.7% (26)**	+3.5% (p=0.45)
Bully victim	47.4% (9)	56.4% (22)	+9% (p=0.20)
Difficulty making friends or few friends	**63.2% (12)**	51.3% (20)	-11.9% (p=0.08)
Body image issues	N/A	46.2% (18)	N/A
School refusal or truancy	52.6% (10)	33.3% (13)	**-19.3% (p=0.004)**
Emptiness	N/A	33.3% (13)	N/A
Frequent lying or deception	31.6% (6)	30.8% (12)	-0.8% (p=0.88)
Moodiness	42.1% (8)	28.2% (11)	**-13.9% (p=0.03)**
Verbal abusive outbursts	N/A	25.6% (10)	N/A
Sexual abuse (of this child)	31.6% (6)	25.6% (10)	-6% (p=0.35)
Impulsivity	36.8% (7)	23.1% (9)	**-13.7% (p=0.03)**
Conflict with authority figures	36.8% (7)	23.1% (9)	**-13.7% (p=0.03)**
Boredom	N/A	20.5% (8)	N/A
Anger	36.8% (7)	18.0% (7)	**-18.8% (p=0.002)**
Learning disability or special education	26.3% (5)	18.0% (7)	8.3% (p=0.17)
Substance abuse	N/A	18.0% (7)	N/A
Multiple schools	42.1% (8)	15.4% (6)	**-26.7% (p<0.001)**
Poor temperament	26.3% (5)	12.8% (5)	**-13.5% (p=0.02)**
Victim of rape	15.8% (3)	12.8% (5)	-3% (p=0.54)
Poor grades	42.1% (8)	12.8% (5)	**-29.3% (p<0.001)**
Alcohol abuse	N/A	12.8% (5)	N/A
Physical abuse(of this child)	10.5% (2)	7.7% (3)	-2.8% (p=0.47)
Suspension or expulsion	31.6% (6)	5.1% (2)	**-26.5% (p<0.001)**
Bully perpetrator	5.3% (1)	2.6% (1)	-2.7% (p=0.47)

Carers also reflected on whether they noticed anything unusual/concerning in the person they cared for during the person's adolescence (n=44) (Table 12). In contrast to the 2011 survey, sensitivity (72.7% vs 52.6%) and body image issues (72.7% vs 52.6%) were the most prominent issue that carers reported noticing in 2017. Both of them were significantly higher than 2011 results. Moreover, emptiness, anorexia, bulimia and hallucinations were also statistically higher. On the contrary, there was a significant decrease in concerns about boredom and arrests. These results may reflect improved empathy and overall mental health literacy by carers.

Table 12: Issues Noticed in Adolescence amongst Carers

Issues	Response Rate 2011 (n=19)	Response Rate 2017 (n=44)	2011 vs 2017 response rate difference (p-value)
Sensitivity	52.6% (10)	**72.7% (32)**	**+20.1% (p=0.003)**
Body image issues	52.6% (10)	**72.7% (32)**	**+20.1% (p=0.003)**
Moodiness	63.2% (13)	61.4% (27)	-1.8% (p=0.77)
Anger	**68.4% (13)**	59.1% (26)	-9.3% (p=0.18)
Emptiness	31.6% (6)	56.8% (25)	**+25.2% (p<0.001)**
Impulsivity	57.9% (11)	50% (22)	-7.9% (p=0.25)
Odd thinking or perceptions	42.1% (8)	47.7% (21)	+5.6% (p=0.39)
Recklessness	42.1% (8)	43.2% (19)	+1.1 (p=0.88)
Alcohol abuse	42.1% (8)	43.2% (19)	+1.1 (p=0.88)
Substance abuse	42.1% (8)	40.9% (18)	-1.2 (p=0.88)
Property destruction	31.6% (6)	34.1% (15)	+2.5 (p=0.76)
Poor temperament	36.8% (7)	29.6% (13)	-7.2% (p=0.29)
Delusions	21.1% (4)	29.6% (13)	+8.5% (p=0.14)
Boredom	42.1% (8)	27.3% (12)	**-14.8% (p=0.02)**
Paranoia	26.3% (5)	27.3% (12)	+1% (p=0.87)
Sexual abuse (of this child)	36.8% (7)	27.3% (12)	-9.5% (p=0.12)
Anorexia	10.5% (2)	25% (11)	**+14.5% (p=0.009)**
Bulimia	10.5% (2)	22.7% (10)	**+12.2% (p=0.02)**
Theft	26.3% (5)	20.5% (9)	-5.8% (p=0.40)
Hallucinations	10.5% (2)	20.5% (9)	**+10% (p=0.05)**
Arrests	26.3% (5)	13.6% (6)	**-12.7% (p=0.03)**
Homicidal ideation	5.3% (1)	6.8% (3)	+1.5% (p=0.54)
Physical abuse (of this child)	10.5% (2)	6.8% (3)	-3.7% (p=0.32)

Further issues that carers noticed during the consumer's adolescence were elicited (n=41) (Table 13). Difficulty making friends was noted by 58.5% of carers (n=24), followed by verbally abusive outbursts (53.66%, n=22). There was significant difference between some of the 2011 and 2017 responses such as decreased response rate in promiscuity, violence victim and in STDs.

Table 13: Further Issues Noticed in Adolescence amongst Carers

	Response rate 2011 (n=16)	Response rate 2017 (n=41)	2011 vs 2017 response rate difference (p-value)
Difficulty making or few friends	**62.5% (10)**	**58.5% (24)**	-4% (p=0.56)
Verbally abusive outbursts	50% (8)	53.7% (22)	+3.7% (p=0.56)
Aggression	37.5% (6)	46.3% (19)	+8.8% (p=0.25)
Promiscuity	56.3% (9)	39% (16)	**-17.3% (p=0.015)**
Frequent lying or deception	43.8% (7)	36.6% (15)	-7.2% (p=0.31)

Rape victim	31.3% (5)	22% (9)	-9.3% (p=0.14)
Fights	31.3% (5)	22% (9)	-9.3% (p=0.14)
Violence victim	37.5% (6)	17.07% (7)	**-20.43% (p<0.001)**
Pregnancy	25% (4)	15% (6)	-10% (p=0.07)
STDs	12.5% (2)	4.9% (2)	**-7.6% (p=0.04)**

Carers with a child sought an evaluation of their child's problems mainly as a result of concern about mood disturbances (46%, n=17) and behavioural problems (43.2%, n=16) (Table 14). In comparison to the 2011 survey, there was a significant decrease in mentioning the following as reasons for seeking an evaluation of the child's mental health and wellbeing: behavioural problems, anger problems, school refusal, temper tantrums, and in doctor recommendation.

Of note, doctor and teacher recommendation was not often the reason for seeking an evaluation. This paints a picture of a young person rapidly losing control of their life and circumstances, and their parents increasingly impacted by multiple issues beyond that expected of childhood and adolescence, but with little outside professional recognition of the problems or support before diagnosis. Comparing, samples from the two survey periods, it appears that, from carers' perspective, health service providers, and teachers to a lesser degree, are continuing to fail to recognize and act on parents concerns for these children.

Table 14: Carer's Reasons for Seeking Evaluation of their Child

Issues	**Response percent**		**2011 vs 2017 response rate difference (p-value)**
	2011 (n=17)	**2017 (n=37)**	
Behavioural problems	**70.6% (12)**	43.2% (16)	**-27.4% (p<0.001)**
Mood disturbances	58.8% (10)	**46% (17)**	-12.8% (p=0.06)
Anger problems	47.1% (8)	29.7% (11)	**-17.4% (p=0.013)**
Substance abuse	41.2% (7)	29.7% (11)	-11.5% (p=0.10)
Police intervention or legal issues	29.4% (5)	21.6% (8)	-7.8% (p=0.25)
School refusal	29.4% (5)	16.2% (6)	**-13.2% (p=0.02)**
Temper tantrums	23.5% (4)	10.8% (6)	**-12.7% (p=0.01)**
Eating disorder	23.5% (4)	21.6% (8)	-1.9% (p=0.72)
Doctor recommendation	17.6% (3)	2.7% (1)	**-14.9% (p<0.001)**
Teacher recommendation	17.6% (3)	10.8% (4)	-6.8% (p=0.15)
Promiscuity	11.8% (2)	10.8% (4)	-1% (p=0.82)

Once an evaluation of their child was undertaken by a professional, 23 out of 41 carers reported that therapy was the main treatment (56.1%), followed by medication (53.66%, n=22) recommended for the person to whom they provided care. About 24.39% (n=10) of carers reported that hospitalisation was recommended. The results were similar to that of the 2011 survey and statistically non-significant.

The Journey of Receiving Support for BPD

Impact of Mental Health Support Services on Carers – Seeking Support

Of the 133 carer respondents who reported their experience of challenges in their carer role, it appeared that they found all of the designated issues very challenging, with a lack of support options available to them as the most commonly cited challenge (48.87%, n=42) (Table 15). The results were similar to the 2011 survey and no statistical significant differences were observed.

Table 15: Challenges Faced by Carers

Challenges	Year	Very challenging	Challenging	Neutral / Not Challenging	Not applicable	Response Count
Unable to access support as a carer	**2011**	**47.4% (37)**	26.9% (21)	17.9% (14)	7.7% (6)	78
	2017	**46.6% (62)**	33.1% (44)	12% (16)	8.3% (11)	133
Lack of support options for me as a carer	**2011**	**50.6% (39)**	27.3% (21)	14.3% (11)	7.8% (6)	77
	2017	**48.9% (65)**	31.6% (42)	11.3% (15)	8.3% (11)	133
Services not available in my local area	**2011**	**42.7% (32)**	18.7% (14)	22.7% (17)	16.0% (12)	75
	2017	**34.4% (45)**	31.3% (41)	19.9% (26)	14.5% (19)	131
Financial cost of accessing services as a carer	**2011**	**37.3% (28)**	29.3% (22)	18.7% (14)	14.7% (11)	75
	2017	**43.9% (58)**	25% (33)	15.9% (21)	15.15% (20)	132

Upon further questioning about the types of support that carers have accessed, the 136 carer responses demonstrated that some types of support were perceived to be more helpful than others (Table 16). Similar to the 2011 survey, these included carer support groups (average rating of 3.73), education and information (3.6), counselling for them as carers (3.21), and mental health professional support (2.92); though no support types were rated as 'very helpful' overall (i.e. an average of >4). Interestingly, the helpfulness of support groups was quite mixed (Table 15). These results suggest that carers of people with BPD may need more individualized support than that currently offered.

Table 16: Perceived Helpfulness of Services Accessed for Support

Services	Year	Very unhelpful	Unhelpful	Neutral	Helpful	Very helpful	N/A	Average Rating	Count
BPD Education information	**2011**	7.8% (6)	13% (10)	15.6% (12)	**37.7% (29)**	14.3% (11)	11.7% (9)	3.43	77
	2017	4.5% (6)	12% (16)	17.3% (23)	**37.6% (50)**	18.8% (25)	9.8% (13)	3.6	133
Support from my GP	**2011**	10.7% (8)	16% (12)	**22.7% (17)**	17.3% (13)	14.7% (11)	18.7% (14)	3.11	75
	2017	12.7% (17)	11.9% (16)	**26.9% (36)**	19.4% (26)	11.9% (16)	17.2% (23)	3.07	134
Support from other MHPs	**2011**	20.3% (16)	17.7% (14)	16.5% (13)	**27.8% (22)**	12.7% (10)	5.1% (4)	2.95	79
	2017	15.7% (21)	19.4% (26)	20.2% (27)	**23.9% (32)**	9.7% (13)	11.2% (15)	2.92	134
Counselling for me as a carer	**2011**	15.6% (12)	11.7% (9)	18.2% (14)	**23.4% (18)**	13% (10)	18.2% (14)	3.08	77
	2017	12.5% (17)	9.6% (13)	16.2% (22)	**22.1% (30)**	13.9% (19)	25.7% (35)	3.21	136
Carer support groups	**2011**	13.2% (10)	2.6% (2)	17.1% (13)	19.7% (15)	17.1% (13)	**30.3% (23)**	3.36	76
	2017	5.9% (8)	4.5% (6)	14.2% (19)	18.7% (25)	23.13% (31)	33.6% (45)	3.73	134

More than half of the 135 carers who responded to further questions about support stated that they had wanted to access support but had not been able to access (Table 17). Similar to 2011 survey, being unable to access supports when needed (54.1%, n=73) and not being taken seriously (54.1%, n=73) rated high on the list of barriers experienced by carers. Further statistical analysis did not show any significant differences between 2011 and 2017 survey responses; that is, both samples experienced high levels of problems with accessing support for their carer roles.

Table 17: Issues that have Prevented Carers from Being Supported in their Role

	Year	Prevented	Neutral	Has not prevented	N/A	Response Count
Unable to access support when needed	**2011**	**62.3% (48)**	16.9% (13)	14.3% (11)	6.5% (5)	77
	2017	**54.1% (73)**	21.48% (29)	11.11%(15)	13.33%(18)	135
Not being taken seriously	**2011**	**60.5% (46)**	23.7% (18)	10.5% (8)	5.3% (4)	76
	2017	**54.81% (74)**	18.52% (25)	5.93% (8)	20.74% (28)	135
Cost of support services	**2011**	**38.2% (29)**	28.9% (22)	9.2% (7)	23.7% (18)	76
	2017	**47.37% (63)**	25.56% (34)	9.02% (12)	18.05% (24)	133
Lack of carer support available	**2011**	**56.6% (43)**	19.7% (15)	18.4% (14)	5.3% (4)	76
	2017	**52.94% (72)**	24.26% (33)	11.03% (15)	11.76% (16)	136

Thirty-seven carers took the time to make further comments about their experiences of what has prevented them from being supported as a carer of someone with BPD.Their comments were diverse and the following extracts reflect come of their comments:

> *“Borderline Personality Disorder does not seem to be recognised by Support Services”*
>
> *“Parts of the mental health community and XXXX don't "believe" in BPD. Therefore when you advocate for your child your met with distain and how she "just a difficult person" not clinically unstable. Trying to get her treatment was so difficult - she had to attempt suicide to get active treatment. Moreover, being a professional counsellor made it difficult to find services where I felt heard and validated despite my occupation. I often felt that I was looked down on as a mother and professional. It impacted my daughter being able to access services sooner.”*

Impact of Mental Health Support Services for the Person Cared For

Similar to consumers with BPD, carers (n=124) rated the full range of listed issues that may cause anxiety for the person they care for as challenging (see Table 18). Of these, lack of long-term consistent support (67.48%, n=83), not being taken seriously (67.48%, n=83), and long waiting lists/times to see mental health professionals (60.16%, n= 74) were overwhelmingly and most frequently rated as being very challenging (Table 12). Of note, when combining ‘very challenging’ and ‘challenging’ scores, lack of long-term consistent support (88.62%, n=109) stood out as one of the biggest challenges carers perceived for the person they cared for. These results suggest that carers have a very good understanding of the struggles the person with BPD faces when attempting to get support. Also, there was a significant increase in 2017 in the response rate of not being taken seriously (44.1% vs 67.48%, $p<0.001$), which is concerning, given the assumption of greater mental health carer advocacy and awareness of carers needs in the community.

Table 18: Carers' Perceptions of the Hardest/Most Challenging Aspects for the Person Cared For

	Year	Very challenging	Challenging	Neutral	Not challenging	N/A not an issue	Count
Fear of losing MH support	**2011**	**40.6% (28)**	18.8% (13)	14.5% (10)	8.7% (6)	17.4% (12)	69
	2017	**42.28% (52)**	31.71% (39)	9.76% (12)	4.07% (5)	12.2% (15)	123
Fear of losing long term therapist	**2011**	**39.1% (27)**	21.7% (15)	13.0% (9)	5.8% (4)	20.3% (14)	69
	2017	**43.55% (54)**	25% (31)	10.48% (13)	6.45% (8)	14.52% (18)	124
Lack of long term / consistent support	**2011**	**55.1% (38)**	27.5% (19)	4.3% (3)	4.3% (3)	8.7% (6)	69
	2017	**67.48% (83)**	21.14% (26)	4.88% (6)	4.07% (5)	2.44% (3)	123
Discrimination because of BPD diagnosis	**2011**	**52.9% (36)**	25.0% (17)	11.8% (8)	2.9% (2)	7.4% (5)	68
	2017	**56.91% (70)**	26.83% (33)	8.13% (10)	1.63% (2)	6.5% (8)	123
Not being taken seriously	**2011**	**44.1% (30)**	**44.1% (30)**	7.4% (5)	1.5% (1)	2.9% (2)	68
	2017	**67.48% (83)**	19.51% (24)	8.94% (11)	0% (0)	4.07% (5)	123
Being treated badly	**2011**	**41.2% (28)**	33.8% (23)	11.8% (8)	4.4% (3)	8.8% (6)	68
	2017	**48.39% (60)**	25% (31)	16.94% (21)	3.23% (4)	6.45% (8)	124
Not feeling respected	**2011**	**51.5% (34)**	33.3% (22)	4.5% (3)	3.0% (2)	7.6% (5)	66
	2017	**56.1% (69)**	28.46% (35)	9.76% (12)	1.63% (2)	4.07% (5)	123
Unable to access support when needed	**2011**	**56.7% (38)**	23.9% (16)	10.4% (7)	1.5% (1)	7.5% (5)	67
	2017	**63.93% (78)**	19.67% (24)	9.02% (11)	5.74% (7)	1.64% (2)	122
Lack of choice of support services	**2011**	**58.2% (39)**	22.4% (15)	6.0% (4)	4.5% (3)	9.0% (6)	67
	2017	**57.72% (71)**	25.2% (31)	10.57% (13)	4.07% (5)	2.44% (3)	123
Long waiting lists / times to see MH professionals	**2011**	**47.7% (31)**	23.1% (15)	9.2% (6)	6.2% (4)	13.8% (9)	65
	2017	**60.16% (74)**	21.95% (27)	8.13% (10)	4.88% (6)	4.88% (6)	123
Services not available in our local area	**2011**	**38.5% (25)**	20.0% (13)	20% (13)	1.5% (1)	20% (13)	65
	2017	**39.34% (48)**	22.95% (28)	21.31% (26)	4.1% (5)	12.3% (15)	122
Financial cost of accessing services	**2011**	**43.9% (29)**	18.2% (12)	10.6% (7)	4.5% (3)	22.7% (15)	66
	2017	**55.65% (69)**	26.61% (33)	8.87% (11)	2.42% (3)	6.45% (8)	124

Similar to respondents from the 2017 consumer survey, when asked about which mental health services had been helpful/supportive for the person cared for, more of the total sample of carers (n=122) rated psychotherapy as being either helpful or very helpful (36.07%, n=44) compared with other services (Table 19). Mental health services support for identifying early warning signs, developing a crisis plan, education and information about BPD, and hospital admissions stood out as very unhelpful across the spectrum of service ratings (by 29.27%, 28.23% , 25.0% and 25.0% of carer respondents, respectively). Further statistical analysis showed that mental health service input to developing a crisis plan was now more unhelpful (29.03% vs 10%, p=0.002), and meditation was referred as more 'very unhelpful' (16.39% vs 5.6%, p=0.02). On the contrary, there was a significant increase in the rating of mental healt support groups as being helpful (16.26% vs 4.3%, p=0.004). Also, while CBT was reported to be either helpful or very helpful in 2011 (rating average of 3.46), DBT replaced that position in 2017 (3.46). In particular, CBT was reported less in 2017 as 'very helpul' (6.5% vs 15.9%, p=0.04). Likewise, hypnotherapy was rated by most of the respondents as not applicable. Many therapy-type services were rated as not applicable by many carers, suggesting that they were not accessed at all.

More than half (56.45%, n=70) of 124 carers reported that the person cared for had wanted to access some of these services but had not been able to do so. Of these, 48 carers took the time to make further comments that give further understanding of the issues faced by the person with BPD when attempting to access these supports. Unlike the 2011 survey, in which prominent experiences were reported as being refused access, being limited in what they could access, and the person not wanting to engage with supports, the 2017 comments reflected a clear shift. People were predominantly described as clearly wanting to seek support, but cost and availability were cited as major barriers to access:

> *"He is desperate to get help but is continuously let down. On 3 different occasions my son managed to get a ride in more than 75km (150km round trip) to make his appointment, got there on time to community mental health only to be told the clinician is off sick today... no phone call to advise worker is sick. This is so bad to some one with BPD he now has panic attacks prior to appointments fearing abandonment and the workers wont show up, making it so hard to get him to appointments. This has also happened twice with XXXX in the previous year."*
>
> *"My daughter cannot afford DBT therapy out of pocket costs. She has just moved out of home. We paid for previous sessions."*

Table 19: How Helpful/Supportive is Mental Health Services According to Type of Service?

	Year	Very unhelpful	Unhelpful	Neutral	Helpful	Very helpful	N/A	Rating Average	Count
Identifying early warning signs	**2011**	**25.4% (18)**	16.9% (12)	11.3% (8)	16.9% (12)	8.5% (6)	21.1% (15)	2.57	71
	2017	**29.27%(36)**	24.39%(30)	11.38%(14)	21.95%(27)	3.25% (4)	9.76% (12)	2.4	123
Developing a crisis plan	**2011**	**28.6% (20)**	12.9% (9)	10.0% (7)	21.4% (15)	4.3% (3)	22.9% (16)	2.48	70
	2017	**28.23% (35)**	**29.03% (36)**	13.71% (17)	16.94% (21)	4.03% (5)	8.06% (10)	2.34	124
Education and information about BPD	**2011**	14.1% (10)	**22.5% (16)**	18.3% (13)	15.5% (11)	12.7% (9)	16.9% (12)	**2.88**	71
	2017	**25.0% (31)**	20.97% (26)	16.94% (21)	23.39%(29)	7.26% (9)	6.45% (8)	2.65	124
Meditation	**2011**	5.6% (4)	9.9% (7)	14.1% (10)	14.1% (10)	8.5% (6)	**47.9%(34)**	3.19	71
	2017	16.39% (20)	13.11%(16)	13.11% (16)	15.57%(19)	5.74% (7)	**36.07% (44)**	2.71	122
Hypnotherapy	**2011**	4.3% (3)	5.7% (4)	8.6% (6)	4.3% (3)	1.4% (1)	**75.7% (53)**	2.71	70
	2017	8.33% (10)	5.83% (7)	9.17% (11)	2.5% (3)	0% (0)	**74.17% (89)**	2.23	120
Psychotherapy long term/ regular therapist	**2011**	12.7% (9)	9.9% (7)	11.3% (8)	**25.4% (18)**	**18.3% (13)**	22.5% (16)	3.35	71
	2017	13.93% (17)	12.3%(15)	15.57% (19)	**26.23% (32)**	9.84% (12)	22.13% (27)	3.07	122
Cognitive Behavioural Therapy (CBT)	**2011**	7.2% (5)	10.1% (7)	11.6% (8)	**24.6% (17)**	**15.9% (11)**	**30.4% (21)**	3.46	69
	2017	15.45%(19)	15.45% (19)	14.63%(18)	**21.14%(26)**	6.5% (8)	**26.83%(33)**	2.83	123
DBT	**2011**	8.3% (6)	8.3% (6)	6.9% (5)	12.5% (9)	12.5% (9)	**51.4% (37)**	3.26	72
	2017	8.2%(10)	7.38% (9)	12.3%(15)	**18.03%(22)**	17.21% (21)	**36.89% (45)**	3.45	122

Trauma Counselling	**2011**	11.8% (8)	8.8% (6)	8.8% (6)	16.2% (11)	1.5% (1)	**52.9% (36)**	2.72	68
	2017	10.57% (13)	6.5% (8)	13.01%(16)	**14.63% (18)**	2.44% (3)	**52.85% (65)**	2.83	123
Hospital admission	**2011**	**23.9% (17)**	18.3% (13)	7.0% (5)	21.1% (15)	7.0% (5)	**22.5% (16)**	2.6	71
	2017	**25% (31)**	20.16% (25)	9.68% (12)	21.77% (27)	9.68%(12)	13.71% (17)	2.66	124
MH support groups (dep'n, anger, PTSD, etc)	**2011**	11.4% (8)	5.7% (4)	8.6% (6)	4.3% (3)	12.9% (9)	**57.1% (40)**	3.03	70
	2017	11.38% (14)	12.2% (15)	8.94% (11)	16.26% (20)	10.57% (13)	**40.65%(50)**	3.04	123
Community support groups (art, friendship)	**2011**	8.6% (6)	5.7% (4)	11.4% (8)	14.3% (10)	14.3% (10)	**45.7% (32)**	3.37	70
	2017	11.2% (14)	8% (10)	9.6% (12)	15.2% (19)	9.6% (12)	**46.4% (58)**	3.07	125

When asked which services have contributed most to support the recovery of the person cared for, 98 carers listed a range of support services. The top 10 supports from both 2011 and 2017 surveys are listed below (Table 20). Psychologists were referred as the key contributors in patients' recovery in the results of both surveys. Psychiatrists, medications, DBT groups and mental health teams were some of the other supports that topped both of the lists. The results were very similar and thus, no significant differences were observed. It should be noted, however, that the percentage of respondents that affirmed the contribution of each type of support was quite low.

Table 20: Services that have Contributed Most to Support the Recovery of the Person Cared For

2011	Response rate (n=63)	2017	Response rate (n=98)
Psychologists	**23.81% (15)**	**Psychologists**	**25.51 % (25)**
Mental health teams	20.63% (13)	Psychiatrists	11.22% (11)
Medications	19.05% (12)	DBT groups	14.29% (14)
GPs	12.69% (8)	Medications	14.29% (14)
Psychiatrists	11.11% (7)	Mental health teams	11.22% (11)
Community	9.52% (6)	Therapy	9.18% (9)
DBT groups	9.52% (6)	Long term	4.08% (4)
Other groups	4.76% (3)	BPD	4.08% (4)
Carers	3.17% (2)	Consistency	4.08% (4)
Alternative diagnosis more accepted	1.58% (1)	CBT	3.06% (3)

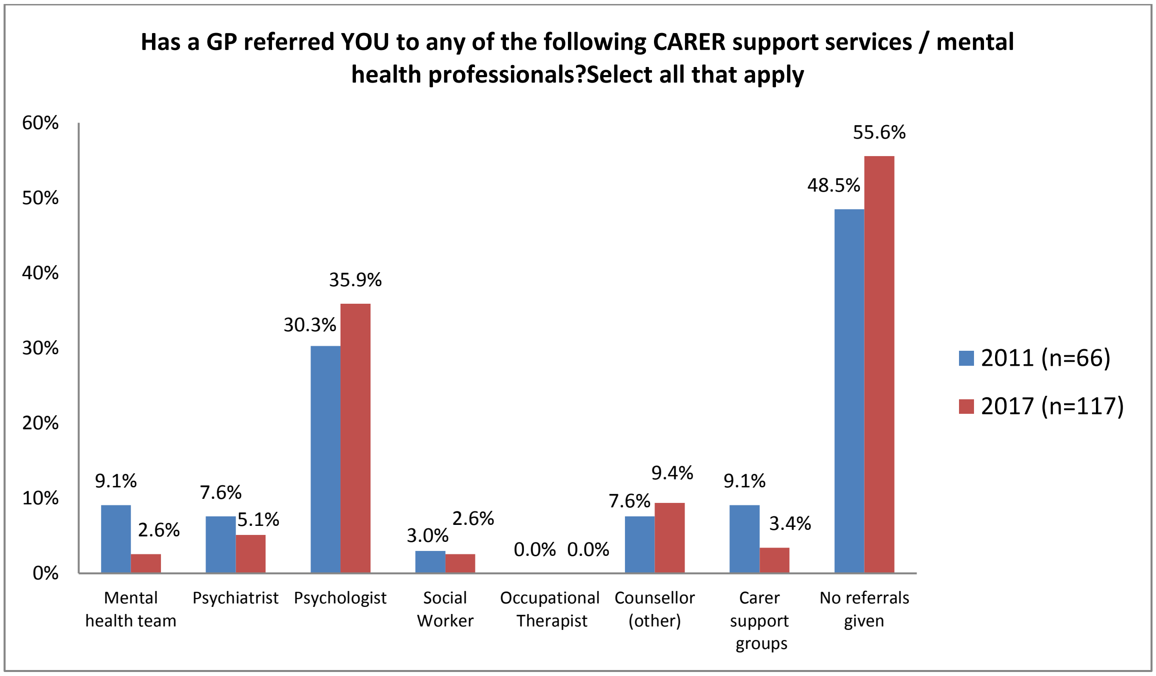
The GP Role in Supporting People with of BPD & Carers

Of the 124 respondents to answer questions about GP support, 51.61% (n=64) said that their GP had not supported them as a carer. This was very similar to 2011 survey results (51.4%, n=37). Of these, 79.03% (n=98) also reported that their GP does not provide them with personal counselling for issues related to being a carer (76.1% in 2011). However, 69.67% (n=85 of 122) reported that a GP has supported the person they care for in terms of issues related to BPD. Of those who indicated that they received support for their caring role (n=58), 36.36 % (n=20) had been receiving support from their GP for less than six months. Referral of carers to carer support services or mental health professionals was reported as mixed (see Table 21 and Figure 6). Of concern, almost half of carers (55.56%, n=65 of 117) reported that their GP had not referred them to other supports. This figure was slightly higher than the 2011 survey (48.5%, n=32 of 66) but did not show any significant difference.

Table 21: GP Referral of Carers to Other Support Services

GP referral of carers to other support services	2011 N (%)	2017 N (%)
Mental health team	6 (9.1)	3 (2.6)
Psychiatrist	5 (7.6)	6 (5.1)
Psychologist	20 (30.3)	42 (35.9)
Social worker	2 (3.0)	3 (2.6)
Ocuupational therapist	0 (0.0)	0 (0.0)
Counsellor (other)	5 (7.6)	11 (9.4)
Carer support groups	6 (9.1)	4 (3.4)
No referrals given	32 (48.5)	65 (55.6)

Figure 6: GP Referral of Carers to Other Support Services

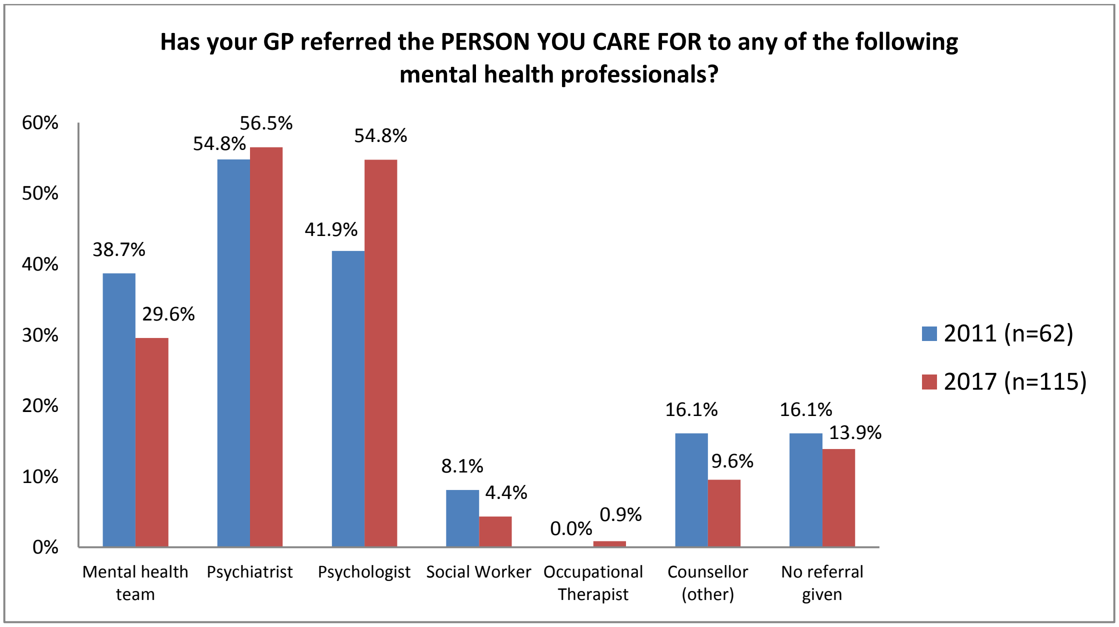


This was in contrast to the GPs that had made referrals for the person cared for to mental health professionals, as shown in Table 22 and Figure 7. GPs appeared to be most likely to consistently refer carers to psychologists and consumers with BPD to both psychiatrists (56.52%, n=65) and psychologists (54.78%, n=63). This corresponds with carers' ratings of psychologists as being among the most helpful mental health professionals in the provision of support to the person with BPD. However, it may also reflect system incentives and processes that GPs feel most comfortable and familiar with in their setting, and those that they perceive are more immediately available to them. In particular, referral to a psychologist aligns clearly with mental health care plan item numbers in General Practice; whereas, GPs may be frustrated in their attempts to work with public community mental health services. The response rate for psychologists was much higher than that in the 2011 survey (41.9%, n=63), but did not show any significant difference.

Table 22: Carer Report of GP Referral ofthe Person with BPD to Other Mental Health Professionals

GP referral to other MH pofessionals	2011 N (%)	2017 N (%)
Mental health team	24 (38.7)	34 (29.6)
Psychiatrist	34 (54.8)	65 (56.5)
Psychologist	26 (41.9)	63 (54.8)
Social worker	5 (8.1)	5 (4.4)
Occupational therapist	0 (0.0)	1 (0.9)
Counsellor (other)	10 (16.1)	11 (9.6)
No referral given	10 (16.1)	16 (13.9)

Figure 7: Carer Report of GP Referral of the Person with BPD to Other Mental Health Professionals



Thirty-nine carers took the time to make further comments about GPs' support. The following demonstrate the range of responses, both positive and negative, with all indicating that, similar to the 2011 survey results, GPs likely need more information, education and support to be effective in supporting carers and people with BPD:

> *“We've been with the same GP for 20 yrs. he is very supportive, never judgemental but has no real clue about mental health or support services.”*

> *“Generally the GP has limited time for counselling, it is a brief chat and more about checking in with the current situation.”*

Comparing GP Support across the Sector

As part of our further examination of the data, we asked “Are GPs doing a better job of supporting carers in the metropolitan or regional areas?” and “Do carers of consumers who use private hospitals have a different experience with GP support?” In 2011, a significant association (p=0.037) with medium effect size (V=0.33) was found between carers’ experiences with GP support and consumers having had a private hospital admission. In 2017, however, the level of carers’ perceived support provided by GPs was neither significantly associated with geographical region nor with the private hospital admissions (Table 23). On the positive side, compared to 2011, GP support had significantly increased in 2017 across all variables except for those who had private hospital admissions- metropolitan (50% vs 69.6%, p=0.03), rural (46.7% vs 69.8%, p=0.04) and ‘no private hospital admissions’ (34.8% vs 62.9%, p=0.03). This suggests that greater equity of GP experience was now apparent, particularly for rural populations and for those who had no private hospital admissions.

Table 23: Association between Carers’ Perceived GP Support with Geographical Region and Private Hospital Admissions for Consumers with the Diagnosis of BPD*

	GP support (2011)		χ2	*P*	Effect size	GP support (2017)		χ2	*P*	Effect size
	Yes	No				Yes	No			
Region			0.08	0.78	0.03			0	0.987	0.002
Metropolitan	21 (50)	21 (50)				55 (69.6)	24 (30.4)			
Rural	14 (46.7)	16 (53.3)				30 (69.8)	13 (30.2)			
Private hospital admissions			4.36	**0.037**	0.33			1.91	0.384	0.16
Yes	11 (68.7)	5 (31.2)				29 (76.3)	9 (23.7)			
No	8 (34.8)	15 (65.2)				22 (62.9)	13 (37.1)			

*Data are presented as number (percentage)

The Role of Public Hospitals

Respondents appeared to be more variable in which questions they answered in this section of the survey, opting to answer some and not others in greater or lesser numbers (10-48 respondents). Of the 122 respondents who reported the usage of hospital services, 39.3% (n=48) said the person they cared for uses only public, 8.2% (n=10) use only private, 23.0% (n=28) use mostly public and some private, and 27.0% (n=33) use mostly private and some public hospital services, and 2.5% (n=3) didn’t know. The results were similar to 2011 survey and did not show any significant difference.

Of the 80 carers who responded to the question about the person they care for ever having been admitted to a public hospital because of issues related to their BPD, 82.5% (n=66) said ‘yes’, 10.0% (n=8) said ‘no’, and 7.5% (n=6) didn’t know. Again, the results were similar to the 2011 survey and did not show any significant difference. Of the 64 carer who responded to the question about the number of public hospital admissions in the past three years related to BPD, 45.3% (n=29) reported that the person they cared for had been admitted five or more times and 31.3% (n=20) reported two to four admissions. In contrast, 9.4% (n=6) had not been admitted during the past three years, and 10.9% (n=7) had been admitted once only. Compared to the 2011 survey, the only significant difference was observed in those who had not been admitted during the past three years (23.1%, n=9, p=0.001). Similar to the 2011 survey, because questions about admission were asked differently to that contained in the consumer BPD survey, these results did not allow for the reporting of cases where the person cared for may have had very high numbers of admissions, as was the case in the consumer survey where up to 40 admissions were reported during that time by one respondent.

Carers reported that the cared for person's longest stay in hospital for mental health issues ranged from three or more weeks (28.13%, n=18), two weeks (15.63%, n=10), or one week or less (53.13%, n=34). The statistical analysis showed that there was a significant decrease in the hospital length of three weeks or more since 2011 (52.5%, n=21, p=0.003) and a significant increase in length of one week or less (27.5%, n=13, p=0.003). These findings are very similar to consumers' reported rates with one distinct difference: three day admissions were reported by 21.88% (n=14) of carers. As with the consumer BPD survey, what these findings suggest is that the hospital treatment for BPD continues to be highly variable and that treatment for BPD and comorbid diagnoses is also variable for this population.

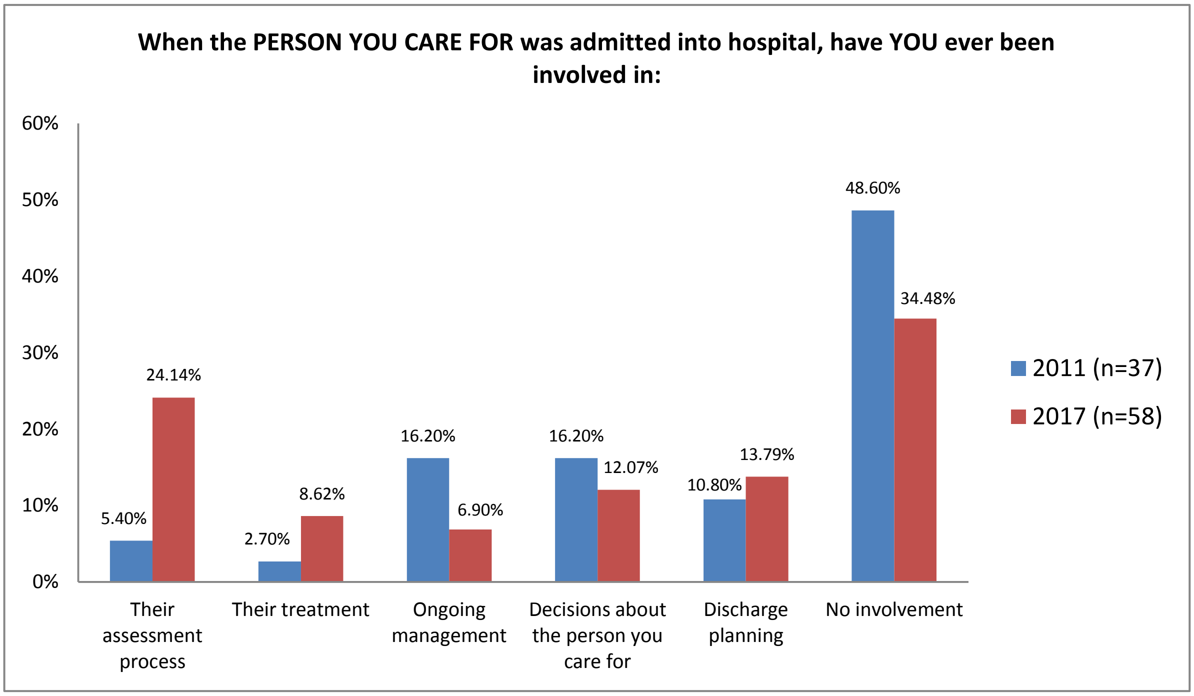
Of the 64 carer respondents who answered questions about whether the person cared for had involuntary hospital admissions, almost three quarters (64.06%, n=41) said 'yes' which was similar to carers responses in 2011 (72.5% - n=29 said 'yes'); their responses were somewhat similar to 2017 survey consumers'responses (57.69%, n=90, p=0.38). A further 28.13% of carers (n=18) said 'no' and 7.81% (n=5) of carers said they 'didn't know'. There were no significant differences in the results when compared with the 2011 survey.

Carers' responses to further questions about public hospital admissions highlighted some significant concerns. The first of these was that 34.48% (n=20 of 58 carers) reported that they had never been involved with the decision-making for these admissions. The result was significantly lower than that of the 2011 survey (48.6%, n=18, p=0.03). On the flipside, respondents' involvement (n=14) significantly increased in the patients' assessment process (24.14% vs 5.4%, p<0.001). This may be related to carer preference, although the responses of 21 carers, who took the time to make further comments, suggests that they had wanted to be involved but were often refused by service providers. This was similar to the 2011 survey. The survey did not allow respondents to choose more than one option. Therefore, it is unclear how involved carers were in the other treatment decisions and processes during the admission. This does not, however, discount the large percent of carers who reported never being involved (Table 24 and Figure 8).

Table 24: Involvement of Carers in the Consumer's Hospital Admission

Involvement of Carers	2011 N (%)	2017 N (%)
Their assessment process	2 (5.4)	14 (24.14)
Their treatment	1 (2.7)	5 (8.62)
Ongoing management	6 (16.2)	4 (6.9)
Decisions about the person you care for	6 (16.2)	7 (12.07)
Discharge planning	4 (10.8)	8 (13.79)
No involvement	18 (48.6)	20 (34.48)

Figure 8: Involvement of Carers in the Consumer's Hospital Admission



The second concern was that 52.38% (n=33) from a total of 63 carers reported that they had experienced times when they had asked for the person they cared for to be admitted to hospital but had been refused, compared with 57.5% (n=23) in 2011. This figure was similar to the experience of consumers with BPD, with approximately half of consumer respondents (49.03% (n=76) reporting that they had asked to be admitted to a public hospital because of mental health issues but been refused, in contrast to 2011 survey results (57.4% n=31). These results suggest that, across the survey periods, consumers have received some improvement in having their requests for admission listened to, but this has been less noticeable for carers.

Of further interest, 17.24% (n=5 from a small total of 29 carers) said that a psychiatrist refused the admission, which was significantly lower than that results reported in 2011 (31.3%, n=5, p=0.02). This phenomenon was similar for results of the consumer survey, with 15.15% (n=10), compared with 24% in 2011, who said that a psychiatrist refused their admission (p=0.15). Also, a third of the carer respondents (31.03%, n=9) did not know who refused the person's admission to hospital. The response rate was non-significantly higher than 2011 result (18.8%, n=3). By comparison, almost twice the percentage of consumer respondents in 2011 (32%) did not know who refused their request for public hospital admission and this was similar in 2017 (37.88%, n=25). Whilst the sample sizes are too small to show whether this difference was significant and the data is not matched in terms of carer-consumer dyads, it suggests that communication quality about the reasons for non-admission has declined for both consumers and carers since the previous survey in 2011.

Twenty-three carer respondents took the time to make further comments. Similar to the 2011 survey, the majority of these responses portrayed highly distressing situations both for the carer and the person they cared for, as the following examples show:

> *"They didn't think she was high risk enough although she was throwing herself in front of traffic and trains and they only just managed to stop in time."*

> *"Mental Health Nurse stated in front of our son "he is calm now, he can go home, it's just bad behaviour" even though he had been admitted to ED after a section 351. She had not spoken to us,his parents, at all or was aware of our son's previous inpatient admissions to that hospital until was we raised it. We observed and commented to her he appeared to still be agitated and emotionally disregulated, this was dismissed and ignored with all our other observations we had written down."*
>
> *"When I had called ambulance out (and police came at the same time) because they could 'settle' my son down at the time, they did not think he required hospital admission. The minute they leave, my son would start being agressive/out of control, self harm again."*

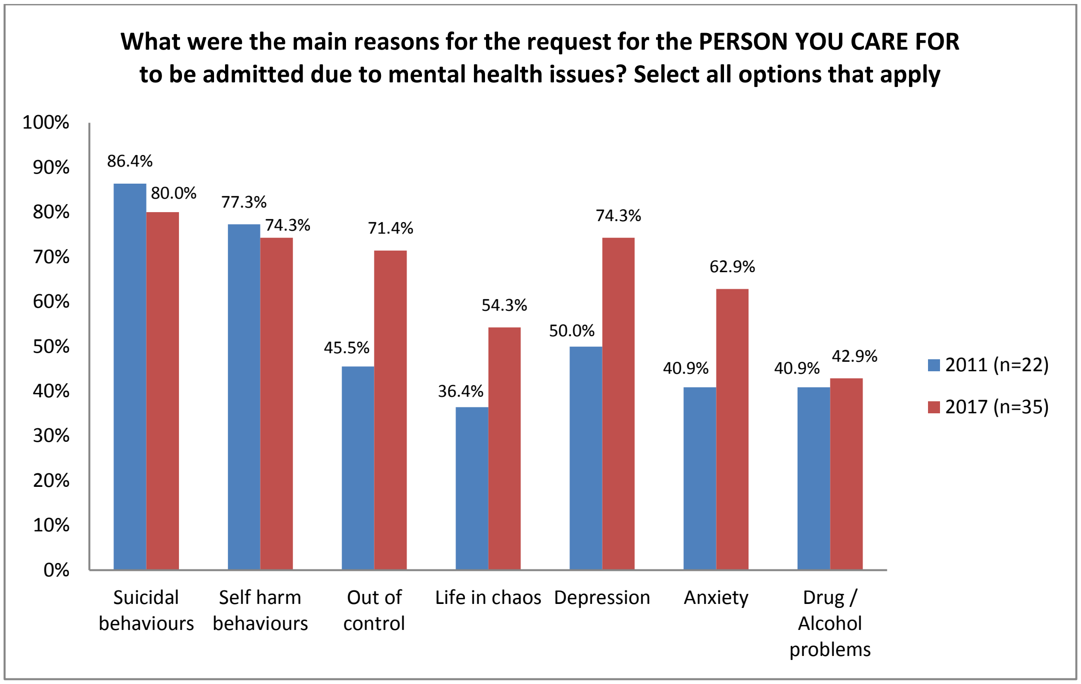
Twenty-nine carers made further comments about how they as a carer felt and what the impact was of this refusal to admit the person to hospital. Their overwhelming response was of feeling helpless, hopeless, highly distressed, terrified that their loved one would suicide, angry and frustrated.

Of the 35 carer respondents who answered further questions about their experience of seeking hospital admission for the person they cared for, the main reasons for this request were directly as a result of suicidal behaviours of the person (80.0%, n=28) and self-harm behaviours (74.29%, n=26) (Table 25 and Figure 9). These results were similar to that of the 2011 survey and did not show any significant difference. However, in 2017, there was a significant increase in the following issues: 'out of control' (71.41% vs 45.5%, $p<0.001$), 'life in chaos' (54.3% vs 36.4%, $p=0.01$), 'depression' (74.3% vs 50%, $p<0.001$) and 'anxiety' (62.9% vs 40.9%, $p=0.001$). Consumers with BPD responding to this question were asked to rate the importance of each of the question domains and all were rated as extremely important. However, because of the different structure of how the question was asked of carers and consumers, detailed comparison is not possible, but both groups rated importance highly across all domains.

Table 25: Carers' Reported Reasons for Requesting Admission for the Person with BPD

Reasons for requesting admission	2011 N (%)	2017 N (%)
Suicidal behaviours	19 (86.4)	28 (80.0)
Self harm behaviours	17 (77.3)	26 (74.3)
Out of control	10 (45.5)	25 (71.4)
Life in chaos	8 (36.4)	19 (54.3)
Depression	11 (50.0)	26 (74.3)
Anxiety	9 (40.9)	22 (62.9)
Drug/alcohol problems	9 (40.9)	15 (42.9)

Figure 9: Carers' Reported Reasons for Requesting Admission for the Person with BPD



Carers were asked whether they had been admitted to hospital for issues related to their own mental health or the burden of caring for someone diagnosed with BPD. Of 34 respondents, 94.12% (n=32) said they had not; only two said 'yes'. This compared with with 2011 survey in which 82.6% of carers (n=19 of 23) reported no admissions for their own mental health and 4 said 'yes'. Across both survey periods, carers of people with BPD appeared to show extraordinary coping skills, despite their experiences.

The Role of Private Hospitals and their Comparison to Public Hospitals

Of the 76 carer respondents to answer questions about private hospitals, 50.0% (n=38) reported that the person cared for had been admitted to a private hospital or clinic in the past for issues related to BPD. Responses from carers about the number of admissions of the person cared for to private hospitals in the past three years compared to public hospitals over the same period were similar, with 34.21% (n=13 of a total of 18) reporting 5 or more admissions by the person to private hospitals, and 10.53% (n=4) reporting that the person had no admissions during the past three years to public hospitals. This was in contrast to consumers with BPD who reported more admissions to public hospitals. The longest stay in private hospital for the person cared for was reported by 76.32% (n=29 of 38 reponses) of carers as three or more weeks, with very low responses across the other shorter admission lengths. This last cohort (3+ weeks) showed significantly higher rate in 2017 than that of 2011 (61.1%, n=11, p=0.02). Further questions exploring issues surrounding private hospital admissions were not asked of carers, therefore further comparisons between public and private hospital care cannot be made.

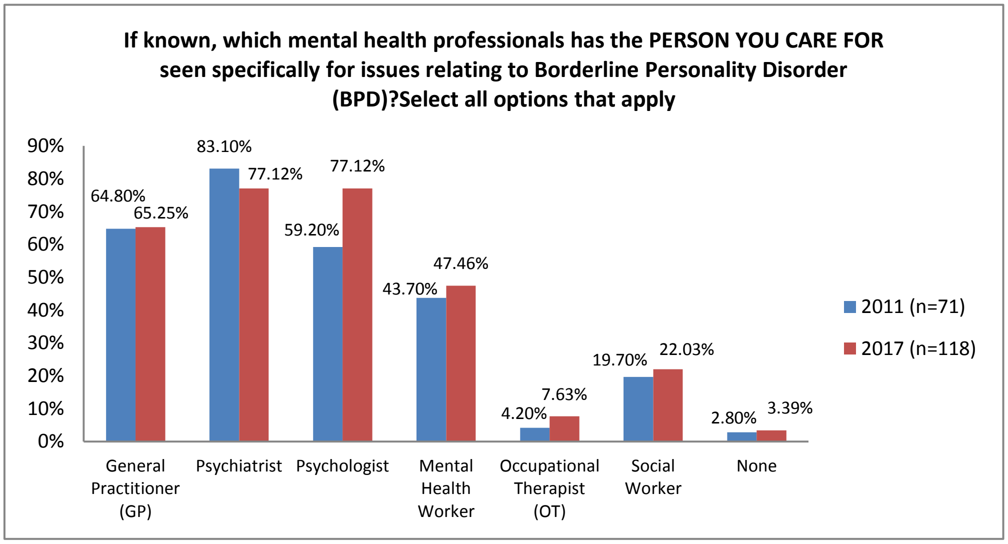
The Role of Mental Health Professional Care

Carer respondents reported that the person they cared for saw a range of mental health professionals for issues related to their BPD, with most of the 118 respondents to this question reporting psychiatrists (77.12%, n=91) and psychologists (77.12%, n=91) as the two main professional groups and occupational therapists as the least seen professional group (7.63%, n=9). A small number (3.39%, n=4) reported no mental health professionals involvement. In 2017, there was a significant increase in use of psychologists (77.12% vs 59.20%, p=0.006), compared with 2011 (see Table 26 and Figure 10).

Table 26: Carers' Report of Mental Health Professionals Seen for Support of BPD

MH professionals seen for support for the person cared for	2011 N (%)	2017 N (%)
General practitioner (GP)	46 (64.8)	77 (65.25)
Psychiatrist	59 (83.1)	91 (77.12)
Psychologist	42 (59.2)	91 (77.12)
Mental health worker	31 (43.7)	56 (47.46)
Occupational therapist (OT)	3 (4.2)	9 (7.63)
Social worker	14 (19.7)	26 (22.03)
None	2 (2.8)	4 (3.39)

Figure 10: Carers' Report of Mental Health Professionals Seen for Support of BPD



Of those who reported that the person with BPD did access mental health professional support, 29.73% (n=33) stated that they had done so for 5-10 years, and 28.83% (n=32) for more than 10 years. The later response rate was significantly lower than the 2011 survey (45.3%, n=29 of 64, p=0.02). Much smaller percentages were reported for all shorter time frames.

Support for being a carer

Responses to questions about the extent to which mental health professionals had supported carers for issues related to caring for a person diagnosed with BPD (n=110) were varied across the spectrum of 'very supportive' to 'not supportive'. The highest number of carers ratings were for GPs, with 34.91% (n=37 of 106) of carers rating them as 'supportive' and 17.92% (n=19 of 106) rating them as 'very supportive'. The status of 'not applicable' was rated prominently across all health professionals except GPs (Table 27). It would seem that GPs are an important source of support for carers. On the contrary, 32.65% (n=32 of 98) of carers reported that psychiatrists were 'not supportive', which is a concern. Further statistical analysis showed that in the 2017 survey, psychologists were stated as more supportive than ratings of that profession from the 2011 survey (14.8%, n=8, p=0.01).

Table 27: Carers' Perceptions of Support from Health Professionals for them as Carers

MH professionals	Year	Very supportive	Supportive	Neutral	Not Supportive	N/A not used	Total
General Practitioner (GP)	2011	15.0% (9)	40.0% (24)	10% (6)	15% (9)	20% (12)	60
	2017	**17.92% (19)**	**34.91% (37)**	19.81% (21)	16.98% (18)	10.38% (11)	106
Psychiatrist	2011	12.1% (7)	13.8% (8)	17.2% (10)	22.4% (13)	34.5% (20)	58
	2017	6.12% (6)	17.35% (17)	14.29% (14)	**32.65% (32)**	29.59% (29)	98
Psychologist	2011	24.1% (13)	14.8% (8)	11.1% (6)	16.7% (9)	33.3% (18)	54
	2017	15.53% (16)	**30.1% (31)**	18.45% (19)	19.42% (20)	16.5% (17)	103
Mental Health Worker	2011	10.5% (6)	22.8% (13)	15.8% (9)	14% (8)	36.8% (21)	57
	2017	7.29% (7)	**21.88% (21)**	18.75% (18)	15.63% (15)	36.46% (35)	96
Occupational Therapist (OT)	2011	9.1% (4)	2.3% (1)	4.5% (2)	2.3% (1)	81.8% (36)	44
	2017	0% (0)	5.81% (5)	3.49% (3)	8.14% (7)	**82.56% (71)**	86
Social Worker	2011	10.2% (5)	4.1% (2)	8.2% (4)	10.2% (5)	67.3% (33)	49
	2017	6.67% (6)	14.44% (13)	7.78% (7)	13.33% (12)	**57.78% (52)**	90
None - have not accessed	2011	3.8% (1)	0% (0)	0% (0)	7.7% (2)	88.5% (23)	26
	2017	0% (0)	1.85% (1)	12.96% (7)	5.56% (3)	**79.63% (43)**	54
Other (please specify)	2011	9.5% (2)	4.8% (1)	4.8% (1)	0% (0)	81.0% (17)	21
	2017	8.11% (3)	8.11% (3)	8.11% (3)	5.41% (2)	**70.27% (26)**	37

#- survey did not allow 'other' to be named

Support and Education Provided to Carers

Mirroring the results of earlier questions that showed significant gaps in carers' involvement in admission of the person to hospital, carers' responses to questions about whether mental health professionals had helped them to understand how to help manage the person's early warning signs and risk of suicide or self-harm also showed large gaps. For example, 78.18% (n=86 of 110 respondents) reported that mental health professionals had not helped them to understand these issues. In addition, a majority of respondents (82.73%, n=91 of 110) had not received a crisis plan from mental health service providers for the person they care for. Of concern, there was a significant increase in the former category in the 2017 survey than that of 2011 survey; i.e. more mental health professionals had not helped carers to understand these issues (78.18% vs 55.4%, p=0.001).

Self-Harm and Suicidal Behaviour from the Carers' Perspective

One-hundred and two carers nominated to complete this section. However, response rates across the questions in this section were very low. Only four carers responded (compared to 0 in 2011) to the question asking whether the person they care for had ever displayed risky behaviours. Three carers (compared to 0 in 2011) said that the person they cared for had self-harmed. It is likely that responses to this question and other questions were self-evident given the many previou squantitative and qualitative responses. These questions may also have been too distressing for carers to complete, although this is unclear, given that 105 carers responded to the question asking if the person they care for had ever attempted to end their life, to which 76.19% of respondents said 'yes' (n=80), 10.48% said 'no' (n=11) and 13.33% (n=14) said they didn't know. These results were similar to the 2011 survey (76.3% 'yes', 15.2% 'no', and 8.5% 'don't know'). However, these results contrast with the 2017 consumer survey in which 68.90% (n=175) of respondents (compared with 85.6%, n=83 of 2011 survey respondents) said that they had ever made a serious attempt to end their life. Unlike the 2011 survey comparisons that suggested that some carers may not be fully aware of suicide attempts by the consumers they care for, the 2017 survey results suggest that carers were perceiving this more often than consumers.

Subjects were asked if they wished to continue with this section of the survey and 95.88% (n=256) said 'yes'. This was equivalent to 95.2% (n=100) of the 105 respondents to this question in the 2011 survey. Of the 2017 survey respondents, 99.61% (n=255) then stated that they had previously had thoughts of ending their life, compared with 100% (n=96) of the 2011 respondents to this question.

Carers' Report of Responsiveness of Services to Crisis, Self-Harm and Suicidal Behaviour

One-hundred and ten carers reported of the length of time that mental health professionals took to respond to the person cared for in a crisis. Results showed a mixed spread of responses: the same day (21.82%, n=24), within 2 days (22.73%, n=25), between 2 days-1 week (21.82%, n=24), longer than a week (8.18%, n=9), did not response (9.09%, n=10), and did not know (16.36%, n=18). Upon collapsing results, 44.55% (n=49) reported a response from mental health professionals within two days and 55.45% (n=61) reported a response of longer than this, including not at all. Upon further statistical analysis, no significant difference was observed between 2017 and 2011 responses (33.3%, n=21 and 66.7%, n=42 respectively). These results suggest that response times to consumers in crisis, as reported by carers, has not improved since 2011.

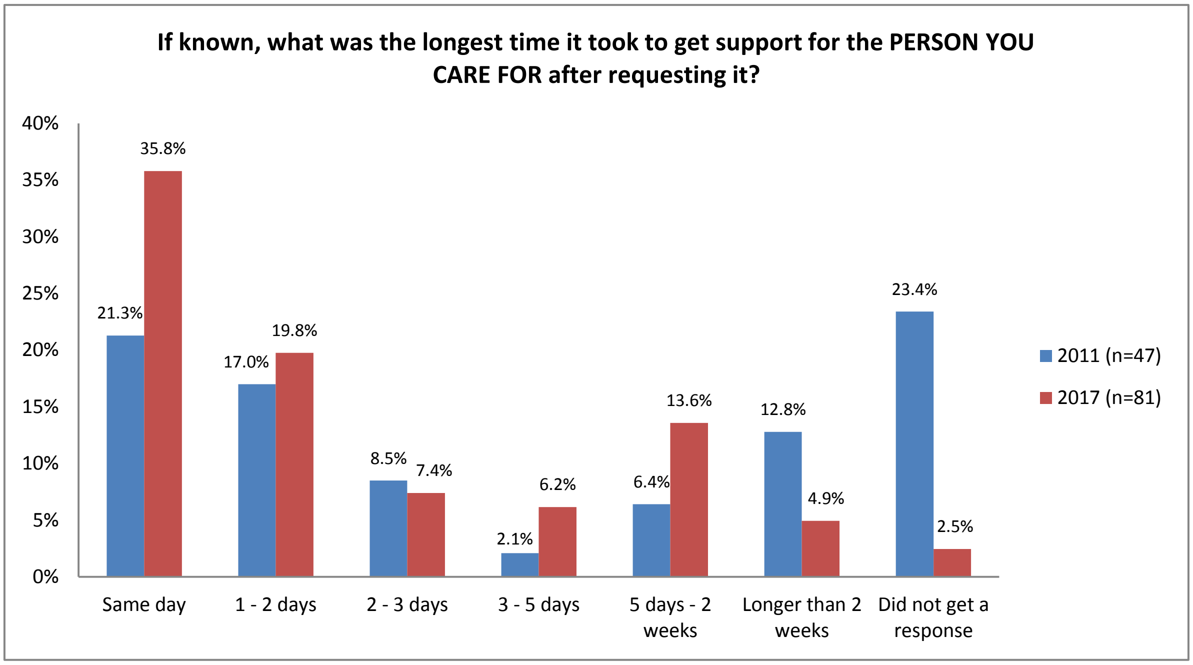
This question was asked again at a later point in the carer survey, in the section on self-harm and suicide as distinct from the term 'crisis'. Carers' responses (n=81) to that question were similar with 55.55% (n=45) reporting that the person with BPD got support the same day or within 1-2 days (non-significant vs 44.55%), and significantly lower as 38.3% (n=18) reporting a response of longer than this, including not at all (vs 55.45%, p=0.01). When compared to 2011 results, both of these reponses were significantly different (38.3%, n=18, p=0.01, and 61.7%, n=29, p=0.001 respectively). In particular, the 2017 survey showed significant improvements in the same day response (35.8% vs 21.3%, p=0.01) and in those who did not get a response while compared to 2011 responses (2.5% vs 23.4%, p<0.001). These results suggest that response times to consumers' self-harm and suicide attempts, as reported by carers, have improved significantly since 2011.

However, a higher proportion of carers than consumers (3.91%, n=10) (compared with 6.5%, n=6, p=0.004 in 2011) that responded to this second version of the question which asked what the longest time was that it took to get support for the person cared for after requesting it, 2.47% (n=2) reported that they did not get a response (p=0.64) (Table 28 and Figure11). This suggests that services are making different judgements about need and crisis when assessing information provided by the carer versus the consumer with BPD.

Table 28: Carers' Perceptions of Response from Services for Consumer's Needs

Response time from services	2011 N (%)	2017 N (%)
Same day	10 (21.3)	29 (35.8)
1-2 days	8 (17.0)	16 (19.8)
2-3 days	4 (8.5)	6 (7.4)
3-5 days	1 (2.1)	5 (6.2)
5 days -2 weeks	3 (6.4)	11 (13.6)
Longer than 2 weeks	6 (12.8)	4 (4.9)
Did not get a response	11 (23.4)	2 (2.5)

Figure 11: Carers' Perceptions of Response from Services for Consumer's Needs



Further questions about responsiveness of services when the person cared for is in crisis elicited a range of patterns across the various mental health service professional groups. In particular, GPs (60.19%) were more commonly rated as`very responsive' or 'responsive' by carers (n=62 of 103) compared to other professionals, and psychiatrists were further noted as 'not responsive' (30.61%) (n=30 of 98) by a greater number of carers than any other profession (Table 29).The results were very similar to results from the 2011 survey (63.8%, n=37 of 58 and 30.2%, n=16 of 53 respectively) and thus did not show any significant difference.

Table 29: Carers' Ratings of Services' Responsive to their Request-Requests for Help for the Person

MH professionals	Year	Very responsive	Responsive	Not responsive	N/A not used	Total
General Practitioner (GP)	2011	22.4% (13)	41.4% (24)	20.7% (12)	15.5% (9)	58
	2017	**24.27% (25)**	**35.92% (37)**	18.45% (19)	21.36% (22)	103
Psychiatrist	2011	11.3% (6)	30.2% (16)	30.2% (16)	28.3% (15)	53
	2017	15.31% (15)	24.49% (24)	**30.61% (30)**	29.59% (29)	98
Psychologist	2011	19.1% (9)	29.8% (14)	19.1% (9)	31.9% (15)	47
	2017	11.58% (11)	**36.84% (35)**	24.21% (23)	27.37% (26)	95
Mental Health Worker	2011	15.4% (8)	25% (13)	21.2% (11)	38.5% (20)	52
	2017	6.38% (6)	**30.85% (29)**	22.34% (21)	**40.43% (38)**	94
Occupational Therapist (OT)	2011	4.4% (2)	2.2% (1)	6.7% (3)	86.7% (39)	45
	2017	0% (0)	6.02% (5)	2.41% (2)	**91.57% (76)**	83
Social Worker	2011	8.5% (4)	4.3% (2)	10.6% (5)	76.6% (36)	47
	2017	1.18% (1)	14.12% (12)	14.12% (12)	**70.59% (60)**	85
None	2011	0% (0)	0% (0)	3.4% (1)	96.6% (28)	29
	2017	0% (0)	6% (3)	6% (3)	**88% (44)**	50
Other (please specify)	2011	0% (0)	4.8% (1)	0% (0)	95.2% (20)	21
	2017	8.82% (3)	8.82% (3)	2.94% (1)	**79.41% (27)**	34

#- survey did not allow 'other' to be named

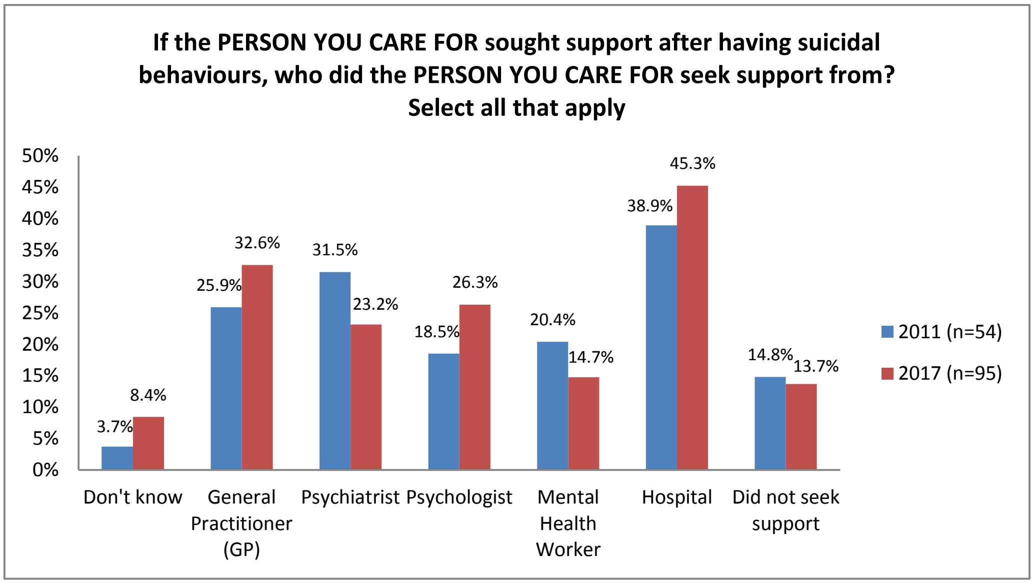
Across the survey periods, differences in seeking help from other mental health professionals were not statistically significant (Table 30 and Figure 12). Of note, carers' results were quite different to consumers' report of the health professionals from whom they sought help after self-harming. For example, across the two survey time periods, carers' ratings of the person seeking help from psychiatrists and mental health workers following self-harm appeared to increase. However, consumers' reported the opposite: in 2017, fewer sought help from their GP (38.86%, n=89) compared with 2011 survey respondents (48.3%, n=42); and fewer 2017 survey respondents sought help from a psychiatrist (31%, n=71 compared with 37.3%, n=31 in 2011). This is different to the consumers' report of psychologists being the health professional group with whom they most often seek support from in these circumstances (41.1%,n=94 from 229).However, the question was inconsistently applied across the two surveys, as consumers were not given an option to nominate hospital from the list of options.

Of concern, the proportion of people not seeking any support from health professionals, as reported by both carers and consumers, appears to have increased (39.30%, n=90 for 2017 compared with 32.5%, n=27 for 2011).

Table 30: Support Sought After Self-Harming – Carers' Report

Support sought from	2011 N (%)	2017 N (%)
General Practitioner (GP)	2 (3.7)	8 (8.4)
Psychiatrist	14 (25.9)	31 (32.6)
Psychologist	17 (31.5)	22 (23.2)
Mental health worker	10 (18.5)	25 (26.3)
Hospital	11 (20.4)	14 (14.7)
Did not seek support	21 (38.9)	43 (45.3)
Don't know	8 (14.8)	13 (13.7)

Figure 12: Support Sought After Self-Harming –Carers' Report

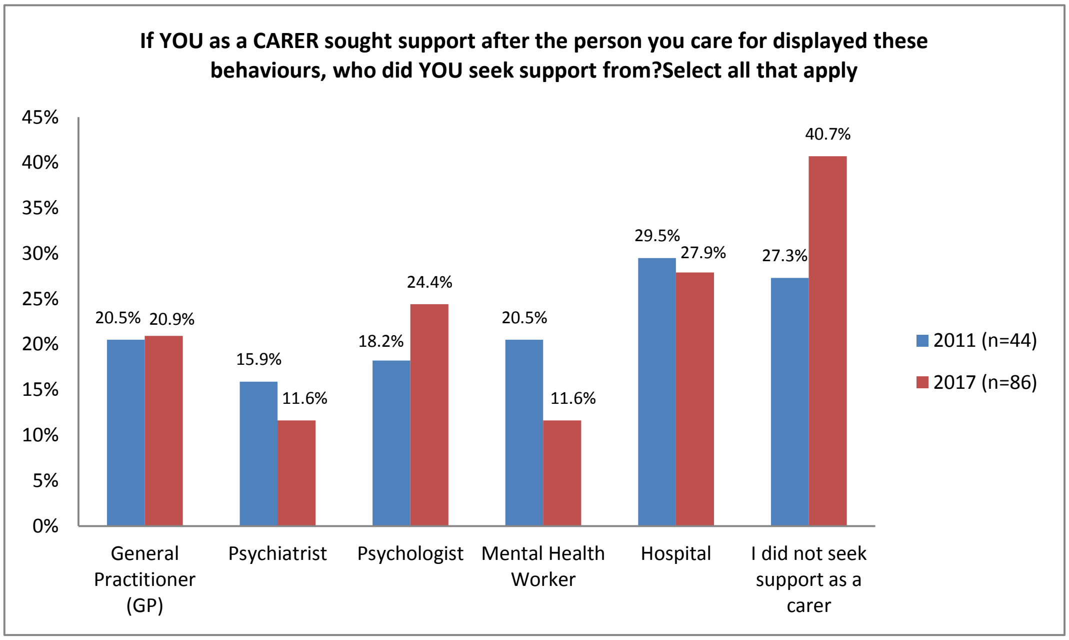


These results contrasted with carers' report (n=86) of the health professionals that they as carers sought help from when the person they cared for displayed these behaviours. Carers were slightly less likely to seek help from psychiatrists (11.63%, n=10) and more likely to seek help from staff at the hospital emergency department (27.91%, n=24). Both figures were slightly lower than the 2011 survey (15.9%, n=7 and 29.5%, n=13 of 44 respectively) but did not show any significant difference. As with results of the 2011 survey, this may reflect the limited communication that many carers have with the psychiatrist who sees the person they care for. It may also reflect hospital emergency departments as continuing to be the only perceived option for many carers. Of great concern, 40.70% of carers (n=35) did not seek any help for themselves, which was significantly higher than that of 2011 result (27.3%, n=12, p=0.03). The range of carers' help-seeking behaviours is shown in Table 31 and Figure 13.

Table 31: Who Carers Said They Sought Help from When the Person They Cared For was Suicidal or Self-Harming

MH professionals seen for support for carers themselves	2011 N (%)	2017 N (%)
General Practitioner (GP)	9 (20.5)	9 (20.9)
Psychiatrist	7 (15.9)	10 (11.6)
Psychologist	8 (18.2)	21 (24.4)
Mental health worker	9 (20.5)	10 (11.6)
Hospital	13 (29.5)	24 (27.9)
I did not seek support as a carer	12 (27.3)	35 (40.7)

Figure 13: Who Carers said they Sought Help from when the Person they Cared for was Suicidal or Self-Harming

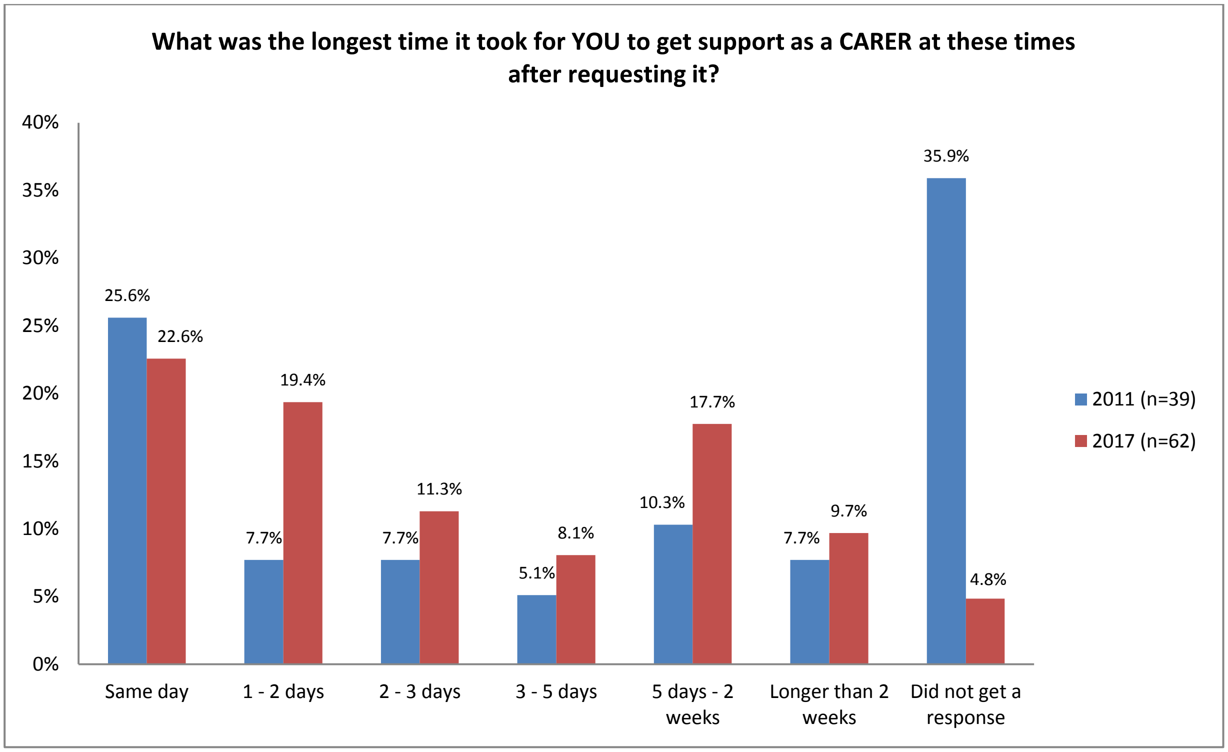


Similar to the consumers who they care for, only 4.8% (n=3 of 62) of carers in the 2017 survey reported that they did not get a response to their requests for help during this time from services. Compared to 2011 survey results, this was a significant difference (35.9%, n=14 of 39, p<0.001), suggesting clear improvement in services' response to carers' requests for help. If these figures are collapsed, 41.93% (n=26 of 62) of carers got support within 2 days but 46.77% (n=29) had to wait 2 days or more and more than half of these did not get any response. Again, there was a significant improvement in the later variable since 2011 (66.7%, n=26, p=0.002) (see Table 32 and Figure 14).

Table 32: The Response Time Taken by Services when Carers Requested Support when Consumers were Suicidal or Self-Harming

Response time taken (carers)	2011 N (%)	2017 N (%)
Same day	10 (25.6)	14 (22.6)
1-2 days	3 (7.7)	12 (19.4)
2-3 days	3 (7.7)	7 (11.3)
3-5 days	2 (5.1)	5 (8.1)
5 days- 2 weeks	4 (10.3)	11 (17.7)
Longer than 2 weeks	3 (7.7)	6 (9.7)
Did not get a response	14 (35.9)	3 (4.8)

Figure 14: The Response Time Taken by Services when Carers Requested Support when Consumers were Suicidal or Self-Harming



The level of crisis when carers sought help was supported by their further report (n=93) of whether or not the person they cared for sought medical attention during these times. Two thirds of carers (61.4%, n=57) reported that this was the case (compared to 65.4%, n=34 in 2011). Carers reported that this overwhelmingly involved hospital emergency department contact (90.7%, n= 49 of 54, compared to 86.7%, n=26 in 2011, p=0.56) with the remainder attending a GP (22.22%, n=12) (respondents could nominate either or both options). These results did not show any significant differences.

When asked further questions about the experience of emergency department treatment for the consumer's self-inflicted injuries, only one carer stated (vs 0 carers in 2011) that this occurred immediately. The rest of the small sample of 3 carers reported that this took more than eight hours (vs one carer in 2011).

In 75.0% of cases (n=42), carers reported that the person they cared for was referred to a mental health professional as a result of the self-harming at these times. The remainder were not, and it is unclear whether the contacts were single contacts or whether ongoing support in the community was provided. Again, the result was almost the same as the 2011 survey (76.5%, n=26).

The Role of Community Support Services in Supporting Carers and Those They Care For

Carer respondents (n=114) had few positive comments to make about other community support services. Similar to earlier responses, their response patterns suggested that they neither found them very helpful nor very unhelpful. The most significant pattern across the responses was that these services were perceived by carers to be not used/not applicable for the person they cared for. The results were similar to the 2011 survey results: for men's shelters (98.18%, n=108 of 110 respondents), youth shelters (87.27%, n=96 of 110 respondents) and women's shelters (83.93%, n=94 of 112 respondents). Perceptions of gambling support as not applicable has significantly decreased in 2017 (87.5%, n=98 of 112 respondents) compared with 2011 survey results (96.8%, n=60 of 62, p=0.02)(see Table 33).

Table 33: Carers' perspective of the Helpfulness of Community Supports for the Person with BPD

Services	Year	Very unhelpful	Unhelpful	Neutral	Helpful	Very helpful	N/A	Total	Weighted Average
Crisis lines	2011	9.4% (6)	14.1% (9)	9.4% (6)	17.2% (11)	6.3% (4)	43.8% (28)	64	2.94
	2017	10.09% (11)	14.68% (16)	12.84% (14)	22.94% (25)	4.59% (5)	**34.86% (38)**	109	2.96
General Groups	2011	4.6% (3)	20% (13)	6.2% (4)	15.4% (10)	3.1% (2)	50.8% (33)	65	2.84
	2017	3.57% (4)	10.71% (12)	11.61% (13)	11.61% (13)	6.25% (7)	**56.25% (63)**	112	**3.14**
Financial	2011	7.7% (5)	15.4% (10)	9.2% (6)	20% (13)	1.5% (1)	46.2% (30)	65	2.86
	2017	18.58% (21)	15.04% (17)	10.62% (12)	9.73% (11)	3.54% (4)	**42.48% (48)**	113	2.38
Housing	2011	15.2% (10)	10.6% (7)	4.5% (3)	9.1% (6)	6.1% (4)	54.5% (36)	66	2.57
	2017	21.93% (25)	13.16% (15)	3.51% (4)	10.53% (12)	3.51% (4)	**47.37% (54)**	114	2.25
Gambling	2011	1.6% (1)	0.0% (0)	1.6% (1)	0.0% (0)	0.0% (0)	96.8% (60)	62	2
	2017	4.46% (5)	4.46% (5)	1.79% (2)	1.79% (2)	0% (0)	**87.5% (98)**	112	2.07
Drug / Alcohol	2011	9.4% (6)	7.8% (5)	7.8% (5)	12.5% (8)	1.6% (1)	60.9% (39)	64	2.72
	2017	10.71% (12)	6.25% (7)	5.36% (6)	5.36% (6)	4.46% (5)	**67.86% (76)**	112	2.58
Relationship counselling	2011	9.1% (6)	9.1% (6)	7.6% (5)	7.6% (5)	0.0% (0)	66.7% (44)	66	2.41
	2017	8.93% (10)	9.82% (11)	4.46% (5)	7.14% (8)	3.57% (4)	**66.07% (74)**	112	2.61
Women's shelter	2011	3.1% (2)	3.1% (2)	1.6% (1)	6.3% (4)	3.1% (2)	82.8% (53)	64	3.18
	2017	3.57% (4)	6.25% (7)	3.57% (4)	2.68% (3)	0% (0)	**83.93% (94)**	112	2.33
Men's shelter	2011	1.6% (1)	0.0% (0)	1.6% (1)	3.2% (2)	0.0% (0)	93.5% (58)	62	3
	2017	0.91% (1)	0% (0)	0.91% (1)	0% (0)	0% (0)	**98.18% (108)**	110	2
Youth shelter	2011	1.7% (1)	3.4% (2)	1.7% (1)	8.5% (5)	0.0% (0)	84.7% (50)	59	3.11
	2017	3.64% (4)	3.64% (4)	1.82% (2)	3.64% (4)	0% (0)	**87.27% (96)**	110	2.43

Appendix 1: Qualitative data from carer experiences of care survey

Quantitative data is in itself reliable data; however, a critical component, especially in the survey construction, was offering carers the opportunity to expand their comments in a numberof questions.

Set out hereunder is that qualitative data which enriches thecontent and informs the outcomes of the survey. This data has not yet been thematically analysed but appears in its raw form.

SECTION ON: BACKGROUND INFORMATION

Question: Do you have any further comments about this section?

Answered question 66
Skipped question 102

The presence of BPD was first picked up by myself in consultation with my daughter's Case Manager, who then reported to the psychiatrist, who then confirmed the diagnosis.
As my daughter is 21yo my husband and I have no legal right to go into the consultation. We never got to speak with the psychiatrist at all. The only contact we had was I wrote a four page letter outlining the past 5yrs, I hope he read the letter.
the 3 practitioners we saw prior to the discovery of BPD were totally incompetent
I have not been involved in my son's consultations and rely on what he tells me to be the mental health issues he experiences.
I DID MY OWN RESEARCH
I had already read widely and knew that my daughter met the criteria as in the DSM 5.
Carers seem to be left to do their own research once they hear the diagnosis of BPD. They should at least be given a reliable website to access.
no support and or education on BPD
Initial diagnosis said borderline traits - it wasn't until i as a parent researched and found family connections i realised my son had BPD and not just traits.
Please note that my spouse has never sought mental health support. She does not believe that she has a problem. I have been getting mental health help for the past few years due to the strain of handling my partner. My psychologist has offered the tentative point of view that my wife sounds as though she conforms to a BPD behavioural type (extreme anger, cycle of elevation/devaluation, chaotic relationships with friends and at work, risky spending behaviour, frantic efforts to avoid perceived abandonment).
I researched the diagnosis myself.
I am also a professional counsellor - I have a deep understanding of mental health disorders but I read up and had long conversations with my daughter’s psychiatrist. Her psychiatrist respected my professional status and this really helped in discussions.
Psychologist indicated concern but no explanation. I researched and followed up with child psychiatrist years later.
Gave me literature to read. Did not give medication.
Mostly I feel left out by the private Health Care Professionals my daughter deals with. The psychiatrists in ED departments are much more inclusive which is more beneficial for us both.
I have always been on a need to know basis which is extremely stressful. I am recognised as my wifes carer and the one who has been supporting her (without support for myself) for the last 17 years. I am currently looking for ways to insist on inclusion in treatment discussions. My wife has just been discharged from hospital (1 week) privat hospital mental healh uni. Released early despite my concerns. Requested inclusion in a discussion re emergency plan, I was refused. Things have gond bad already and i dont know what to do. Over it!
My daughter has been unwell since she was about 12. The BPD diagnosis has come after many years of mental illness.
When people have multiple mental illnesses, it is hard to predict which will be most prominent at any particular time.

No one explained what BPD is however as a nurse I am quite familiar with mental disorders
Tracie went to a mental health hospital and it took them in excess of 4 weeks to diagnose her
Multiple psychiatrists, following a diagnosis of bipolar over a long period of time

It would be great if mental health profession spend some time with family member (ie. carer) to discuss consumer MH issue in order to work out a better plan to suit the cultural practices. Although I may have had theory knowledge in MH . I strongly believe practical approach is essential to better develop an idea to care for both party. It furthermore help minimises the possibility of burn out.
I had already read about Borderline personality disorder before the diagnosis so I had some background knowledge. Also I am a registered nurse so had some familiarity with this condition.
My sister has been diagnosed with BPD, so I can recognise some of the symptoms in my child. My child has a case manager in a public mental health hospital but they are about to discharge him as he hasn't recently threatened suicide or self harmed, and they say they have no treatments for his chronic dysthymia and his 'stubborn' and 'wilful' personality, and his underlying negative self regard.
A mental health nurse provided a typed information page - generic characteristics of BPD. Only after we requested it.
Partner was not informed of diagnosis at the time.
There are handouts you can find and read if you are that way inclined, but there is no-one from any government department or agency that comes and sees you after the diagnosis and explains the symptoms, what to look for and how to handle the sufferer
My son was identified as having BPD traits. They described BPD at the time as being a disorder that doesn't fit into any other category, the "too hard to diagnose further" basket.
At the time of diagnosis, my daughter was 16-17 years old. I actively sought information from the professionals about my daughters diagnosis and felt as though i had to yell and scream to get any brief answers.
My daughter's psychiatrist does not really include me in any discussion therefore I feel quite alone in dealing with her.
We really didn't know what was going on with our son for ten years before the diagnosis.
Appears to be a lack of understanding about BPD. My daughter had been seeing people for a number of years and not picked up till 22yrs old. Would have been beneficial to pick it up a lot earlier.
I have done a lot of reading myself and over the past few years due to the possibility of BPD.
Mum has obviously had BPD for as long as I can remember, it made for an unpleasant childhood with her. Shame it's taken so long to diagnose
I am a nurse and work with adolescents so I think it was assumed I knew and understood BPD
I wasn't at the appointment when diagnosis occurred.
We as parents were not told she had axis 11 BPD. We found out when I asked for her diagnosis as we were moving to the UK. This meant we didn't know exactly what mental illnesses we were dealing with. Which caused more trauma to my daughter and further self harm cutting. I feel this was so wrong that as parents we weren't told or offered any support whatsoever. I feel she has PTSD as well. Her life at 34 now is like she has no hope and finding a job. She sees a psychologist who used to work at spectrum my daughter was a client with them and did groups and stayed in the residential for approximately 7 months. No further follow up or support was provided after that. Just breakthrough which was of no benefit toy daughter. I feel follow up was needed for her to move out to be more independent. I feel she has gone backwards. Her meds never been reviewed . She avoids seeing her GP. Self care not good. Uses alcohol n dope. Overweight. Has no hope for her life.
Stepping Stones diagnosed emerging borderline. We were not told by them or ELMHS. We found out after a suicide attempt from male nurse at Frankston hospital. I was so angry nobody had told us.
I have always been told the same thing from all Acute Care Nurses & Doctors - I'm not allowed to know any specific information about my Mum's diagnosis because of patients' privacy.

It was me that pushed for a diagnosis after living with severe mood swings including rages. I found the description online that fit the symptoms and asked to meet with his psychiatrist. The diagnosis was very unclear and I felt I got NO support as a carer at any stage, even when my partner was in an intensive outpatient DBT program.
Not at the time of diagnosis later when I asked and did my own research through neabpd

SECTION ON: IMPACT OF MENTAL HEALTH SUPPORT SERVICES ON YOU AS A CARER

Question 26: As a carer for someone with BPD, please rate how challenging each of the following has been for YOU: 'Other'

Answered question 19

My daughter does not accept the diagnosis so these questions are not patcularly relevant.
Support is available in my area, just had to find it.
a lot of supports just aren't relevant to BPD experience
400 km round trip to support service
The longer one is a carer, the more you find out and it is easier
Services do not cater for multiple disability
Mental Health Professionals did not provide information. I had to seek it out.
Daughter was living in Vic for several years
In my area there is reasonably easy access to a few formal services providing information.social..and peer support.
Compassionate non- judgemental approches from mh field is needed its essential
Services telling me she was over 16 so they couldn't help me. She had to seek help. But I know that she thought nothing was wrong with her. Her life was normal to her. The services did not get along with her and so I had to find others that would listen but none did.
When I was seeking support 7 years ago, there was nothing I could find. I ended up on an international forum for families and began my journey there. Today I have all the support I need, I am a member of BPD Community (in Victoria).
Unemployed/ partner is a pensioner
Lack of partnership between carers & professionals
Some services were there but during stress of caring for her I was never directed to support, not until I searched out support independently did I start to gain some benefit.
Unaware of services until recently for carers. Case worker told me about Spectrum course for carers & sufferers of BPD. Separate courses. Very good.
My own depression and anxiety. I take aropax n valium . I see a psychologist
I attended a BPD course for carers by Southern Health. Haven't had any support for 2nd child who has gone off the rails.
ARAFMI was amazing. The medical programs were unsupportive and uncommunicative.

Question 27: From the following support services that YOU have accessed as a CARER, how HELPFUL/ SUPPORTIVE have the services been? "Other"

Answered question 23

Carer Peer Worker with EACH/COPES and BPD Bouverie Centre were greatest help.
Support group specifically for BPD carers was the most helpful. No one else can understand what we go throu.
after more than a year i found family connections before that all main stream services offered no support at all, in fact made my son and i feel worse as they did not understand his condition. neither do country gps. they think my son just has bad attitude
My own psychiatrist
Not sure if carer support group is available

Only recently started seeking support as a carer.
I haven't accessed any carer support groups other than a general one at the probate hospital she goes to.
No written information or verbal advice given by psychologist
As GP/Psychiatrist did not share/explain the diagnosis, there was no knowledge or education around what it meant until I 'googled' to learn what it was.
telephone assist from Spectrum Vic best for info during crisis
Sanctuary was an absolute life saver for me
I discovered the Sanctuary Support group at the beginning of 2017 and the group is fantastic!!
Sanctuary Group in SA is great
I have not sort support or other services for myself. This was many years ago
Even before diagnosis wasnt much help from health sector was obviously something wrong. Need more support through the diagnosis support. Was good to know that it was BPD and also explained the health sector stigma. Its appauling, things breach peoples human rights and ppl dont care. Psychiatrists and mh workers are totally invalidating and judgemental. When with the Health Sector get ppl well instead of making them sick.
This was over 10 years ago. Within the last few years when the addiction was viral with her and I sought other help then services to help me deal with problems where there. But she is very addicted now and her dual diagnosis is very distressing.
A lot of information has come via books, so many books, because there are limited resources for both consumers and carers. There is a wonderful support group here in Adelaide called "Sanctuary" which has been a blessing. Sadly I am no longer able to attend so now I'm out in the wilderness again. The least helpful and the most damaging experiences for all of us have come in the Emergency Department of our major public hospital.
Carer Peer support
Support groups not local, need to travel and need to be able to fit in 'attendance' whilst in caring role
2 day course with Alan Fruzetti especially useful. Also Sanctuary support group but it is 3 hours away.
Have accessed support though my work -Employee Assistance Programme
Never offered any locally
What counselling is there for parents? We feei like we are on the verge of a breakdown dealing with it all.

Question 28: HaveYOUwantedtoaccesssupportforyourselfasaCARER but not been able to? "Please provide further comments"

Answered question 63

Very difficult to find support for person I care for when they are unwell. And no support for me in my caring role including with things like helping with cleaning etc.
I have personally been proactive in seeking information about BPD since my daughter's diagnosis, aiming to 'arm' myself with information to support both her and myself. Therefore I sought out services and organisations so I could attend workshops, forums and support networks, getting as much information as possible aiming to be well informed and prepared.
There is nothing availible. No restbite even when my partner with bpd tries to organise it for me.
Can't afford to pay for counselling for the rest of the family.
dont know how to go about getting this support
COST & TIME
The only support I receive is when I visit a counsellor at my expense, for my own wellbeing. I don't receive any support in regard to BPD
Dont know how
its about the kind of support and so much has been dependant on what my mother was prepared to do - this has impacted on my children greatly - my mother has lived me their whole lives they are now 19/ 17/ 15

felt so incredibly isolated and overhelmed barely coping until i found family connections group 3 months ago
Most of the psychologists I have contacted charge something like $200 even after the Medicare rebate. This is not affordable for me.
Sometimes it's more difficult than other times
I really wanted to attend a support group for Parents and Carer's in my area. However, I was told there wasn't enough 'interest'. When I asked how they measured 'interest', they admitted they had even completed an interested consumer survey with their clients or the public...

At the time it seemed to be considered a behavioural and parenting issue. Since it was a totally immersive experience, I had nothing left to seek help for myself.
Cannot find much info about BPD at all
Mental illness not understood. Only one psycologist in sa
access is available but often have to wait for appointments -
Councillors have always been fixated on me being depressed seperate from a caring role. Almost like caring role is not relevant. Now travelling close to 1 hour to see a councillor re caring role. This is a free service offered to carers, community organisation.
I have been trying to access support for many years but no support groups are available or ones I contact don't respond.
There is nothing in our area plus I work full time plus am the carer for my daughter as a single parent. The financial pressures of caring for my daughter are enormous.
Services do not cater for situations where person has complex needs due to many different interacting disabilities
Due to other commitments and finances I haven't been able to.
I really did not know how to cope or where to turn to
When husband's mood swings & suicidal threats were high I rang our GP very alarmed but he would not talk to me. Sent message to 'ring CAT' or Police. I did not know what the CAT did & I did not think it was a Police matter. Was very angry & felt let down.
have accessed my own sessions under better access
There needs to be professional help for whole family by same person ... either group or individual sessions, but one dr.
Didn't realise there was any carer support in the area of BPD until I was so desperate for help that I started looking online and reaching out to whoever I could find
Due to privacy legislation impossible to obtain info & support from daughter's Vic treatment team (esp during DBT) and therefore I was left in another state being desperately concerned but financially liable for all of her health costs.
After 3 years im finally booked to see a psyhcologist who is appatently interested in boarderline because i have begged to have a contact with someone who may be able to help myself and eventually my daughter. I have not seen him yet.. There is no list of psychiatrist or psychologist who deal with BPD to refer to.
It has been very difficult to find support. I have been seeing my local GP - but I felt I was taking up her valuable time with my seemingly petty queries and problems. I have not been sure where else to turn to, other than my doctor. Talking to mental health professionals who look after my son is prevented due to confidentiality. My son also does not give them permission to disclose any information to me. My son's mental health professionals have not been able to provide me with alternative people I can talk to. Often they tell me to discuss matters with my son, that he should be the one who will tell me what is going on.. but I am not able to trust what he tells me.
Some years ago I tried on two occasions to access Centrelinks Carer Payment unsuccessfully in spite of already been in the caring role for many years..With the help of a professional worker I was eventually awarded this monetary support.
Unable to find the right source until recently
The local doctor doesnt want to discuss my daughter with me due to confidentiality. But it would help my mental health as his patient. And help daughter also !
Oh maybe. As a child I guess, given all the abuse and neglect you endure as a child with a parent who is BPD. I think it is important to remember this and overlook behaviours that put others at risk in the name of being PC or avoiding it because it isn't seen as PC.
When issues were surfacing decades ago I never saw myself as a carer so didnt access carer help. If I had of known early I would have used them earlier

Very hard to obtain support as they generally seem discouraging of being so close as a carer and encourage me to distance and make the person suffering with BPD rely on themselves instead, which isn't particularly helpful in reality
Time, location and lack of knowledge from other carers.
I have dabbled with a some counselling sessions, but am not sure how helpful they have been, as i have felt unclear exactly what i need from them.
There was nothing available in the early years. Few years ago I attended a BPD workshop which was relly helpful and last year BPD conference. That was also good.
I didn't know where they were. When I did find some eg. Spectrum, they told me I lived to far. Others told me she was an adult. Etc
Financial assistance but no luck
When I was desperate for information that was accurate and up to date, it was not available. Even today I believe there is so much misinformation. As recently as a month or two ago, on the All in the Mind program on Radio National, an eminent psychiatrist from NSW was talking about BPD. It seemed to me his insight was skewed towards a particular impression of the disorder which suited his purpose where he was promoting his novel about a relationship between a man with bipolar and a woman with BPD...further he said he encouraged his students not to diagnose (while acknowledging that a diagnosis was important to consumers and carers), but rather to 'treat the symptoms'.
Although, I have respite from one particular organisation that visit me regularly, they were unable to provide counselling based on my believe . Quite disappointed at times when we are from a different culture. The philosophy teaching contrast.
As I am a friend (in a romantic relationship) of a BPD sufferer I have been shut out of the core support network. This hinders my involvement to a large degree.
See above comments re 'Sanctuary' support group. Sadly I can no longer attend.
Current adolescent mental health service has just closed file due to "son's lack of engagement". My son still needs a mental health response and we need advice and support. Requested review of decision and an in-house referral to intensive mobile outreach service, this was declined. Attempted to access Carers Vic, 6 free counselling sessions, denied sessions, need to wait until 12 months have passed since previous sessions.
We live in a coastal area and despite requiring there are no support groups
There are no BPD or mental health carer support groups in my area and because my son can function on his own, there are limited options for support available. I have found the GP less that helpful. Because he is unwilling to accept help, there is little support for me offered.
10 psychologist appointments doesn't go very far.
Lack of support groups
My main area of concern is the lack of working with families from the professionals who directly support my daughter. I am grateful for any help that they provide directly to her however, in my opinion, families also require information and support so that we can all be on the same page and work together.
Have only found suitable support in the last 12 months. we had no diagnosis for ten years so it was hard to work out what we were dealing with and what type of support all family members needed.
Some counselling is available through MIFSA but not specialist pyschologist therapy. Sometimes I really need help with ongoing strategy to support BPD daughter.
Time constraints, cost of support, inability to take time away.
See previous
Because I am also a consumer I am not seen as a carer. This side of me gets ignored and it makes me feel angry.
As mentioned previously I was not directed to any support so it was purely what I found on the Internet.

Didn't know where to seek help. Or that help existed.
I work in Mental Health and debrief with my co-workers and my wife
Not many carer groups in Brisbane are up on bpd so their lack of knowledge and understanding keeps me feeling unsupportef and not included
I was able to access psychological counselling for myself, but it did not focus on me as a carer, whereby naturally the psychologist was putting my mental health needs first, and not focusing on providing me with skills to care for my Mum.

Orgs like ARAFMI and COPMI were very supportive. Where are the biggest gap was - actually having any kind of partnership or communication with the primary treatment personnel, i.e., psychiatrists in the DBT program.
I had to find help my self !! No services suggestions from public mental health

Question 30: Do you have any further comments about this section?

Answered question	**37**
Skipped question	**134**

One major hurdle throughout early diagnosis in particular, was there was NO support or understanding at all from most general psychiatrists - particularly in the private sector, with many who refused to even acknowledge the BPD diagnosis and even questioned it's inclusion in the updated DSM-5.
I am the mother of my eldest son who has BPD. I live in QLD and he live sin Melbourne so it is difficult to say that I'm his carer however he has withdrawn from his family and the only communication is via email. communication via email is often nasty and vitriolic and he appears to actively prevent any way of moving forward by talking through his issues. As a parent I feel unable to support him and worry what is happening in life... our family have been torn apart
What support? There is only this group(that I'm aware of) and the few times I went to a meeting, I did not gain any support. Only a sense that others are facing the same challenges. It was a sharing of issues/challenges, but no constructive recommendations.
Not sure where carer support is available in Adelaide
It is difficult as support services differ with effectiveness and the individual person providing it
Parts of the mental health community and DHHS don't "believe" in BPD. Therefore when you advocate for your child your met with distain and how she "just a difficult person" not clinically unstable. Trying to get her treatment was so difficult - she had to attempt suicide to get active treatment. Moreover, being a professional counsellor made it difficult to find services where I felt heard and validated despite my occupation. I often felt that I was looked down on as a mother and professional. It impacted my daughter being able to access services sooner.
Initially, mental health support by phone was only available part-time on some weekdays.
As the carer I cannot find anyone who can specialise for me or my daughter in her situation. No understanding so support is not tailored to her needs
Need to more activly seek out carer support. Not being recognided as a carer is an issue. Even wife accepting I am a carer is an issue.
I found it much harder to get access to support as a carer when I lived in Perth. Since moving to a regional area I've found it much easier to find the support I need.
Borderline Personality Disorder does not seem to be recognised by Support Services
Times I called services but phone was busy or answering machine and I chickened out of calling back
the services are there in our area if people are aware of them and then choose to access them
now over 20 years and no improvement. ,
SA has had very little support service in place over the years when we have been in crisis situations with our daughter. She therefore has gone to Vic where more support systems were in place however this did not assist me. Costs for her health services, accommodation etc have been astronomical and we have had to purchase permanent accommodation for her in order to support her.
Needs to be borderline association that has all information gathered in one place Australia wide for people to access, to decide the coarse of action to get help.

Support from support group fabulous but to access real support or talk time with my daughters treating psychologist most difficult because of privacy issues etc. that is difficult when you are caring for someone who definitely does not make best decisions based on their own level of "emotional stress".
The most difficult thing for me is to find a service that understands the situations that arise, can support during the times of crises and then to follow up with on going support.
Ignorance about BPD from family and friends and doctors and community makes me feel belittled and disbelieved and misinterpreted about what I go through with caring for my daughter and the emotional toll it has on my husband and my other 2 daughters
There has not been much support for me, I eventually received support through carers australia and BPD Foundation Family Connections. There is limited support, and not many people knew what it was.
Carer support seems to be more available during the work day which makes it impossible for full time workers to access
There was no such thing as carer support. I was looked at an overprotective mother who didn't want to cut away from my daughter. I was so angry at these words.
In our area , we are unable to access any support services.
Can the consumer's doctor have a session with the carer ? Why ? I believe I am out of touch of what the consumer said about their condition. Especially when I have had experienced consumer misled the counsellor in an appointment. Later, abuses me of her existing MH issue.
Previously accessed Medicare funded GP Mental Health Plans - limited number of sessions available Costs still involved: e.g 'out of pocket costs' after Medicare payment to provider, travel to therapists - 3 hrs away (return trip), fuel money, time off work Lack of family therapy available, waiting lists, 'doors closed' to support due to geographic area, funding, waiting times or eligibility requirements and confusing and limiting referral pathways
It seems that there is not enough knowledge about the extreme challenges facing carers of a BPD sufferer within the general mental health services that are available. When my daughter has an " episode" I am always told to call the police or an ambulance.
We live in rural South Australia. There seems to be little support for families dealing with BPD. I had never heard of it until one year ago.
Although giving 24 hour care to our daughter we never receive feedback on how she is going in her therapy, in DBT training from mental health professionals. Parents and Carers appear to be completely left in the dark about feedback. We should be working together to reinforce what they are working on not ignored.
We have found it difficult to access much support in the ACT. Mainly because we spend our time trying to find support for our daughter. The access to services for mental health in the ACT is very limited.
I think not been taken seriously was more from friends and family which in my sleep deprived stressed out self made me wonder if I was over exaggerating the situation, time has proven I certainly wasn't and support earlier on may have benefitted me and I turn my daughter as well.
Being an illness that is new, not many people have heard of we didn't know carers could get support.
We as parents and carers should be more involved in their therapy treatment process also to tell about what goes on in their life on a daily basis because we are with them most of the time. For example drinking and smoking dope should psychologist know???. Taught how to deal with challenges and how to best manage situations.
Very little support for people with BPD, issues around parenting.
Nobody has advised who offers counselling to parents, not even my GP.

Mum needed urgent specialist Dialectical Behaviour Therapy. GP's she was seeing were not familiar with this type of therapy and all my attempts to search for it came up with very expensive and unaffordable costs to access.
Carers are on the front line. They need to be integrated into treatment in order to not feel isolated, and in order to keep safe, healthy and avoid burnout. And in order to help.

SECTION ON: IMPACT OF MENTAL HEALTH SUPPORT SERVICES FOR THE PERSON YOU ARE CARING FOR

Question 31: From your perspective, rate what has caused the most anxiety or been the hardest/most challenging aspect for the PERSONYOUCAREFOR? “Other”

Answered question 22

Long waiting lists for BPD recovery programs have probably been the greatest issue - due to there being limited programs and such long waiting lists. Also services which will accommodate the person I'm caring for in a crisis - such as PARCs rehab units. We have had to resort to private health insurance to cover a stay in hospital (psych unit) when my daughter is in crisis.
As my daughter is accessing the private system, she has a better experience than those using the public system.
service provision is virtually non existent, so much so i have had to study myself to be able to run a support group my self in our local area and offer my services for free to support others. i start my first free support group 25th July
Varies with individuals and organisations
Finances are a big issue
Lack of professional knowledge
As my daughter is over 18 now the nature of the communication is greatly diminished and I am not involved in discussions and therapy much at all now. So I have no idea what they are saying, suggesting she do etc.
Sometimes psychiatrists will presume parent (mother) caused some or all of the problems that person with disability has OR psychiatrist will presume the mother must also have a mental illness until they extensively get to know me and realise that I do not have a mental illness
Husband did not believe he had a mental illness
"long term therapist" ?? Constant change of address, always 'restarting' her life, hoping for solutions.
He doesn't want support and won't see a therapist.
The only help I have got has been through private mental health services and it is very expenisive for a retired person on limited income. However, if that is the only option then you must find the funds and go without other things.
When finally seeing a therapist. She complained of having to see different people, not being believed. Being told that she couldn't be seen because she missed too many appointments. She had a real fear of rejection and if someone different was there she didn't want to tell them her life story again and again. So much pain she would tell me. Not worth it mum!
Because of the alienated relationship with our daughter, I do not feel comforatable responding to the above.
My biggest challenge as a carer has been trying to convince my daughter to commit to DBT therapy. As yer she has failed to do so.
My daughter said "No wonder people kill themselves" as a comment about how hard it was to find and set up services.

We have paid for her care though our health insurance, and have just taken out an individual policy for our daughter as she is now too old to be on our family policy. We have also paid for private psychological counselling. You could die in the ACT waiting or public health access for mental health.
Since we have entered the private health system this has reduced some challenges but has also caused others...
Difficult to find health professionals who specialise in BPD & new treatments Psychologists & Psychiatrists.
The first 2 questions in this section assume services and support are in place, when in fact we do not have them to lose.
Mum took her own life while being on a wait list for a bed in a suitable mental health Ward. The CAT Team that assessed her the day before her suicide said that because "she looked well" (was dressed) there was no urgent need to hospitalise her even though they were told she had been verbally suicidal in the 24 hrs prior. Mum knew they weren't taking her seriously and she was desperate. She felt abandoned and alone with no help in sight. The CAT Team didn't understand the intense rejection my Mum felt when they told her she had to wait for a bed.
Ongoing support groups post-DBT were either not available or fell through.

Question 32: If known, from your perspective as a carer, how HELPFUL / SUPPORTIVE have the following mental health services been for the PERSON YOU CARE FOR? “Other”

Answered question 27

Disability support group has also been helpful (for another disability)
Getting the person I care for to engage in these services has been a challenge - still is!
Cant access mental health groups
MY LOVED ONE DECLINS TO SEEK ASSISTANCE. COST IS TOO GREAT. LOVED ONE UNMOTIVATED TO SELF HELP
this issues has been my mum denies access and dont want the support so we only get it when at risk to self or others
none of the government main stream service have helped or understood at all. Only recently family connections whom have been brilliant. After more than a year of pushing i have only in the last few weeks managed to get my son in to community mental health for DBT but they do not ave capacity to run group work only individual one on one therapy for 30 min per fortnight. this has had some minor impact but only new and not frequent enoogh
Once again varies widely.
Most issues around ineffectiveness is around ineffective implementation.
My daughter has become so isolated, does it start anything for fear of failure, has very few friends anymore, is unable to get anywhere independently so relies solely on me to get around.
A special Support Worker (Carer) who understands the person taking them out e.g. to movies
Tried CBT at my suggestion when nothing else was working. Did not work as husband did not believe anything would work.
had numerous helpful admissions but suicided whilst an inpatient
Anglicare
Wanted to access Art Therapy but not much available and costs too much
Insufficient long term social and general support groups insufficient.
I said N/A as she doesnt do them
These have only been available through private mental health
What I understand about this question is. That when my daughter attended these she picked up a great deal of ways to deal with some of her issues. She would come home and tell me that they listened and she knows what she has.

Paid privately for hypnotherapy and psychologist due to the wait
The responses above cover a period of time over 20 years.
The N/A responses refer to care not provided or accessed by my son. Crisis plans left to us to fill in
He has seen psychologists but not on a regular basis or long term
Going through CAT therapy successfully at the moment.
Again different challenges through the private health system.. Eg. Psychchiatrists that refuse to continue seeing her
My daughter has not been offered any groups
Mum didn't have the capacity to understand her diagnosis and was ashamed of it. She was reluctant to participate in any sort of therapy and only sought out a GP when she wanted anti anxiety medication and sleeping tablets.
Since changing from ELHMS Core to IMOS help has been a lot better and more consistent

Question 33: If known, has the PERSON YOU CARE FOR wanted to access *any of these support services but has not been able to? "Please provide further comments"*

Answered question 48

Due to the dual diagnosis of BPD and Bipolar the person I care for is often too tired to attend programs or to anxious/depressed. Becomes angry and upset if pushed too hard (according to her). Sometimes medications literally put her to sleep in the middle of the day or late morning, so attending day programs is often not possible.
No help groups.
She has been to hospital on numerous occasions for self harming and asking to be kept in and they just send her home
REFER TO COMMENT AS ABOVE
Needs to find support group for BPD, finds other groups are majority older males.
is desperate to get help but is continuously let down. On 3 different occasions my son managed to get a ride in more than 75km (150km round trip) to make his appointment, got there on time to community mental health only to be told the clinician is off sick today... no phone call to advise worker is sick. this is so bad to some one with BPD he now has panic attacks prior to appointments fearing abandonment and the workers wont show up, making it so hard to get him to appointments. this has als happened twice with DASSA in the previous year.
Particularly in the early years when the public system was being accessed, they were very unhelpful. When we moved to the private system it was easier
Doesn't like groups. Has become very disillusioned regarding any help being useful.
Crisis plan and identifying early warning signs non existant.
Cannot access dbt without private insurance or willing to pay tens of thousands of dollars
She is unable to get to supports unless I drive her.
With an intellectual disability and mild autism, the cognitive level of support services is too high for the person with a disability to understand. There are no services that cater for both mental illness and intellectual disability and in particular no services for intellectual disability and borderline personality disorder
Any public therapy due to long waiting lists
Until 12 months ago tracie didn't really own the dbt
I was very proactive in getting her support and paying for a private health fund.
hospital bpd group ... rejected with a dr certificate because she had not attempted suicide 3 times.

Daughter initially received Disability support pension but even with this only limited assist was available. When DSP was cut off she was unable to work part-time plus keep study going so she could only go when a crisis ensued. Now she has limited number of appts with a Psychologist a year but finds this also very difficult payment wise.
Wants help but does not engage with people who are put in front of her because they do not know how to engage with her effectively. Only get response while in hospital Responding to suicide attempts and have to fight to be heard or see psychiatris then be told different things every time we see a new one.
Daughters psychiatrist retired in Dec 2016 so she is still mourning her loss and hasn't seen anyone since. A big backward slide in her behaviour!
My son does not want to access any services for on going therapy. He likes to go to hospital during times of crises and be centre of attention. He wants medication, a quick fix... does not want other therapy.
She is private
Hospital will deny admission unless the person has self harmed or attempted suicide
Has attended local ED departments in "crisis" and been discharged home within hours.
Mental health workers, of all categories, change, some unavoidably, because of change of address.
It has been hard to find someone who knows about BPD and will bulk bill.
Only through private mental health services
Wanted to access the short stay unit at Flinders Medical Centre but going through the emergency department first is hard work due to waiting times
Financial support: the government need to realise how much costs are involved ie with therapy, medications, time off your own work due to stress and exhaustion carers cope with day to day
problems have been cost and lack of the personal interest when she has inquired. She has found a supportive environment in an alternative if not cultish group of people. A group that causes us concern as parents, we see it as enabling a distorted view of herself, her family and the world.
Have no information provided in regards of the above caption.
The person I care for has shut me and her family out of her life for the time being. I have no idea what, if any, support services she has accessed or tried to acess in the last month. Nobody has been able to make contact.
DBT has been recommended, but not provided by mental health service due to it: " it is not evidence based " Trauma counselling not provided by mental health service need to source privately with MH plan or private health insurance Psychotherapy has been consistent from mental health service, due to availability of psychiatrist and our son's engagement. 'Clinical' setting a barrier to engagement no other options or suggestions provided to overcome the barrier.
Partner has been looking for psychiatrists but due to very long waiting lists unable to access any in time.
The person i care for wants to access DBT 12 month program, and apparently is on the waiting list which she has been told is another 8 months to date.
My daughter was under 18 when diagnosed. There are no services available for this age group in WA
Would like to access more hospital admissions but not permitted
Every time my daughter is admitted they discharge her the next day which doesn't give any time to work out a plan or they leave things in her hands to organise further help. Which she never does
My daughter desperately wants to make new friendships but is concerned about being seen as "loser".Her social anxiety is also an issue. Anger management has never been offered, wants to work on her social anxiety can't get in.Would love to do Art therapy,but where?
DBT therapy 18 month waiting list in the northern suburbs. Private too expensive.

She has tried to access counselling but the waiting list is too long. Hence we have paid for private counselling. The worst situation is when the ongoing crisis of BPD/anxiety/ drinking/bingeing and purging /self harming all kick off at the same time. She falls apart, gets absolutely drunk and if we take her to hospital, they drop her out, say the CAT team will follow up and link her into all the services she needs. Only it doesn't happen. She once waited three weeks for a call from the CAT team. Even after numerous suicide attempts (overdoses, cutting, injuring herself) it seems too difficult to find the support she needs, which is distressing for all of us. This is where her alcohol misuse has become such a problem - it's how she copes and self soothes.
Because he works for mental health he gets everything handed to him on a silver plate even free too.
She stays home and is isolated as is scared to go out
Dealing with child protection, who dictate who client can see or not. No consistency, no consideration, no practical support.
Person has top level health care
My daughter cannot afford DBT therapy out of pocket costs. She has just moved out of home. We paid for previous sessions.
He has been refused admission to hospitals, told to deal with substance use first. Told dbt program at public hospital would only lead to more dangerous self harm behavior.
After living with BPD her whole life, without any diagnosis or treatment up until the age of 55, when her second marriage ended and she was hospitalised after the first of many suicide attempts, it was too late. Mum wouldn't accept her diagnoses, wouldn't participate in treatment, and continued to blame others for the way she felt and behaved. After believing this so firmly for 55 years, it was just too late to do anything to change it, as hospital staff and doctors couldn't make her do the therapy, her psychiatrist refused to keep treating her as she wouldn't attend sessions or follow medical instruction, and hospitals refused to keep her in Acute Care under the Mental Health Act for any more than a few days after each of her suicide attempts, insisting she must be treated "in the community" and not in hospital.
Ongoing support groups post-DBT were either not available or fell through. Very disheartening.

Question 34: If known, from the above services in the past, what has contributed most to support the recovery of the PERSON YOU CARE FOR? For example, support from GP or Psychologist, Group Therapy, Mental Health Team, medication, etc

Answered question 98

Support from non-government mental health service. Counselling & psychology services.
All of the above. Community support workers through a Mental Health Team are generally very beneficial, as is a GP who is interested in or specialises in MH. GPs who are not experienced in MH are USELESS and do more damage than good! As do hospital staff - general nursing and doctors who cannot recognise a generalised MH psychotic episode from drug induced psychosis.
Psycologist
community mental team to some degree but feel the majority was left up to myself
GP support
Our family GP
Friendship groups have had the most beneficial
AFTER CARE (A VERY PARTICULAR SUPPORT WORKER)
The person I cared for took her own life.
Psychiatrist
Meditation and yoga helps a bit. Hospital stays halt the self destruction for a few weeks. DBT and any group therapy exacerbates the issues

support from a psychologist with long term experience of BPD
Psychologist weekly
Psychologist Psychiatrist
Group Therapy, medications
GP and for the first time in 20 years govt mental health worker - been supportive but can only offer what services have - she has at least validated what its like for me and my kids and impact over the last 20 years
not much so far but im hoping in time DBT. But the family connections support group gave real tools to help defuse and keep home life a little calmer but it takes a lot of practice to maintain these skills as they dont come naturally.
mental health team
DBT
Consistant therapy, medication, diet, exercise, and SLEEP. Her MH Team is amazing these days. Sleep health has been a major hurdle for my daughter. With a light medication to help her go and stay asleep has been paramount in improving her day to day experience.
Consistency of care from one GP. Respect.
Geelong Clinic DBT course has helped. But not much transition skills out of the course and into the world.
None
Pre-discharge from hospital plan for support through community services
Group therapy- travel over 1 hour to attend. Hospital stay for medication balance and rest.

Her psychiatrist, psychologist and many many private hospital admissions that have kept her alive and safe in crisis.
Support from GP, Psychologist, and getting on the right medication
Medication and an individual Support Worker taking patient out into the community to do things as a companion, that the patient likes e.g. movies companion
Mental health team at hospital and psychiatrist.
Long term and constant therapy sessions
Psychologist and dbt
Group therapy; Groupworx Individual psychotherapy
Good Gp, good psychotherapist, community support
Medication
Out reach worker Psychiatrist
Medication & me learning how to manage his difficult behaviours. Then when diagnosed with Front temporal dementia, Alzheimer's Australia & Carers Vic have been very informative & supportive about behaviour & communication managemen
DBT, stable relationship, supportive individual therapist and psychiatrist
Connection with others
recently ... gp, psychiatrist and Anglicare
Psychologist but haven't been able to access much else
DBT Psychologist (regular attendance) Could not cope without her serequel meds
Gp psycologist addiction specialist
Nothing yet
Regular sessions (fortnightly) with psychiatrist.
Nil

Pre pLanned communuty support on discharge from hospital (private and public)
medication,hospitalisation
GP and Psychologist
Psychologist, Drug and Alcohol councillor, one Pschiatrist,A therapist for OCD who came to our home as she found it hard to get to appointments,Medication
Maori support and cultural activities.
They have not recovered
When hospitalised the patience of the staff is stretched to the limit thus discharging without any follow up
Gp Mental health nurse Hospitalisation
DBT
Hospital stays when in "crisis" to keep her safe and medications
Medication and consistent workers, if a "good fit".
GP, we haven't really had a decent therapist.
DBT and Psychologist Psychiatrist was useless and she is a specialist in this area (not Martha Kent).
Support from GP, Psychologist and Psychiatrist - all of whom she has been seeing for many years. Continuity very important. Took years to find Psychologist and Psychiatrist who she jelled with.

establishment of a trusted mental health team including psychiatrist, clinical psychologist, GP, nurses in hospital, pharmacist and including the social network as part of the treatment team.
GP support but primarily family support
Pschyiatrist, Pschylogist, DBT
Psychiatrist
Private Psychologist
My daughter had in the past spoken well of her GP and the psychologist who treats her for complex PTSD was able to help her with some techniques.
Inconsistent
Group CBT
Attending long ongoing intensive treatment for her eating disorder with Statewide Eating Disorders Services (SEDS). The skills learnt here carry over to Borderline
Staying long term with one clinician in order to build trust
Private psychologist (seen initially) Recovery is still a goal and it feels long way off currently. I think the list should include 'support from direct family members' as we feel we have done the 'hard yards' to provide hope, resilience, love, commitment, safety, case coordination and the daily support required.
Support from psychologist.
Very supportive and knowledgeable gp
The CAT Team
Support from GP, Psychologist & Counsellor
NA, DBT
The psychologists he has seen have been helpful but is difficult to access the on a long term basis due to cost, and it is difficult to get him to attend if it is sporadic.
Psychologist support when it is regular and ongoing. This is sometimes dependent on my daughter turning up to appointments but also limited due to financial costs, staff turnover and limited access to some services because she does not fit into the 'criteria'

A whole team approach. A mixture of pharmaceutical and holistic measures
CBT but this stopped due to lack of funding
She has a psychiatrist and a psychologist but as she has just been admitted to hospital after another serious Panadol overdose you would have to say she is not getting better. She has been with the same psychiatrist for 7 years, he failed to diagnose her disorder - this was done by 2 other psychiatrists in his absence. He will not speak to me at all regarding her condition - the psychiatrists in the hospitals are much more inclusive.
Previous psychiatrist
DBT Pyschologist and mostly from a DBT group course. Medication has settled her mood.
It is very relational for him. He will only converse with people who are genuine and intelligent in his eyes. He has moved to the city. Is struggling financially but has found a GP and Psychologist who he has begun seeing regularly. I am not sure if he has mentioned BPD to the Psychologist but I noticed on her website that she is DBT trained so I a hoping that she has worked a few things out... Currently I pay for his medical bills.
Psychologist
CAT therapy is the only thing that has helped in ten years of suffering.

She is about to return to a residential rehab programme, mainly for her alcohol abuse, but also for her eating disorder and BPD and anxiety. She spent three months there, moved to a more relaxed day programme, crashed and burned two weeks ago. We picked her up after a three day bender and kept her with us, albeit drunk all the time, and she has just re-entered a hospital detox unit where she will stabilise. She's been lucky enough to find out today she's able to return to the residential programme. It is a huge relief to us, because she is safe and getting help. We really can't cope with her.
Getting herself private health insurance so she could have an extend stay at a health clinic. Then she had a whole team working with her. The first real support she's ever had.
Support groups and uniting recovery.
GP has been great Current Private psychiatrist had been good in listening to her and allowing her to take planned admissions into private clinic, alltnough this has been haphazard at times Previous private psychiatrist has been atrocious Her psychologist was great (and consistent) in public system but now she's over 18 determining her area eye is proving very difficult and her private psychologist feels she would've better linked o to a public service
Support from Psychiatrist & group therapy
Residential at spectrum. CBT psychologist. Groups . Wise choices at spectrum three years ago.
Support worker attached to housing.
Her sister gets most of the burden as Mental Health Services are apart of the tangled web that attracts this BPD sufferer to be seen to change with M.H. professionals but in reality not change any mental or physical states (has not changed in the last 30 odd years)yet has used up hundreds of MH professionals time.
DBT Therapy
Psychologist
All services failed my Mum. GP's prescribed her benzodiazepines like lollies without any background checks which would have revealed she was abusing these medications, using them to overdose again and again. Hospital staff, CAT Team, Psychiatrist all failed her as she was too hard to manage. I've learnt that if you are a mentally ill adult and don't have the capacity to understand your diagnosis or want to participate in treatment, nothing can or will be done to get these people better. I remember asking an Acute Care nurse after Mum's 3rd suicide attempt, will she keep doing this? To which the nurse replied, yes. They obviously see this a lot, and seem unable to do anything about.
Medication combined with therapy
Consistency, and colaberating with IMOS ! Team work and having everyone one the same page !

Question 35: If known, from the above services, what has been the least helpful/prevented/interfered

the most with the recover of the PERSON YOU CARE FOR?

Answered question 99

Public Mental health services & Families SA.
Not being able to access CAT Team support due to unavailability on weekends (usually due to them being understaffed). Lack of knowledge and experience of police personal. Lack of knowledge and experience of hospital ED staff - nurses and doctors, in recognising psychosis and not believing the carer that things are 'not right'. Affordability and availability of respite options for when the person I care for is in crisis. Support services for carers to access MH based SPECIALISED counselling - grief & loss.
General gps treating her badly or like a drug addict
affordability
psychiatrist brought up and then left person with deep seeded trauma with no follow up around coping with this.
Unable to access services in a timely manner and long waiting lists.
The biggest challenge has been trying to get linked in with appropriate services that aren't terribly expensive. Waiting lists are large for gov services. Her GP abandoning her was not helpful either. He told her, in front of me, that she was "too hard" and needed to find another GP
AFFORDABILITY BURDENSOME TO KEEP REPEATING SITUATION TO A CRISIS LINE/SERVICE
All of the above
Affordability.
Finding a dedicated psychologist/counsellor, with skills in BPD seems impossible
Not being taken seriously
Mental health team, because when a crisis hits, when you ring the support team they have no idea of your history or current treatments, so they response is always go to the hospital. The hospitals response is always- why are you here, if you are chronically suicidal sitting in emergency for hours before you can see the mental health team is pointless.
Not taken seriously in emergency dpt in hospital
all of the above
GP and psychologist suggesting bi-polar diagnosis
not taken seriously
ED and how they treat families and people with BPD
no insight or willingness to engage
no support at all, country clinicians have no idea about BPD, they all think it is bad attitude and the client needs to grow up, or they are spoilt ect. Nurses (general) often fear BPD patients as they are a scared and dont know how to help, there is a lot of stigmatism. General nurses in country hospitals are not allocated any additional time that BPD clients may need to talk and express them selves when they are down and suicidal. Almost always BPD clients in the country area's given a low dose sedation 5-10 mg of olanzipine or similar and thrown out the door, no admission or assessment, 9/10 not even a risk assessment attended. So stressful for family whom are often right at their witts end with sleep deprivation and stress.
Not taken seriously
The attitude displayed in the public system. Punishment as a form of therapy is NOT conducive to mental health!
Early on money was a big issue. Getting her to a psychiatrist (at $300 a visit) meant that intervention was delayed by several years. Moreover, not being believed by psychiatrists, GPs, etc was crushing.
Unable to access support when needed. Lack of knowlege of BPD.

Finances: she is saving to go to the psych appointment. She can't work full time due to BPD issues. So money is a problem.
All of the examples above
Sometimes availability of services or affordability of private services
Being discharged from hospital far too early. Lack of engagement in recovery activities.
The distinct lack of programmes In the community for young people with chronic mental illness to engage them socially, work on independence, development of life skills etc. Lack of discharge planning from hospital - good support in hospital, they go home and straight back to the behaviours and no support.
Cost of some services Having lack of consistency (see the same psychiatrist every time) in the public system
Group sessions on DBT or CBT which are run on an intellectual level way beyond the capability of the patient. This makes the patient feel useless and confused.
Affordability.
Identifying early warning signs
Hospital stay
lack of ongoing support medication
Being fobbed off
Lack of cooperation from my daughter has led to any services coming to a standstill
Not taken seriously In patient admissions
being "discharged" from hospital against medical advice and against my wishes which resulted in her suiciding
Attitudes of service providers
money always a problem personality clashes gp inconsistency/ interest because of change of address.
Not being taken seriously, slow diagnosis, lack of communication and general education from mental health professionals especially within the acute/hospital setting. Cost of psychology and being able to access enough of it. Medicare "rationing" how many sessions can be made available with private psychologist.
affordability availability unable to access support when needed few practitioners who understand & treat BPD clients
Affordability and availability
Not diagnosed because not 18 No access to private psychiatrist. To expensive No access to psyhcologist because there is no list of who deals with this! Only care in perth WA for adolesants is Perth clinic and it 3 to 5 thousand a week! Can't even find a group session for myself to go to, to learn to cope and communicate with my daughters distress and illness
Affordability is a big issue when relying on Centrelink payments alone.
Unable to access support when my son needed to.
Availability of services not always available when needed.
not enough support, cost,seeing someone once a fortnight does nothing when they can have a hundred or so issues in one day.
there is nothing wrong with her (in her mind) No-one will help unless she seeks help. Therefore no help for carer either.
Hospitalisation. Being treated as if she was beyond help.
One particular psychiatrist who said he could not continue to see her as she could not get to appointments on time ... Hospitals who just send her home (even when they know she has BPD and is unwell at the time . Affordability. Not taken seriously Her alcoholism and OCD
Definitely not taken seriously when admitted to hospital

Lack of available services Lack of hospital beds when needed
Psychologist is unhelpful and doesn't take her seriously
Not being taken seriously by health professionals
Workers, of whatever description, who are not compatible, or change too often, and rude, disrespectful hospital staff, particularly Emergency staff.
Queenscliff Community centres and hospitals dont take BPD seriously. At one stage my daughter was seeing a nurse, she needs proper treatment.
The psychiatrist
Not being taken seriously / misunderstood
in public mental health it has been impossible to establish a trusting mental health treatment team because as soon as you establish a relationship the person leaves. There is no continuity in the service and it gives the impression that you are just a number and diagnosis. You are not treated as a person and you don't have anybody to confine on long term.
Finances Unable to access support when needed Lengthy wait times for DBT Not taken seriously at emergency department
My daughter is still in denial. She uses her disorder when she is in court cases. Otherwise she says, I haven't got any disorder mum. But I know that she knows. Not being able to access services when needed. This is the largest issue. When she was ready, there were no vacancies.
Publib mental health service - no help, non existent
Hospital admission' s, Mental Health Team, Mental Health Support Services
Psychiatrist
We believe her psychologist had a predisposed assumption that our daughter had PTSD, then complex PTSD, because of a belief that we as parents were abusive. This has had the effect of legitimising her alienation from us and her large extended family, over recent years. She has lost a major support network. Relational dysfunction is a key element of BPD, and this has been enabled by her psychologist we believe. That which has been the least helpful is a misdiagnosis and also telling her that recovery is not possible.
Vonlantary discharge from hospital has put me (carer) in a' catch 22' situation, whereby, I cannot seek further intervention for consumer treatment (attempted suicide - outburst) . Social worker was not present when requested .
The counsellor appointed by the religious organisation that deals with her housing appears to have no training in BPD and very little awareness of issues that affect people with the condition. As this counsellor has become her primary contact with the outside world, there is very little anyone can do to help, due to privacy constraints.
Attending public hospitals especially the Emergency Department
All of this

Hospitalisation has disrupted the family bonds and exposed our son to young people who provide an unhelpful influence. Time away from learning settings. Poor or no follow up post discharge. Not been taken seriously. Also "carer blaming" in front of our son during a crisis ED admission...this comment was made by a mental health professional in ED just this last week... " you just wound him up" (during a display of emotional dysregulation by our son) when all we were doing was setting a boundary in regard to his mobile phone. Extreme lack of support services. Carers required to phone around and around and share personal details again and again to no avail. Fragmented services. Poor communication. Lack of discharge summaries, we were told "they are only for the professionals". Affordability - transport costs, need to budget for 'out of pocket expenses' and private insurance
Unable to access psychiatrist.
Mental health team - some very dismissive of me as the carer, I felt they were not looking holistically at the involvement of family.
Psychiatrist
Lack of access to mental health services support network.
Unable to access support when needed bit also nonvompliant when she dors access services

Psychiatric services were the worst because they basically said he was being naughty and to ignore his behaviour. A GP we saw said the same thing and did not refer him to a psychologist which was a major set back.
When my daughter does access services such as getting counselling, she presents very well and is very articulate so professionals often dismiss her diagnosis. However, for her, symptoms appear to go in a cycle and soon thereafter she can spiral out of control.
Spending extended periods of time in an ED where staff are not mental health trained.
Not taken seriously, cost of therapy due to only 10 services allowed by medicare
No on going therapist
Not being taken seriously, being misunderstood,admission for 1 night stays in hospital were very unsettling. Availability of support services that fit with student studying and part time working. Our daughter pays for her services and it is extremely expensive for her. We have had to pay for top Private Health Ins for her DBT course for outpatient pyschiatric education.
I have to say that spending time in the local mental health ward made things worse for a time. There seemed to be a lack of coordination.
Mental health triage complete waste of time. Salisbury mental health lack of support and services closed down. Catherine house Adelaide /do they know what they are doing? Margaret Tobin centre/puts them on prescription medication to sedate them. Glenside same thing different day
Persistent psychologists administering CBT. It just didn't work.
A GP who missed obvious symptoms. Failure to follow through on mental health plans - no one coordinates these, and you're dependent on the individual being sufficiently motivated to comply with treatment. Doesn't work with BPD! At the hospital, when we have taken her in, the nursing staff find her frustrating to deal with. She's usually drunk, and/or has self harmed. They make judgements and think it's all excuses. Lack of appropriate and/or services has been a huge problem in the ACT, and we have used Wesley Hospital in Ashfield NSW on about five occasions, for residential stays of 3-7 weeks. Thank god for private Heath insurance.
Lack or support and services and long wait times. When admitted to hospital after Suicide attempts they just release her few days later with no follow up support
Gp
Her private psychiatrist refusing to see her anymore because she (on my encouragement) told him she did not feel that he was listening to her on what her needs were. This resulted in not only him not wanting to see her any more but one with admitting rights to that I patient clinic willing to pick her up
Not taken seriously. Emergency dept at Hospital sent person home, no support at all until years later after further attendances.

Just discharged and no follow up.from spectrum. Very disheartening and dissatisfied. Left unsupported.
Child protection, very unhelpful or supportive, constantly victimising
Person is so manipulative and has top health cover most of these services do not help her at all.
Waiting around at the hospital. Need more pacer units to avoid hospital casualty. My son was admitted to Stepping stones & hospital in last 18 months.
Prejudice and discrimination against bpd....lack of knowledge, compassion and understanding...lack of accessable, quality, long term dbt programs. Bpd
Being suicidal and not taken seriously enough by CAT Team, made her wait to be admitted, wouldn't enact the Mental Health Act because she didn't physically appear unwell enough. Hospital staff overestimating my Mum's capacity to understand her diagnosis and trusting that she will follow medical instructions once discharged. DBT was (or seemed at the time) unaffordable and not easily available to access. GP's not understanding BPD at all, are easily manipulated by BPD patients who only want benzodiazepines. Laws preventing family members from getting medical information on their family member, due to patient confidentiality.
Lack of availability for ongoing support/stress relief.

Availability of support service out of business hours ! Emergancy departments lack of understanding and empathy to my daughter. Causing things to be more difficult. Many complaints have been put in re ED treatment ie daughter left in restraints unattended.. left in restraints for hours whilst sedated. Injecting when she has said she would swoll meds when already restrained.. hopefully things will change as I have not accepted explainition of Bering injected and restrained for more than 3 hours whilst she is sedated

SECTION ON: GENERAL PRACTITIONERS

Question 43: Do you have any further comments about this section?

Answered question	**39**
Skilled question	**129**

She had received referrals but the cost has been restrictive. But with her GP telling her to find another, things have been up in the air for a while. I see a GP separate to her.
GP's have limited interest or knowledge of BPD, and have never referred us to any professional for help
I have recently changed GP's because of the lack respect for my daughters mental health. I cannot see a GP who doesn't even believe me when I say she's BPD. I can't even respect him as a person. It's taken some time to find a GP who wont sit in judgement of me and my daughter.
The 'caree' found the support offered ill-informed and formulaic.
Very bad support if any at all. Mental health referred her to psysciatrist who put her on medication which she stops taking every now and then
I access councilling service at university where i am enrolled. University councillor referred me to a community organisation.
I am never asked if I need support or how I am going because I work in mental health sector.
We've been with the same GP for 20 yrs. he is very supportive, never judgemental but has no real clue about mental health or support services.
GP lacks knowledge of how to handle BPD
My partner and I have different GPs, hers has supported her constantly and is wonderful, my GP does not know of my partners diagnosis however he has referred me in the past to see a psychologist, which I only went to once due to financial difficulties
It is incredibly difficult when the person with the disorder does not acknowledge the disorder is causing issues or that they do not have themselves in control
from diagnosis to actively seeking help herself took 22 years.
GP doesn't seem to understand the difference between BPD and Bipolar
My current GP has a sibling with MH illness so understands issues associated with my health. My previous GP advised me in the early stages of my Daughter's mental health problems to lock her out of the family house and never let her back in.
I love in a rural town. Its usless
My GP has been giving me a Mental Health Care Plan to see a Psychologist for over 10 years ! This is due to the fact my family and I get affected by living and caring for someone with BPD and I need her support and guidance I have resorted to antidepressants several times and my husband has once. (effects of BPD on others)
Person I care for WILL NOT go to the GP
He won't go...'there is nothing wrong with him'
My daughter has now a good and reliable private mental health team and private hospital where to go to when need be, where she feels valued and is taken seriously. This started when Open Dialogue principles were adopted to her treatment several years ago and I was included as a member of the treatment team. The focus was changed from medical model to psychosocial model with the acknowledgment that medication is a vital part of the treatment but cannot help my daughter effectively without psychosial support and therapies.
No

Because I couldn't see anyone about her mental illness, I sought to see professorial so I could cope with my anxiety.
The GP has only goven referral becasue we has a family have asked.

Mental Health Team don't have the training, so can't offer anything. All the referrals directly or indirectly go through M.H.T for Support Services .They don't allow people with BPD to access services.
No consideration for carer GP don't understand you get 10 minutes and one GP asked me what BPD was and as soon as I said it he turned to me to talk even though my daughter was present in the room. I had to direct him to talk directly to my daughter
My own excellent GP does not know enough, or have enough time in the normal consultation, to offer appropriate counsel.
I have a Question 4 enquiry - It has never crossed my mind that I could receive counselling from GP??
It is obvious that tha list of key contacts in any crisis management plan needs to include a wide range and greater number of people. The person I care for has only two people on her list, which leaves her extremely vulnerable in a crisis, should either or both of them be unavailable.
GPS need to consider the needs of carers because they are carers
Generally the GP has limited time for counselling, it is a brief chat and more about checking in with the current situation.
My niece is very defensive and volatile so even when supports accessed she sabotages
As we are only able to access a maximium of 10 sessions a year and that involves doctor visits (and possibly different counsellors) it is difficult to maintain his desire for help. It becomes too difficult for him.
The GP has been supportive but we have done all the work. I get a sense they are uncomfortable with this illness although my daughter has improved.
The GP referred him but our son rarely went beyond one visit. In Adelaide he finally decided to access a "pain therapist" for the constant stomach pain he has. He tried a few and found one he liked. then asked the GP to refer him to her. I noted on her website that she is DBT trained and actually a psychologist.
The GP does not have the knowledge or experience to deal with Borderline
I live 8 hours drive from my daughter with BPD, her GP is fantastic and has helped me when I've been with her. I don't have a GP as good near me that I have found.
Only about the appalling lack of available and/or appropriate services locally.
Because I am a consumer as well I get nothing as a carer
I feel doctor or psychologist doesn't consider obesity from medications or whst she eats or discuss her health in being overweight.
The question about hospital admissions - it is considered counter productive to admit some people with bpd, to hospital. Thus they are rejected when they need help, re-traumatised and left with no where to go.

SECTION ON: HOSPITAL ADMISSIONS – PUBLIC

Question 49: When the PERSON YOU CARE FOR was admitted into hospital, have YOU ever been involved in: "Other"

Answered question **21**

at the second last admission I was included, otherwise prior to that because he was delusional I was excluded at his request. The last admission I was called to take him home from emergency that was all
all above accept the last one
most of the time we are just told what is happening at the time it happens, no real open disclosure, no inclusion in decision making an frequently clinicins dont want to hear what you are saying. often felt frowned upon like we are a bother. Usually discharged home when i am terrified my son will reattempt suicide with no action plan and never any new prescribed medication as clinicains always say nothing works he needs to attend therapy, then discharged out of care and control in a tertiary hospital country will never admit family member, usually detained and transported to Adelaide. Hours in the back of an ambulance to get to adelaide assessed and discharged the same day.
All of the above

He talked his way out within a few hours. The doctor who assessed him left me a phone message saying he was just 'confused and upset'.
I've been involved in all these steps.
All of the above
I have only been involved in the above when I have pushed for information over last 3 years. I have not routinely been involved
This occurred once only other discharges have been without plans or query as to where she was going plus negative follow-up or referral to services.
Im her mother. They always have to talk to me
I have asked to be involved, but my son does not want me to be.
Little discussion with hospital staff. Rarely involved in decision making.
I was told about her entry into hospital as I am her caregiver and my phone number is with them , however, she was discharged sometimes against her will. Or she would just leave at times.
Vaguely ... they said you listen ... not very cooperative about my perspective on the consumer behaviour . No further discussion taken place from my side of the world.
despite attempting to be involved and act as advocate
Informed about discharge, but not involved in the planning
Our lived experience has been that it is difficult for MH professionals to work in partnership with families. It is SO different to occasions when our son has been treated in hospital for medical conditions, a partnership viewed as best practice
As she's an adult they don't really listen to anything I try to say
Only because I wrote them a letter..
All of the above except no involvement.
In private care I was involved in the whole process. In public system I was largely ignored

Question 51: What were the main reasons for the request for the PERSON YOU CARE FOR to be admitted due to mental health issues? "Other"

Answered question 7

Manic episode due to being perscribed a medication that didnt go with her body chemistry
all of the above often all at the same time and we are in crisis. Often family in tatters and other members of the family wanting to move out of home due to the stress it causes when family member is having an episode or suicidal ideation's, panic attacks or anxiety attacks

Really , I have wanted my son to be admitted to hospital on several occasions for many of the points mentioned above, in particular suicidal behaviour, self harm behaviours, being out of control, having his life in total chaos and for drug problems.

Paychosis
Sleep apnoea due to surfing constantly on FB, and getting involved in Indecent behaviour with younger boys.
This request for crisis/containment admission has taken place in the last 10 days.
Harm to others

Question 52: If known, who refused to admit the PERSON YOU CARE FOR into hospital? "Other"

Answered question 10

Mental Health Triage & staff at local hospital
emergency department even though GP wanted admissions

GP usually, but have also had mental health nurses - after my son stood in front of her ripped all his clothes off in a car park due to extreme anxiety and depression while ripping hair out of his head and making his scalp bleed while crying and sobbing i want to die life is horrible i can not feel normal emotion, she still did not help me to get my son admitted and took 3 weeks to phone me back asking why he missed his next appointment....
and psychiatrists
All at some time or another
Ambulance personal attending at the time and police officers.
Was admitted as ambulance was called but let out soon after.
Psych ward
First mental health nurse refused. We insisted on assessment by a psych registrar. He refused admission stating "he doesn't meet the requirements for admission"
Mental health triage

Question 53: If known, please provide further comments/information relating to this refusal of hospital admission.

Answered question 23

Belief that person was "attention seeking" and didn't need treatment.
I needed respite, she was quite ill and they wouldnt help
We were sent home as they told us they couldn't offer any beds in the unit.
stigma
many some examples above
They didn't think she was high risk enough although she was throwing herself in front of traffic and trains and they only just managed to stop in time
Crisis often hand balled back to the CAMHS team where care is non intensive and too infrequent
When in hospital they give her all the rights to make her own decision about what she wants even though she is only 16. I don't want her locked up i just want her stabalised enough to get some DBT started! And have some regular sessions with psychiatrist so she can get some stuff out! to get a plan established and to show her that getting help will help!
When I had called ambulance out (and police came at the same time) because they could 'settle' my son down at the time, they did not think he required hospital admission. The minute they leave, my son would start being agressive/out of control, self harm again.
Rather than refusal it's been more a refusal to let stay even though suicidal ideation and planning is still current because they have felt they can't do any more to help
Mental health nurse did not take my concerns very seriously.

Reasons were because she didn't want any help. Not willing to get help.
Mental Health Team did not want to know.
They ... have presumably determine the cause of the consumer (example - whirling a knife towards family member ???). Consumer was out of controlled, and I suggested other option to place consumer with residential care, but was turned down. I have no other option, but to take risk and bring the consumer into my care, and knowing that this behaviour is not going to stop. We have to take extra measure to prevent accident.
We were told frequently that "people with BPD shouldn't be admitted to hospital" and people who self harm "should not be admitted to hospital because it willingly encourage them to do the same thing over and over" She will only be seen by mental health staff if she is medically stable. This involves an 6-8 hour wait in the waiting room (part of her treatment plan apparently). If they decided to keep her it is only overnight. They administer sedation, she falls asleep very quickly and is discharged immediately on waking in the morning.
The hospital admission was refused because they did not think it would help his suicidal behaviour. They observed him in emergency all night, then sent him home.
Mental Health Nurse stated in front of our son "he is calm now, he can go home, it's just bad behaviour" even though he had been admitted to ED after a section 351. She had not spoken to us,his parents, at all or was aware of our son's previous inpatient admissions to that hospital until was we raised it. We observed and commented to her he appeared to still be agitated and emotionally dysregulated, this was dismissed and ignored with all our other observations we had written down.
She is constantly dismissed and disbeleived as 'she only has Bpd ' and the same story is always that she is not suitable for admission as 'hospitals are bad for people with BPD" . Her suicidal ideation is not taken seriously even though she has made several serious attempts.
Often there are no beds available for my daughter

She was released from hospital before she was ready which lead to her almost suiciding AGAIN. We weren't taken seriously and it took extreme episodes for her to be admitted again and finally two psychiatrist to diagnose her with BPD. On a separate time she walked out of a public hospital and went home after we pleaded for her to be watched as she was suicidal. We told the hospital she had left after finding out from her flat mate and they hadn't even realised.
In public system. They continually told me they didn't have enough beds - even after Suicide attempt
When they see bpd on record they refuse admission...even when I've begged them. Many times. Nowhere else to go.
Can not remember

SECTION ON: SUPPORT SERVICES MENTAL HEALTH PROFESSIONALS

Q54 Briefly describe how YOU as a CARER FELT and what the IMPACT was of not being able to admit the person you care for into hospital.

Answered question 29

Continued self harm by individual. Worry that person would kill themselves. Impact on social life due to need for continued monitoring required of the person.
It put a big strain on our relationship and emotions, i also suffer some mental health issues and this caused them to jump in severity to me being suicidal.
Fear and helplessness
totally depressed , alone, angry,

No sleep, family disruption, loss of work as have to take time off to care for family member, when you go to work you are so consumed with fear concern and stress for your loved one you can barely concentrate. You become tearful and emotional and often struggle to contain your self as the person with BPD often become violent aggressive and highly sensitive and when you are tired yourself it is almost impossible to react calmly. Frequent SAPOL calls for assistance.
That it was left to me only to manage
Helpless. No one seems to care. To them my daughter is just a drunk young person and gets treated badly no matter where she is.
Desperate for someone to take us seriously as to how disregulated daughter was and how unsupported I was feeling. Hopeless because no one ever understands how bad things are. Worried that I will loose daughter either to suicide or to homelessness because of aggressive behaviours.
Useless helpless no hope
Frustrated, despondent, angry, alone, not respected, fearful, upset and scarred at what would happen to my son and the rest of the family during these times of crises.
Terrified of person suiciding
I felt hopeless as there seemed to be no one to help, despite accessing the services I was told could help eg ecat team at local ED. The impact meant that I would either be up all night making sure the person I care for did not self harm or driving around the streets looking for her after she ran off because no one (health professionals) cared or could help her.
I knew that it could cost them there life, nobody took me seriously, I was powerless.
I was devastated that there was no where else she could go to. She didn't want to come home, so she walked the streets. So worried and so guilty that I didn't know what to do for her. Helpless in not knowing what to say to calm her or make her understand as she told me , it hurts better to be dead mum, just leave me alone I'll be ok. .
Anxious ,Help less , were do we go from here.
Deprived, misunderstood, silence , helpless, lost, anxiety , hurt ......
Felt abandoned and very worried for our daughter who was clearly unwell and yet receiving no assistance. She was unsafe and was discharged because "people with BPD shouldn't be admitted to hospital" and people who self harm "should not be admitted to hospital because it willingly encourage them to do the same thing over and over"
At the time I felt helpless. On another occasion I stayed 19 hours in emergency with him while they tried to find a bed in a hospital, he had told me that if he did not get into hospital he would take his life, and I believed him. He was eventually admitted into a locked ward for two days.

AS CARERS we felt: Shocked, traumatised, disillusioned and immensely unsupported. The IMPACT was: In an attempt to return home our son became so dysregulated he left the car and walked off. We needed the police to do a welfare check to see if he made it to his destination (a friend's home). He has since chosen not to return home and he is still staying at a friend's home with his family. This is the first time he has left the family home we are desperately working with youth workers to re-stabilise the relationship and reconnect with zero assistance from MH professionals (as they have closed his file). We had to request and wait for an ED consultant to provide a discharge letter. Our expectation's following discharge were the ECATT team would be in touch with the other services involved (we are yet to know if that happened) but we were not seen as part of the care team partnership.
Despair and frustration and deep concerns for her future
When my daughter was completely out of control, self harming, putting herself at extreme risk etc, i felt ill equipped to be able to support her at home however there was no other options. The impact of her behaviours on my family (husband and two children under 10) has at times been devastating. I actively seek information and knowledge and am university qualified in the field of disabilities, so feel that i have a lot of knowledge about peoples behaviours and interventions and supports available. However, this situation has been the most challenging in my life.
It's a devastating impact on my family and on the public emergency resources because police and ambulance end up caring for her most of the time
I feletanxious and exhausted and felt that I had the burden of keeping our daughter alive. I also felt that I was the only one who cared about her illness and I was the default mental health system. All of this with no knowledge, and also while being depressed and exhausted myself. The only time I have a break is when she is in hsopital and someone else is looking after her.

Not being taken seriously even through her words and actions where extremely serious . Shocked that she was sent away from hospital and help
It makes me very angry having nearly lost her many times. They just don't get it how serious this condition is
Absolute despair. It was the most traumatic time of my life to think my daughter was going to die and I was unable to prevent it..
I felt hopeless. If there's no support for my mum then what else can I do. At the time I felt so sure she was just going to try suicide again. And she did
I feel like a complete failure as a parent, not being able to relieve my son's suffering. I am furious at the discrimination and lack of care and treatment options. My son lives on the fringes of society excluded from a 'normal' productive life within the community. We are estranged because the mental healrh system does not have accessable dual diagnosis treatment.
I felt like things had not been taken seriously

Question 63: Any further comments about support services YOU would like to accessor have previously accessed as a CARER or for the PERSON YOU CARE FOR?

Answered question	***39***
Skipped question	**129**

Respite services - useful.
Carer Peer Workers have often been the greatest support in caring for a person with BPD, along with specialist representatives from organisations such as Spectrum and Bouverie Centre.
I would love to access respite and group help
feel that carer is very much left out of the picture especially as a partner
A "nurse on line" type of support would be very helpful to talk through crisis issues
I have accessed Aftercare FACES The most helpful have been Mental Health Carers (ARAFMI) Illawarra who provided education and a specific support group for BPD carers.
Support groups
Family connections brilliant
Services bratty greatly as do individuals within organisations.
An education/information workshop on BPD for support workers held in Launceston a few years ago, organised by a Victorian mental health umbrella organisation specialist was a revelation, and the best, most comprehensive and helpful thing I had experienced in 30 years of caring.
It took many phone calls to find out if there eere services available for me. Finally got onto carer support who clean my house and babysat a couple of times. Very limited funds. Also kids can access social outings group but there again very limited funds. Very difficult for children of sufferer too.
Belonging to a couple of Providers of carer support has been very helpful - especially in just talking and sharing with other carers, comparing experiences
University councillor.
If I didn't actively advocate to
Group for carers of the mentally ill but only rarely as the other carers do not have as complex problems to deal with with the patient as I have to deal with with my adult child with mental illness, that is my child has multiple mental illnesses all interacting
More online resources that are easy to read and find on what to do when an episode is occurring and the warning signs prior to.
I keep trying to find someone to support me in managing supporting my children and what is best for them and cant
arafmi organization.
I would like to see a Spectrum type service in SA as is used in Vic to support BPD people and their carers.
Impossible to find right support. Spent hours looking through internet and calling people to find person to go to that is experienced and affordable.
My husband and I go to monthly meetings at Sanctury in the MIFSA building in Adelaide which is a group for people caring for someone with BPD .And have been to groups that they offered at one stage I would like to do the "Family Connections" course but have no time at the moment I go to counselling at Uniting Communities (Pitt St, Adelaide) and go to their womens group there monthly I go regularly to a Psychologist for support. I have rung Lifeline on numerous occasions for crisis support I have rung ACIS several times I have rung police several times to come to my house to calm her or take her or to find her when she was lost for several days, OR when they brought her home from the city in drunken states or when they rang saying she would be arrested if we didnt come to a "bar" soon to collect her as she was creating havoc in drunk state I have gone to ALONON to learn/get support Our family have been together to a councillor ....
I have attended some retreats, art therapy and courses aimed at carers such as "Don't make it worse", suicide prevention, dealing with grief.

We can't access Support Services.
This is hard to complete and needs a time frame limit. Today, I know how and where to gain support for myself (and for my daughter - but she doesn't want it). However, that is because I am immersed in the BPD Community (here in Vic). If I didn't have that, I would be at a loss to know where to go for either myself or my daughter. When I was pleading for help 6 years ago, I got the bum's rush from everywhere I turned - except Lifeline and WIRE. Further, I didn't even appreciate that I was considered a 'carer' and had services to support myself.
Short stay in Residential care unit would be helpful. The consumer I cared usually has a pattern during cold winter month. Bad behaviour emerges during these period (autumn, winter).
I would like to be more closely involved, but social workers and GP's are guarded about what they can do because of privacy issues. This leaves loved-ones out in the cold and unable to help.
I see a psychiatrist regularly for Bipolar and Anxiety, so this gives me a chance to discuss issues with my daughter. The problem here is I need to discuss my own mental health issues so valuable time for me is taken up discussing my daughter. My psychiatrist concentrates on my needs which is helpful.
Other BPD carers & the general mental health carer support group have been the most supportive There is need for more peer support
Family therapy (intensive support) Outreach services Personal counselling (to support us to navigate the mental health service system and to help us recover from the trauma we have been through)
Being treated with due respect by health professionals stopped when my niece turned 18
Most of the support revolves around trying to ignore the behaviour and setting boundaries. I do feel that most of the support is from people that don't really understand BPD. I have accessed Sane on line forum and found people there very understanding, but it is not the same as having support nearby.
I have accessed a course for Carers of BPD through Family Connections which was helpful. I feel that I need to do it again as there was a lot of information to absorb. The course was recommended by the Sanctuary in SA
Like to access Social Anxiety support service, Anger management workshops,Art therapy. No one is coordinating anything for us. We do it all ourselves. BPD clients need a CASE MANAGER.
Most of my support came from books and online websites once I knew what we were dealing with. Sanctuary Support group in Adelaide was fantastic but I live three hours away and have only been 4 times. They keep in contact through email. Doing a weekend family connections course with Alan Fruzetti was great. It would haver been better if I could have done the actual Family Connections 12 week course but have no access to that in the country. I have sought and accesses various counselling over the years to deal with the stress our family was experiencing. My son has always resisted any support that we tried to steer him towards. He saw most of the services as fools. If I had known about BPD earlier, I would have understood what he was going through.
After a serious overdose in 2016, we saw the hospital social worker with our daughter, who was almost 24 years then. We never saw her again, despite her promising us numerous services.

My support group is great, occasional respite would be great as well
More support with how to cope. The. support group is too far away for me to go to. Need support groups here in the West.
For me MINd Australia have been a god send ! Also neabpd family connections program

Question 68: ***Do you haveany further comments about this section?***

Answered question ***32***

Skipped question ***136***

Counsellor is most easily accessible outside of normal working hours & responds in a crisis.
The psychiatrist and the private Mental Health unit the person I care for attends under her psychiatrist is the first point of call for responding when she is in crisis. Other than me!
With my loved one's dual diagnosis, she was always kicked out before receiving any real help.

When in crisis it is impossible to talk to professionals as they are already booked with other clients, you have to make appointments weeks in advance. Psychiatrist will usually arrange an emergency appointment within a week, she sees her psychologist weekly so can usually manage until her next appointment. That is after years of therapy. Early in the journey, a trip to the hospital was our only choice. When she had access to a private Mental Health nurse who would talk to her after hours, she managed to stay out of hospital much more often. Suicide attempts were less frequent.
Varies.
The person I care for is in Victoria and I'm not sure about some of this.
Mental health listen to you. Can't offer any constructive help. Are short term only. Referred her to psyciatrist. Have a long history of her but doesn't seem to make the situation anymore urgent.
Access to Psychologist or Social Worker services is limited and not readily available
I call the Mental Health Line
If I didn't actively advocate for my daughter and seek out information I would have no support. But in essence the support I have is just about confirming the research I have done myself or my lived experience. It does not make my role any easier as a carer.
Apparently Doctors think that the Carer can cope regardless of the Carers own health e.g. the Carer is worn out but is still expected to carry on
GP not contacted in a crisis.
rapid moods swings means any of the above are too late. By the time she gets to dr, her crisis is passed. They don't see the anger or frustration - only me(and her children) witness these.
Daughter has youth worker and mentor at school who has been very responsive
This page questions are cofusing. We are not getting help as mentioned on page before
Can not get access to them when she is in a crisis. Only after
The MH Carer support group has been very good.
Currently she is responded to by a mental health worker fairly promptly, but this has not always been the case. I have never been given a copy of a crisis plan, but i have been aware she has had one, from time to time.
Mental Health Team puts up road blocks rather than provide assistance .
this assumes that the person is either self harming or actively suicidal. If my daughter was suicidal (I have no doubt that was/is probable), she did not admit it, or acknowledge it.
Unable to receive responsible contact personal - not available when there is a crisis in the background
My daughter has a cadre worker through MIFSA (Mental Illness Foundation of South Australia). They change from time to time, some are better then others. They are limited in what they can doing to help, helpful with getting to and from appointments etc. The current ione is particularly good, has some counselling training.
Other: emergency services are very responsive
I am an RN and stoll battle with getting crisis dupport with presenting at an ED even though I know yhe system and am a good advocate

Have rung the ACIS team in Sth Australia. They talk but my daughter says they don't help. Can't get in to doctor,Pyschologist or pyschiatrist at short notice. She doesn't want to go to hospital, they have treated her badly before. We just spend hours talking to her at home.
Response varied
I'm not sure how to accurately respond to this. When she has been in crisis, we have taken her to hospital. But it's complicated as its usually due to a combination of comorbid conditions all kicking in at the same time - usually exacerbated by alcohol abuse.

Her last crisis was a disaster, we presented at emergency where we were told it was not our area, but Di deem an admission necessary, because she was just 18 she was terrified of been admitted into a public ADULT clinic, so she told them she wanted to go to a private clinic of which they could not help her with. Her private psychiatrist never returned her calls resulting in her going home and hurting herself even more whereupon she ended up in a public hospital and no private clinic willing to take her. Her private psychiatrist continued to not take her calls and in the end I had a meltdown with the public hospital who seemed to manage to get her into the private clinic because they needed the bed in the public
My daughter has never had a social worker or occupational therapist.
Accessing professionals in this case only prolongs the state of BPD that this person has that is to use MH professionals to be seen to change without actually changing.
We both just go it alone ...been let down too many times by the brutal system
I have been on my own when my partner has been in crisis, relying solely on friends for support and respite. I have had huge struggle knowing when to call a mental healthcare team and so never did even though there were times I was concerned for the emotional and physical safety of my partner, myself or our child.

SECTION ON: RESEARCH: CHILDHOOD AND ADOLESCENCE STATISTICS

Question 1. Do you have any further comments about this section?

Answered question 9

Majority of public services were dismissive.
Not answered as a parent. Answered as spouse based on infomation provided by a parent. Diagnosis was after marriage and birth of first child. Significant problems before this but covered up.
It is difficult to decide which problem came from which mental health diagnosis when patient has many mental health diagnoses
This section was dedicated to the person with bpd however I filled it out as best as I could on behalf of my partner
BPD was not diagnosed in adolescence even though now it is quite clear this is what was wrong. My daughter was therefore treated for conditions she did not have. Useless, damaging and expensive waste of time
Sometimes picked up by ambulance, behaving oddly or dangerously in public space.
My mistake was that I trusted psychiatrist and doctors, their judgment on the treatment with medication excluding family and other therapy forms even when I suggested such as anxiety, relaxation and counselling. Focus was solidly on medication and excluding carers from decision making and interviews even when it would have been helpful and preferable from the patient's point of view and for educating the support network and helping them to understand what is happening and how best support the patient.
Our daughter felt so ashamed, we didn't find out she had been bullied at primary school until she was 21.
She told me she didn't deserve love and hated herself. Can't change who she is.

Appendix 2: Survey: experience of carers supporting someone with the diagnosis of Borderline Personality Disorder

DEMOGRAPHIC INFORMATION

1. In which State/Territory do you live?

QLD
NSW
ACT
VIC
TAS
SA
WA
NT

2. Location

Capital City
Regional Town
RemoteTown

3. What is your Gender?

Male
Female
Other

4. What is your Age?

Under18
18-24
25-39
40-49
50-64
Over65

5. What is your Marital status?

Single
Spouse/Partner
Separated/Divorced
Widowed

6. Are you of Aboriginal or Torres Strait Islander descent?

Yes
No

7. What is your country of birth (if not Australia)?

8. If you were not born in Australia, how many years have you lived here?

9. What language do you speak at home (if other than English)?

BACKGROUND INFORMATION (CARER)

10. What relationship do you have with the person you care for? I am their:

Parent/Guardian
Spouse/partner
Sibling
Son/Daughter
Friend
Other

11. What is the gender of the person you care for?

Male
Female
Other

12. What is the age of the person you care for?

Under18
18-24
25-39
40-49
50-64
Over65

13. What is the marital status of the person you care for?

Single
Spouse/Partner
Separated/Divorced
Widowed

14. Is the person you care for of Aboriginal or Torres Strait Islander descent?

Yes

No

15. In what country was the person you care for born (if not Australia)?

16. If the person you care for was not born in Australia, how many years have they lived here?

17. In what language does the person you care for speak at home (if other than English)?

18. What is the primary diagnosis of the person you care for?

Borderline Personality Disorder (BPD)
Anxiety Disorder
Post Traumatic Stress Disorder (PTSD)
Obsessive Compulsive Disorder (OCD)
Bipolar Disorder
Schizo-Affective disorder
Eating disorder
Don’t know
Other (please specify)

19. Does the person you care for have any other mental health diagnoses?
Select all options that apply.

Borderline Personality Disorder
Anxiety Disorder
Post Traumatic Stress Disorder (PTSD)
Obsessive Compulsive Disorder (OCD)
Bipolar Disorder
Schizo-affective Disorder
Eating Disorder
No other diagnoses
Don’t know
Other (please specify)

20. If known, what medications does the person you care for take for mental health issues?

None
AntiDepressants
AntiAnxiety
AntiPsychotic

Don’tknow
Other (please specify)

21. If known but you are not sure of what the medications are for, please list the names here.

22. When was the PERSON YOU CARE FOR diagnosed with Borderline Personality Disorder (BPD)?
Within the last year
1–3 years ago
3–6 years ago
5–10 years ago
Longer than 10 years ago
Don’t know

23. Which medical professional made the diagnosis of BPD?
General Practitioner (GP)
Psychiatrist
Psychologist
Mental Health Nurse
Don’t know
Other (please specify)

24. Did that medical professional explain to YOU AS A CARER what Borderline Personality Disorder means?
No
Yes

25. Do you have any further comments about this section?

IMPACT OF MENTAL HEALTH SUPPORT SERVICES ON YOU AS A CARER

26. As a carer for someone with BPD, please rate how challenging each of the following has been for YOU:

	Very Challenging	**Challenging**	**Neutral/ Not Challenging**	**Notapplicable**
Unable to access support as a carer				
Lack of support options for me as a carer				
Services not available in my local area				
Financial cost of accessing services as a carer				
Other (please specify)				

27. From the following support services that YOU have accessed as a CARER, how HELPFUL/SUPPORTIVE have the services been? Select ‘N/A’ on the righthand side of the scale for any services you have not previously used.

	Very	**Unhelpful N/AUnhelpful**	**Neutral**	**Helpful**	**Very Helpful**
Education and information About BPD					
Support from my GP					
Support from other mental health professionals					
Counselling for me as a carer					
Carer support groups					
Other (please specify)					

28. Have YOU wanted to access support for yourself as a CARER but not been able to?
No
Yes
Please provide further comments

29. Rate how each of the following has prevented you from being supported as a CARER of someone with BPD?

	Prevented	**Neutral**	**Has not**	**N/A**

	Prevented
Unable to access support when needed	
Not being taken seriously	
Cost of support services	
Lack of carer support available	

30. Do you have any further comments about this section?

IMPACT OF MENTAL HEALTH SUPPORT SERVICES FOR THE PERSON YOU ARE CARING FOR

31. From your perspective, rate what has caused the most anxiety or been the hardest/most challenging aspect for the PERSON YOU CARE FOR?

	Very Challenging	Challenging	Neutral	Not Challenging	N/A not anissue
Fear of losing mental health support					
Fear of losing a longterm therapist					
Lack of longterm/consistent support					
Discrimination because of Borderline Personality Disorder diagnosis					
Not being taken seriously					
Being treated badly					
Not feeling respected					
Unable to access support when needed					
Lack of choice of support services					
Long waiting lists/times to see mental health professionals					
Services not available in our local area					
Financial cost of accessing services					
Unable to comment					
Other (please specify)					

32. If known, from your perspective as a carer, how HELPFUL/SUPPORTIVE have the following mental health services been for the PERSON YOU CARE FOR? Select 'N/A'on the right hand side of the scale for any services the person you care for has not accessed, or if you don't know.

	Very Helpful	Unhelpful	Neutral	Helpful	Very Unhelpful	N/A
Identifying early warning signs						
Developing a crisis plan						
Education and information about BPD						
Meditation						
Hypnotherapy						
Psychotherapy (longterm and/or regular therapist)						
Cognitive Behavioural Therapy (CBT)						
DBT						
Trauma Counselling						
Hospital admission						
Mental health support groups (e.g.depression, anger management, PTSD, etc)						
Community support groups (e.g. art therapy, friendship groups, etc)						
Other (please specify)						

33. If known, has the PERSON YOU CARE FOR wanted to access any of these support services but has not been able to?

No

Yes
Don't know

34. If known, from the above services in the past, what has contributed most to support the recovery to the PERSON YOU CARER FOR? For example, support from GP or Psychologist, Group Therapy, Mental Health Team, medication, etc.

35. If known, from the above services, what has been the least helpful/prevented/interfered the most with the recovery of the PERSON YOU CARE FOR? For example, unable to access support when they needed to, not taken seriously, affordability or availability of support services, etc.

36. Has the person you care for been admitted into hospital for issues related to BPD in the last:

3 months
6 months
9 months
18 months
More than 18 months or no admissions

GENERAL ADMISSIONS

37. Does/has a GP supported YOU as a CARER?

No
Yes

38 .Does/has a GP supported the PERSON YOU CARE FOR with issues relating to BPD?

No
Yes

39. Does a GP provide You with personal counselling for issues related to being a CARER?

No
Yes

40. How long have YOU as a CARER been receiving personal counselling from a GP?

Less than 6months
6-12 months
1 –2 years
2 –5 years
5–10 years
Longer than 10 years

41. Has a GP referred YOU to any of the following CARER support services/mental health professionals? Select all that apply?

Mental health team
Psychiatrist
Psychologist
Social Worker
Occupational Therapist
Counsellor (other)
Carer support groups
No referrals given
Other (please specify)

42. Has your GP referred the PERSON YOU CARE FOR to any of the following mental health professionals?

Mental health team
Psychiatrist
Psychologist
Social Worker
Occupational Therapist
Counsellor (other)

Carer support groups
No referrals given
Other (please specify)

43. Do you have any further coments about this section?

PUBLIC & PRIVATE MENTAL HEALTH SERVICES

44. Select from the following options which one best describes the PERSON YOU CARE FOR access to public and/or private mental health/hospital services?

Only use public mental health services/hospitals
Only use private mental health services/hospitals
Use mostly public mental health services/hospitals and some private
Use mostly private mental health services/hospitals and some public
Don'tknow

HOSPITAL ADMISSIONS - PUBLIC

45. Has the PERSON YOU CARE FOR ever been admitted to a publichospital because of issues relating to Borderline Personality Disorder (BPD)?

Don't know
No
Yes

46. Approximately how many hospital admissions has the PERSON YOU CARE FOR had in the past 3 years because of issues relating to BPD?

None
1
2
3
4
5 or more

47. If known, has the PERSON YOU CARE FOR ever been admitted into hospital involuntarily (i.e. without their request or consent to be admitted)?

No
Yes
Don'tknow

48. If known, what has been the longest stay in hospital for the PERSON YOU CARE FOR for mental health issues?

Not applicable
1 day
3 days
1 week
2 weeks
3 or mor eweeks
Don't know

49. When the PERSON YOU CARE FOR was admitted into hospital, have you ever been involved in:

Their assessment process
Their treatment
Ongoing management
Decisions about the person you care for
Discharge planning
No involvement
Other (please specify)

50. Have you ever asked for the PERSON YOU CARE FOR to be admitted into hospital because of mental health issues but been refused?

Don't know
No
Yes

51. What were the main reasons for the request for the PERSON YOU CARE FOR to be admitted due to mental health issues? Select all that apply.

Suicidal behaviours
Self-harm behaviours
Out of control
Life in chaos
Depression
Anxiety
Drug/Alcohol problems
Don't know
Other (please specify)

52. If known , who refused to admit the PERSON YOU CARE FOR into hospital?

General Practitioner (GP)
Psychiatrist
Psychologist
Case Manager
Mental Health Unit Manager
Director of Nursing
Clinical Director
Don't know
Other (please specify)

53. If known, please provide further comments/information relating to this refusal of hospital admission

54. Briefly describe how You as a CARER FELT and what the IMPACT was on not being able to admit the person you care for into hospital.

55. Have YOU as a CARER ever been admitted into hospital for issues relating to YOUR MENTAL HEALTH or the burden of caring for someone diagnosed with BPD?

No
Yes

56. If You have been admitted, how many admissions have YOU as a CARER had in the past 3 years?

None
1
2
3
4
5 or more

HOSPITAL ADMISSIONS - PRIVATE

57. Has the PERSON YOU CARE FOR ever been admitted to a private hospital/clinic because of issues relating to Borderline Personality Disorder (BPD)?

No
Yes
Don't know

58. Approximately how many hospital admissions has the PERSON YOU CARE FOR had in the past 3 years because of issues relating to BPD?

None

1
2
3
4
5 or more
Don’t know

59. If known, what has been the longest stay in hospital for the PERSON YOU CARE FOR for mental health issues?

Not applicable
1 day
3 days
1 week
2 weeks
3 or more
weeks Don’t
know

SUPPORT SERVICES – MENTAL HEALTH PROFESSIONALS

60. If known, which mental health professionals has the PERSON YOU CARE FOR seen specifically for issues relating to Borderline Personality Disorder (BPD)? Select all that apply.

General practitioner (GP)
Psychiatrist
Psychologist
Mental Health Worker
Occupational Therapist (OT)
Social Worker
None–have not accessed support from mental health professionals
Don’t know
Other (please specify)

61. If known, how long has the PERSON YOU CARE FOR been accessing support from mental health professionals?

Less than 6 months
6–12 months
1–3 years
3–6years
5–10years
More than 10 years
Don’t know

62. To what extent has each of the following mental health professionals supported YOU as a CARER for issues relating to caring for a person diagnosed with BPD?

	Very Supportive	**Supportive**	**Neutral**	**Not Supportive**	**N/A Not used**
Select all options that apply					
General Practitioner (GP)					
Psychiatrist					
Psychologist					
Mental Health Worker					
Occupational Therapist (OT)					
SocialWorker					
None–have not accessed support as a carer					
Other–(please specify)					

63. Any further comments about support services YOU would like to access or have previously accessed as a Carer or for the PERSON YOU CARE FOR?

64. Has a mental health professional helped YOU understand early warning signs or when the person you care for might be more at risk of suicide or self harm?

No

Yes

65. Have YOU received a CRISIS PLAN for the person you are caring for?

No
Yes

66. When the PERSON YOU CARE FOR is in a crisis and has requested help, on average how long does it take for a mental health professional to respond to them?

The same day
Within 2 days
Between 2 days –1 week
Longer than a week
Do not respond
Don’t know

67. From the services listed below, please rate how responsive each has been when the PERSON YOU CARE FOR is in a crisis?

	Very Responsive	Responsive	Not Responsive	N/A not used
Select all options that apply				
General Practitioner (GP)				
Psychiatrist				
Psychologist				
Mental Health Worker				
Occupational Therapist (OT)				
SocialWorker				
None/ have not accessed support as a carer				
Other (please specify)				

68. Do you have any further comments about this section?

GENERAL SUPPORT SERVICES

69. From your perspective as a carer, please rate any of the following support services that the PERSON YOU CARE FOR has accessed. Select‘N/A’on the righthand side of the scale for any services the PERSON YOU CARE FOR has not previously accessed, or if you don’t know.

	Very Unhelpful	Unhelpful	Neutral	Helpful	Very Helpful	N/A
Crisis lines						
General support groups						
Financial support						
Housing support						
Gamblingsupport						
Drug/Alcohol support						
Relationship counselling						
Women’s shelter						
Men’s shelter						
Youth shelter						
Other (please specify)						

SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR

70. Would you like to continue with this section?

No –prefer to skip section
Yes–continue with this section

71. Has the PERSON YOU CARE FOR ever displayed risky behaviours? (eg. Behaviours that show little care for their life / getting hurt

No
Yes
Don’t know

Do not wish to answer
Skip this section

72. Has the PERSON YOU CARE FOR ever self-harmed? (eg. Cutting, burning, pouring cleaning products onto themselves, etc)
No
Yes
Don’t know
Do not wish to answer
Skip this section

73. Has the PERSON YOU CARE FOR ever attempted to end their life?
No
Yes
Don’t know
Do not wish to answer
Skip this section

74. If the PERSON YOU CARE FOR sought support after having suicidal behaviours, who did the PERSON YOU CARE FOR seek support from? Select all that apply
Don’t know
General Practitioner (GP)
Psychiatrist
Psychologist
Mental Health Worker
Hospital
Did not seek support
Skip this section
Other (please specify)

75. If known, what was the longest time it took to get support for the PERSON YOU CARE FOR after requesting it?
Don’t know
Same day
1 -2 days
2-3 days
3-5 days
5 days –2 weeks
Longer than 2 weeks
Did not get a response
Skip this section

76. If YOU as a CARER sought support after the person you care for displayed these behaviours, who did YOU seek support from? Select all that apply.
General Practitioner (GP)
Psychiatrist
Psychologist
Mental Health Worker
Hospital
I did not seek support as a carer
Skip this section

77. What was the longest time it took for YOU to get support as a CARER at these times after requesting it?
Same day
1 -2 days
2 -3 days
3 –5 days
4 days–2 weeks
Longer than 2 weeks
Did not get a response
Skip this section

78. IfKnown,asaresultofthePERSONYOUCAREFORselfharmingofattemptingtoendtheirlife,didthePERSONYOUCAREFORseek

Don’t know
No
Yes
Prefer not to answer
Skip this section

79. Who did the PERSON YOU CARE FOR see for medical attention relating to harming themselves or attempting to end their life?

Don’tknow
General Practitioner (GP)
Hospital–Emergency Department Prefer
not to answer
Skip this section

SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR–EMERGENCY DEPARTMENTS

80. What is the longest time the PERSON YOU CARE FOR had to wait in an emergency department for treatment of self inflicted injuries?

Don’t know
Immediately
1–4 hours
5–8 hours
More than 8 hours
Prefer not to answer
Skip this section

81. If known, as a result of the PERSON YOU CARE FOR harming themselves, was the PERSON YOU CARE FOR referred to a mental health professional (for example psychiatrist, psychologist, socialworker, mental health team, etc)?

No
Yes
Don’t know
Skip this section

RESEARCH: CHILDHOOD AND ADOLESCENCE STATISTICS

82. Did you notice anything unusual in infancy or toddlerhood?

Colic
Excessive separation anxiety
Inability to be consoled
Inability to self-soothe
Sensory problems
Picky eating
Poor temperament
Sensitivity
Moodiness
Motor delay
Cognitive delay
Social delay
Verbal delay
Physical abuse (of this child)
Sexual abuse (of this child)
Other (please specify)

83. Did you notice anything unusual in childhood?

Poor temperament

Anger
Sensitivity
Moodiness
Impulsivity
Difficulty making friends or few friends
Conflict with authority figures
School refusal or truancy
Frequent lying or deception
Suspension or expulsion
Multiple schools
Bully victim
Bully perpetrator
Victim of rape
Poor grades
Learning disability or special education
Body image issues
Emptiness
Boredom
Verbal abusive outbursts
Alcohol abuse
Substance abuse
Physical abuse (of this child)
Sexual abuse (of this child)
Other (please specify)

84. Did you notice anything unusual in adolescence?

Moodiness
Sensitivity
Poor temperament
Anger
Impulsivity
Recklessness
Property destruction
Arrests
Theft
Alcohol abuse
Anorexia Bulimia
Body image
issues
Emptiness
Boredom
Hallucinations
Delusions
Homicidal
ideation
Paranoia
Odd thinking or perceptions
Physical abuse (of this child)
Sexual abuse (of this child)
Other (please specify)

85. Did you notice anything else unusual in adolescence?

Violence victim
Aggression
Frequently lying or deception
Verbally abusive outbursts
Difficulty making or few friends
Promiscuity
Pregnancy
STDs

Rape victim
Fights
Other (please specify)

82. What first prompted you to seek evaluation?

Anger problems
Temper tantrums
Behaviour
problems
Teacher
recommendation School
refusal
Doctor recommendation
Mood disturbances
Eatingdisorder
Substanceabuse
Police intervention or legal issues
Promiscuity
Other (please specify)

83. What treatment was initially recommended?

Therapy
Medication
Hospitalisation
Day treatment
Alcohol/drug rehabilitation
Halfway house
Other (please specify)

84. Do you have any further comments about this section?

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Related Publications:

Lawn, S., McMahon, J. (2011) Foundations for Change Part 1- Experiences of Consumers with the Diagnosis of Borderline Personality Disorder (BPD). An Independent Report of the Data from a National Survey Undertaken by the Private Mental Health Consumer and Carer Network, July 2011 ISBN 1 920966 26 9 http://pmha.com.au/pmhccn/PublicationsResources/Surveys.aspx

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