

VISIT AND MONITORING REPORT

The experience of people with  
the diagnosis, families and  
services in Scotland

UPDATED NOVEMBER 2018

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## Unlabelled

Today I shrugged it off like a useless coat  
whose heavy arms had strangled me so long  
and now were cut off at the seam.

Today I learnt my personality is A-ok,  
I'm not malignant or dysfunctional,  
I'm not the woman you cross the street to escape.

Today I learnt the pain that's been consuming me so long  
is not my fault, is not my fate, is not my punishment  
for things I didn't do.

People have hurt me to the point I wear their scars,  
perhaps because they couldn't help themselves,  
heal themselves or love themselves.

That doesn't mean I have to hate them,  
doesn't mean I have to hate myself,  
doesn't mean I have to wear a coat that I've out grown.

I'm born again of possibility.  
To know that you believe in me  
is reason more than I dared hope

to find myself another coat that keeps me warm,  
that suits my beautiful curves,  
that we've gone shopping for together

'cos I couldn't be this liberated were it not for you!

- *By Jo McFarlane*
- *from 'Stigma and Stones: Living with a diagnosis of BPD', poems by Sally Fox and Jo McFarlane*

# Our mission and purpose

## Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

## Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

## Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

## Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

## Executive summary

***You don't feel so alone and you realise 'it's not just me'. You feel like you belong and that you're not an outcast anymore. You're not alone anymore.***

This is the first time the Mental Welfare Commission (the Commission) has looked specifically at the care, treatment and support of people with borderline personality disorder (BPD), often also known as emotionally unstable personality disorder (EUPD).

It is estimated that around one in 100 people in the general population have BPD. It is one of the most common types of personality disorder and is often described as a condition defined by an ongoing pattern of varying moods, self-image, and behaviour.

We wanted to find out about the experiences of people with the diagnosis, the views of families/carers, and of professionals involved in delivering care. We consulted with people across Scotland to gather their views and initially met with around 50 people with BPD<sup>1</sup> to help us to decide what we should focus on.

We then went on to have further contact with over 70 people with BPD, and with family/carers on an individual basis. Thirty five people with BPD spoke to us in focus groups.

Online surveys were completed by 119 general practitioners (GPs), 110 Accident and Emergency (A&E) department staff and 84 consultant psychiatrists from across Scotland. Staff delivering therapies completed detailed questionnaires.

Many of the testimonies we received suggested deficits in current provision for people with BPD, in addition to stigma and often negative associations with the condition.

We present a picture of people's varying experiences in being given this diagnosis, the therapies and supports that differ widely across Scotland and the challenges in being supported either in crisis, or when trying to stay well.

This report also shows what can be achieved when people with BPD have access to effective therapy, support and understanding.

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<sup>1</sup> We included both people with a formal diagnosis of BPD and those who self-identify as having that condition.

The Royal College of Psychiatrists in their recent report 'Personality Disorder in Scotland: Raising awareness, raising expectations, raising hope'<sup>2</sup>, describe the current provision of mental health services for people with a diagnosis of personality disorder in Scotland and a consensus view on good practice for services.

Our report focuses on the experience of people living with the diagnosis and the views of medical professionals.

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<sup>2</sup> Royal College of Psychiatrists, *Personality Disorder in Scotland: Raising awareness, raising expectations, raising hope*, August 2018.

## Key findings

### Assessment and diagnosis

People's experiences of receiving their diagnosis were varied. Whilst we heard of positive experiences, many spoke of feeling let down in this aspect of their care. Often there were delays in receiving a diagnosis, it was not given in a sensitive way and there was a lack of follow-up information about the diagnosis and what this meant for the individual. Some people only found out about their diagnosis by chance.

### Treatment

Psychological therapies were highly valued by people we consulted with. Mindfulness, cognitive behavioural therapy (CBT) and dialectical behavioural therapy (DBT) were among the most common that people received, and most people told us they had been helpful.

Access to therapies and waiting times varied across the country. Psychiatrists and GPs told us that better access to evidence-based psychological therapies for people with BPD would improve the care and treatment of their patients.

Although no drug is specifically licensed for the treatment of BPD, a high number of people reported that they found medication to be helpful, particularly in managing anxiety.

### Support and staying well

People found GPs, community psychiatric nurses (CPNs) and psychiatrists helped them manage their condition. Although good professional support was vital to staying well, achieving goals required a wider network of resources. Specialist resources remain scarce, and general mental health services were often reported as difficult to access and inconsistently available. General practitioners often found it difficult to access mental health service support for their patients locally.

What people with BPD told us helps them stay well, and what services and professional staff thought about this, often differed. Self-management and peer support, including peer-run support groups do exist, but are not always easily available.

### Crisis

People with BPD perceived different approaches to them when they were in crisis compared to people with other mental health problems and these approaches were not always helpful.

Few people had crisis plans in place. The police and other emergency services could find it hard to access appropriate help for people with BPD in crisis. Many people with BPD reported a negative experience of using A&E services; A&E staff shared their view that these departments were not well placed to meet their needs.

Staff reported that a lack of information sharing across services caused difficulties when people presented in crisis.

### **Stigma**

Stigma is a reality in the life of people with BPD and its effect on people can be dramatic. It affects confidence and self-esteem, and stigma was the most commonly reported trigger for crisis.

Perceived stigma from professional staff left some with difficulties in maintaining and developing relationships, and in participating in treatment. People with BPD reported that they were often treated with less sympathy and understanding than people with other mental health problems.

### **Family/Carers**

Family/carers said that, at times, the emotional impact of caring for individuals with BPD could be high, including feeling overwhelmed or powerless. They also faced particular challenges in gaining information, particularly in times of crisis.

## Recommendations

### Scottish Government should

1. Through the work of the Health and Justice Collaboration Improvement Board<sup>3</sup>, and the development of Action 15 of the Mental Health Strategy<sup>4</sup>, ensure an integrated service response to improve access and outcomes for people with BPD. Particularly in relation to response to crisis, A&E departments and GP practices.

### Integration Authorities should

2. Review the recommendations in the Royal College of Psychiatrists report, and ensure that:
  - Personality disorders are included in plans for mental health services.
  - People with personality disorder have equal access to and quality of service across geographical areas.
  - There is a personality disorder lead for each health board - to advocate for appropriate services and promote a consistent and evidence-based approach.
  - There is continuation of the work which was commenced in developing Integrated Care Pathways (ICPs) within each health board.
3. Commissioners and managers of health and social care services should review this report to consider aspects of their current practice which can be improved, specifically:

### *Diagnosis, assessment and treatment*

- Assessment and diagnosis is carried out by skilled mental health practitioners, in collaboration with the person being assessed and ideally involving family/carers.
- People with BPD are provided with written information about the diagnosis and offered post diagnosis follow up.
- Anyone with a diagnosis of BPD is offered timely access to evidence-based psychological therapy.

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<sup>3</sup> <https://beta.gov.scot/publications/health-and-justice-collaboration-improvement-board-terms-of-reference/>

<sup>4</sup> As part of the Mental Health Strategy 2017-2027, Scottish Government Ministers made a commitment to provide funding to support the employment of 800 additional mental health workers to improve access in key settings such as A&E departments, GP practices, police station custody suites and prisons.

- GPs supporting people with BPD have timely access to support from mental health services when required.
- Mental health services in each Health Board should be able to access support and advice from an identified personality disorder lead.

#### *Recovery and staying well*

- Provision of jointly commissioned services that support recovery and staying well, and remove barriers to access, developed in consultation with people with BPD.
- Local authorities, and health and social care partnerships, work together to develop provision of relevant services under Sections 25-26 of the Mental Health (Care and Treatment) (Scotland) Act 2003<sup>5</sup>.

#### *Responding to crisis*

- Engage A&E, primary care and mental health staff in reviewing Psychiatric Emergency Plans to ensure crisis pathways support people with BPD.
- Individualised crisis plans are developed collaboratively with the person who has the BPD diagnosis, shared with all agencies involved and regularly reviewed.
- A&E staff have access to mental health staff for support, and can access care and crisis plans.

#### *Training and awareness*

- A tiered approach to staff training that includes GPs and A&E staff as important stakeholders, with an emphasis on attitudes, values and a lived experience perspective (with reference to Transforming Psychological Trauma, Knowledge and Skills Framework for the Scottish workforce<sup>6</sup>).

#### *Family/carers*

- Carers are directed to appropriate carer support and key information is shared with them as appropriate.

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<sup>5</sup> Sections 25-27 of the Mental Health (Care and Treatment) (Scotland) Act 2003 relate to local authority functions, provision of services, care and support services. Section 26 relates specifically to services designed to promote well-being and social development.

<sup>6</sup> NHS Education for Scotland, Psychological Trauma, Knowledge and Skills Framework for the Scottish workforce, 2017. [www.nes.scot.nhs.uk/media/3971582/nationaltraumatrainingframework.pdf](http://www.nes.scot.nhs.uk/media/3971582/nationaltraumatrainingframework.pdf)

## About personality disorder

***It is an illness; you just can't physically see it – all I ask is dignity and respect.***

Personality disorder is usually defined as a deeply ingrained and enduring pattern of behaviour and inner experience. This affects thinking, feeling, interpersonal relationships and impulse control. It leads to significant functional impairment and distress. These patterns tend to affect all areas of life and functioning, and tend to be inflexible and long lasting. The prevalence in the general population of all personality disorders is six to 10 per cent.<sup>7</sup> In general mental health care settings, prevalence rates of personality disorder are estimated to be nearer 50 per cent, with BPD being most common.

Borderline personality disorder is a type of personality disorder with a long-term pattern of abnormal behaviour, characterised by unstable relationships with other people, unstable sense of self and unstable emotions. A person with BPD may experience acute episodes of anger, depression and anxiety that may last from a few hours to days. Symptoms can often result in impulsive actions and problems in relationships with other people. It is recognised that there are challenges in providing support and treatment for people with BPD. This can impact on people's experience of care.

It is estimated that 75 per cent of people with BPD engage in deliberate self-harm and the lifetime suicide risk in BPD is estimated between eight and 10 per cent.<sup>8</sup>

One of the factors which may contribute to the development of personality disorders is early life trauma and neglect. It has been shown that early life Adverse Childhood Experiences have a broad effect on multiple social, educational, physical and mental health outcomes,<sup>9</sup> yet not all people with a diagnosis of personality disorder will have experienced trauma.

For the purposes of this report, we refer to BPD (DSM-V), which is also often known as EUPD (ICD-10). Many or all of the sub-categories of personality disorder are likely to be replaced in future International Classification of Diseases classification with an overall general category of personality disorder.

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<sup>7</sup> J. Samuels, *Personality disorders: epidemiology and public health issues*, International Review of Psychiatry, vol. 23, pp. 223-233, 2011.

<sup>8</sup> J. Oldum, *Borderline personality disorder and suicidalities*, American Journal of Psychiatry, vol. 163(1), pp. 20-26, 2006.

<sup>9</sup> V. J. Felitti, R. F. Anda, D. Nordenberg, D. F. Williamson, A. M. V. Spitz, M. P. Koss and J. S. Marks, *Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) study*, American Journal of Preventative Medicine, vol. 14(4), pp. 245-58, May 1998.

## Current policy

The Scottish Government Mental Health Strategy 2017-2027<sup>10</sup> does not specifically mention BPD, but many actions relating to prevention and early intervention will, in the longer term, be of benefit. The actions particularly relevant to BPD include:

- Increasing the workforce to provide access to dedicated mental health professionals in all A&E, all GP practices, every police station custody suite and in prisons. Over the next five years increasing additional investment to £35 million for 800 additional mental health workers in these key settings (Action 15).
- To test and evaluate the most effective and sustainable models of supporting mental health in primary care by 2019.
- To fund work to improve provision of psychological therapy services and help meet targets already set.
- To develop more accessible psychological self-help resources and support national rollout of computerised CBT with NHS 24 by the end of 2018.

The Scottish Government have also made a commitment to developing a National Trauma Training Strategy. NHS Education for Scotland (NES) were commissioned and have subsequently developed 'Transforming Psychological Trauma: A Knowledge and Skills Framework for the Scottish Workforce'. This framework describes four tiers of training designed for a range of roles. The first basic level, trauma-informed practice, is relevant to all of the workforce; with the fourth, trauma specialist level, for staff who are involved in care and treatment with trauma-specific services. The principles of trauma-informed practice are not solely designed to treat trauma, but to address barriers and enable access to the care, treatment and support that people need for a healthy life. Use of the framework by services could help lead to better outcomes for people with personality disorder.

A further important step has been the recent publication of 'Personality Disorder in Scotland: Raising awareness, raising expectations, raising hope'<sup>11</sup> by the Royal College of Psychiatrists (RCPsych) in Scotland. The College identified personality disorder as a priority at its strategy day held in 2016. They established a short-life working group that produced the report, which describes the current provision of mental health services for people with a diagnosis of personality disorder in Scotland and a consensus view on good practice for services.

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<sup>10</sup> Scottish Government, *Mental Health Strategy 2017-2027 - a 10 year vision*, 2017.

<sup>11</sup> Royal College of Psychiatrists, *Personality Disorder in Scotland: Raising awareness, raising expectations, raising hope*, August 2018.

## Why we carried out this visit

We chose to visit people with BPD because we wanted to follow-up on some of the issues we had found in our work. Consultation with people with lived experience by our engagement and participation officer highlighted that BPD was an area people wanted us to look at.

We wanted to hear the voices and experience of people with BPD and those who supported them, to find out about the difficulties they face and, if necessary, to make recommendations to improve care, treatment and support.

The Commission has carried out investigations, Mr QR<sup>12</sup> and Ms CD<sup>13</sup>, where we found that individual care was compromised, partly as a consequence of the response to a diagnosis of personality disorder.

Through other aspects of our work, including our telephone advice line and our visiting programme, we are often told about difficulties faced by people with BPD, their carers and the staff who work with them.

We focussed on people with BPD who were living at home at the time of our visits. The Commission regularly visits low, medium and high secure mental health services across Scotland and prisons. We are aware that a small number of people with BPD will be in prison, or secure psychiatric services, as a result of contact with criminal justice services and we are often contacted for advice about individual cases. These cases tend to present complex issues and we address them on an individual basis.

We also met regularly with staff from the Royal College of Psychiatrists, who were working at the same time on a national report looking at describing current provision for personality disorder services and making recommendations on good practice for services providing care for people with BPD across Scotland.

## How we carried out these visits

Prior to starting our visits, we consulted with as many people as possible to hear from them directly about the difficulties they face. Our consultation meetings with people with lived experience and carers, both individually and in groups, informed our visits. We are very grateful to all the people who contributed their experiences.

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<sup>12</sup> Mental Welfare Commission for Scotland, *Investigation into the care and treatment of Mr QR by NHS Board D*, 2017.

<sup>13</sup> Mental Welfare Commission for Scotland, *The care and treatment of Mrs CD*, 2014.

This consultation work was carried out mainly by the Commission's engagement and participation officer (lived experience) who met with 35 people, including three who identified themselves as carers of someone with the diagnosis. We were aware that it would be difficult for us to look in detail at all the issues people may identify, so we asked them to tell us three key priorities we should look at.

The key priorities identified as the most important areas in the lives of people with a diagnosis were:

- Stigma and discrimination
- The assessment and diagnosis of BPD
- Access to treatment and support
- Support after therapy and treatment finishes
- Access to help in crisis and out of hours

Other issues identified included: access to peer support, loneliness and isolation, activity and occupation, the use of medication, involvement and attitudes of family and the police. This is broadly similar to the National Institute for Mental Health in England<sup>14</sup>, which identified helpful features for personality disorder services including: early interventions, specialist services, choice from a range of treatment options and individually tailored care.

The information we collected during the consultation helped us to decide on the questions we would ask in our questionnaires and at future meetings.

We sent out a flyer in summer 2017 letting as many groups and individuals as possible know about our forthcoming work.

In November and December 2017, the Commission met with people who identified as having BPD. We engaged with 106 people from a range of urban and rural settings. We also spoke with a range of professional staff and carers.

We prepared an information sheet for individuals explaining how we would use, record and protect the data that we collected. All information given by people with BPD was stored anonymously.

We obtained 70 completed questionnaires from people with BPD. The questionnaires asked about the main priority areas identified at consultation. The questionnaire was completed directly, online or in paper form. We also offered a telephone interview or personal interview with a member of our visit team for those who preferred this way of completing the questionnaire.

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<sup>14</sup> National Institute for Mental Health in England, *Personality Disorder: No longer a diagnosis of exclusion*, 2003.

Some people told us that they preferred to give feedback as part of a group and we held eight focus groups addressing the same topics. Thirty six people attended these groups.

We wanted to find out from health professionals about their experiences caring for people with BPD. We asked medical directors in each health board area to send out three online surveys: to GPs, consultant psychiatrists and to A&E departments. We received 313 individual responses from professional staff from 11 health board areas.

We monitored the Commission's telephone advice service over a three month period to identify calls that were possibly related to a diagnosis of BPD. We identified over 30 relevant calls which were mainly about people in crisis. Around half were from staff involved in care and support, and the rest from carers and people with BPD.

We looked at a sample of certificates received at the Commission about hospital detentions under the Mental Health (Care and Treatment) (Scotland) Act 2003 (the Mental Health Act) where personality disorder was identified as the type of mental disorder. We looked at these in detail to see what type of personality disorder was involved.

Responses from individuals and focus groups were analysed using a qualitative approach to extract key themes. The professionals' survey responses were analysed via a spreadsheet. Where numbers are used in this report we have largely referred to the convention set out in [Appendix One](#).

We describe our findings in the next part of this report. In each section, we set out:

- What people's rights are.<sup>15</sup>
- What people we consulted told us and how this shaped what we asked about.
- What we were told by people with BPD and by staff involved in their care and treatment.

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<sup>15</sup> Mental Welfare Commission for Scotland, *Rights in Mind: A pathway to patients' rights in mental health services*, 2017.

## Assessment and diagnosis

***My psychologist handled explaining the diagnosis well and gave me information. I found this enlightening and helpful. It helped me understand how I was feeling and was a huge relief.***

### Rights

People have the right to information about their diagnosis in a way that they understand, and an opportunity to discuss this with the team providing care and access to mental health services when they need them. This reflects Article eight of the European Convention on Human Rights (ECHR) and the Patients' Rights (Scotland) Act 2011.

### What people told us at consultation

People varied in their reactions to their initial diagnosis; from finding it a huge relief to having a less positive experience, with lengthy delays.

### What we then asked about

We asked people with BPD about their experience of assessment and receiving their diagnosis.

Current guidelines are clear that the assessment, diagnosis and treatment of BPD is the remit of mental health services. The National Institute for Health and Care Excellence (NICE) guideline on the recognition and management of BPD states<sup>16</sup>:

'Community mental health services (community mental health teams, related community-based services, and tier two/three services in child and adolescent mental health services) should be responsible for the routine assessment, treatment and management of people with BPD.'

NICE guidance relates specifically to services in England and Wales, however, for NHS Scotland, the standards are generally considered to be helpful in the provision of best practice for clinical staff.

The recent Royal College of Psychiatrists in Scotland report offers further guidance on diagnosis and formulation, endorsing the practice of:

'Making a diagnosis collaboratively with each individual, including a full formulation of their particular situation. This should include an assessment of the person's strengths and areas of difficulty, and be linked to a shared treatment plan with short and longer term goals.'

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<sup>16</sup> National Institute for Health and Care Excellence (NICE) guideline, *Borderline Personality Disorder: recognition and management*. CG78, 2009 (Reviewed 2015, checked 2018).

It suggests that diagnosis should be based on 'an understanding of the person's presentation over a significant period of time', not on a single interview and should ideally involve family or carers who know the person well.

## **What we were told by people with BPD**

### **Assessment process**

People described a wide range of experiences of assessment. Where there was a sense of collaboration between individuals and professionals, the experience of assessment was described positively and people said this approach should be more widespread.

*"The diagnosis was reached over time through contact with my CPN and although it was a slow process I felt supported along the way. I was not officially diagnosed until I met with the psychiatrist."*

However, the majority described the experience negatively, with a feeling of assessment being 'done to' rather than 'in collaboration with' them. Some were unaware of having been assessed for BPD and there was little discussion with them about how their diagnosis was reached; Questionnaires or assessment tools were sometimes used with little explanation or support.

*"No formal assessment tool was used. I was not told I was being assessed for BPD. Did not speak to family or friends. Did not listen to my view as to why I did not agree with BPD diagnosis, resulted in me feeling dismissed and very angry."*

*"I didn't know I had this diagnosis until I was discharged and I never got an explanation of it."*

Only a minority said family and friends were consulted, or invited to comment, during the process.

*"At the time I was given the diagnosis I was not completely capable of taking it in... I wish someone had informed my children as I could not tell them, I didn't know how. It took me years to sit down and explain it to them."*

### **How the diagnosis is given**

The majority said the diagnosis of BPD was made by a psychiatrist. A few were diagnosed by their GP, CPN or psychologist.

The manner in which the diagnosis was given made a difference. The importance of non-judgemental attitudes, a compassionate approach and having time to discuss the diagnosis was consistently highlighted as being important.

*"I had already realised that I had BPD prior to having a breakdown. My psychiatrist discussed with me the possibility that I might have another diagnosis but decided that BPD was more accurate. From the start, I was treated with respect by psychiatrists."*

*"The psychiatrist in hospital was good, they explained what BPD was and staff on the ward printed out info from MIND."*

Positive experiences of therapeutic relationships helped reduce the sense of shame and blame that might be experienced when receiving the diagnosis; but these emotions were present in the face of perceived staff insensitivity, and inadequate discussion or explanation.

*"It was deeply distressing. The delivery was abrupt, insensitive, and unsupportive and left me feeling I was simply faulty."*

*"During one of the weekly ward rounds, with a room filled with doctors and nurses, I was told 'You wanted a diagnosis - you have borderline personality disorder'. I asked what that meant and was told it was me. I felt I was met with a cold, not a good attitude, and I felt ashamed. There were no further explanations and I just felt confused."*

In this case, discussion about the diagnosis was avoided altogether:

*"I was diagnosed by one psychiatrist, but when my doctor changed they told me they didn't believe in labels and would not discuss it with me. I found this unhelpful, I wanted to know more."*

In other cases, although a diagnosis of BPD had been made, the individual was not informed until much later:

*"I only found out about my diagnosis a year after I had been diagnosed when I requested a copy of my medical notes."*

*"I was apparently first diagnosed in 2010 with BPD but was not told until 2016. I am still angry and upset by my experience of learning about my diagnosis."*

Finding out about the diagnosis by accident, perhaps by seeing the diagnosis in medical records or correspondence was particularly distressing. More than one in 10 of the people we consulted described this experience.

*"I have never been told my diagnosis face to face and only found out by being copied into an e-mail by mistake."*

*“No one gave me a diagnosis, I found out by a statement written for me by my CPN when I applied for personal independence payments.”*

*“I only found out about the diagnosis by accident. I was seeing my GP at a normal clinic appointment. My GP looked on computer for any correspondence from the then psychiatrist... They asked if EUPD meant anything to me... then read on further in the letter and said ‘oh no, you weren't meant to know that - it says here to not disclose to the patient’.”*

### **Information about the diagnosis**

Lack of information about the diagnosis was consistently highlighted as a significant problem. The majority told us they received no information when the diagnosis was given. A few were given leaflets and information about websites developed specifically for BPD.

*“I was assessed after several periods of crisis by the psychiatrist and told that I had BPD and there were no drug treatments available to help me. I was not given any further information.”*

*“My psychiatrist gave me statistics but no useful information.”*

Most people had to find out about the illness for themselves and the MIND website<sup>17</sup> was consistently highlighted as a very helpful source of information.

*“MIND is one of the best sites for explaining the diagnosis in a positive light.”*

*“USA sites are really unhelpful and very negative – they also talk about dangerousness and I feel I am more likely to hurt myself than anyone else.”*

Suggestions about how information about the diagnosis could be improved included:

*“Users should write their own leaflets and information as professionals don't always know how it feels.”*

*“A follow-up appointment offered quickly after diagnosis, with an expert who has understanding and can help you with your goals would be better.”*

Overall people told us that assessment and diagnosis should be improved. It should be collaborative, involve family where possible and the process should be more ‘humanised’; carried out by professionals who listen, are caring and see the person not the diagnosis.

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<sup>17</sup> MIND [www.mind.org.uk](http://www.mind.org.uk)

## **Delays in diagnosis**

A delay in being given a diagnosis of BPD was a common issue raised. From first symptoms to a diagnosis of BPD being given took over five years for most respondents. Very few said they were given the diagnosis within one year.

*“I have had 12 years of contact with psychiatric services... my CPN suggested my diagnosis to my psychiatrist and I got my diagnosis two years ago – it made sense to me.”*

*“I had been experiencing symptoms and telling doctors, counsellors and therapists about them for more than 10 years. On receiving a BPD diagnosis, my symptoms seemed so incredibly textbook that it was astounding that nobody had made the connection before. With hindsight, the diagnosis should have come years earlier than it did.”*

## **What staff told us**

We received 84 responses to our survey sent to consultant psychiatrists. The majority viewed it as their role to make the diagnosis of BPD and inform the patient.

Some consultants told us patients had often received the diagnosis before being referred to their service.

We asked how diagnosis of BPD was made. Some consultants described a clear, thorough and multidisciplinary diagnostic process:

*“We have a pathway - typically the patient would be seen by a member of a multidisciplinary team (MDT) and discussed at MDT. If borderline traits are impacting significantly on functioning and requiring ongoing mental health team input, then they are typically referred to medic for diagnosis. This is discussed with the patient and any relatives/carers, with discussion of treatment options and expectations. This would then be discussed with the whole MDT to ensure accurate formulation, consistency of approach, with reference to the local care pathway.”*

(Comment by general adult psychiatrist)

*“Multimodal structured assessment including detailed history, with emphasis on adverse experiences and developmental history, structured measures, a trait-based interview, informant histories, collaborative formulation and multidisciplinary review.”*

(Comment by specialist personality disorder service)

A small number of consultants mentioned the use of screening questionnaires and standardised assessment tools in making the diagnosis, but many responses offered little detail of how a diagnosis of BPD was made.

A number of respondents made specific reference to family involvement in the assessment process. Most said they did involve family and friends where appropriate, in contrast with the experience of people with BPD as detailed earlier.

*“The patient sees a medic and/or CPN over a number of appointments and if possible a member of family is invited to come to clinic for collateral history.”*

Psychiatrists said patients did not always want their family to be involved. When consent was given, sometimes family members were difficult to contact.

We did not ask GPs specifically about diagnosis or assessment, but some did comment on this aspect of care.

*“I would estimate that I see patients with BPD/EUPD once per day; that includes those in whom I am very suspicious are likely to have BPD/EUPD but have not been formally diagnosed. The problem is to diagnose this condition accurately is challenging and time consuming for mental health experts... In addition, many patients would not agree to be assessed for this condition.”*

Both people with BPD and GPs shared concerns that a diagnosis of BPD, once made, sometimes led to services being withdrawn or access to mental health support being denied.

*“I'd like to see people with BPD afforded the same degree of access and support to our mental health services, as for other patients.”*

*“Diagnosis of BPD/EUPD, when made, appears to automatically result in discharge from all specialist input and acts as a bar to any further referral/GP request for assistance in management.”*

These experiences raise concerns about the equity of access to mental health services for people diagnosed with BPD. The practice described is in direct conflict with recommendations from the NICE guidelines<sup>18</sup> and from the Royal College of Psychiatrists.

*‘People with borderline personality disorder should not be excluded from any health or social care service because of their diagnosis or because they have self-harmed.’*

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<sup>18</sup> National Institute for Health and Care Excellence (NICE) guideline, *Borderline Personality Disorder: recognition and management*. CG78, 2009 (Reviewed 2015).

## Treatment

*I am fortunate to live in an area that has a dedicated therapy. This holistic approach has transformed my life more than I could have imagined. Before I was self-harming all the time, I felt a successful suicide was imminent and had ditched all my friends to stop them rejecting me. I'd not been able to hold down a job and was living on benefits, in poverty. Following therapy, now five years ago, I hardly ever self harm. On the rare occasion that I have, it's been minimal. The support and care that I have received from the therapy team and the community mental health team could not have been better or more empowering.*

*"Recovery from BPD is the goal of treatment, and a realistic prospect for many."*  
(Comment by consultant psychiatrist)

### Rights

Everyone has the right to adequate healthcare for their physical and mental needs, and NHS care which is patient focussed and encourages participation. This includes access to mental health services including early intervention, good support from primary care and the local authority, if assessed as needing these. This reflects Articles two and Article three of the ECHR and Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>19</sup>.

### What people told us at consultation

We heard about the difficulties accessing psychological therapies, the benefits and drawbacks of the different types of therapies and a general lack of support outside of these therapies.

### What we then asked about

We asked about treatment and support for people with BPD received from a range of different sources and how helpful they found it.

### What we were told by people with BPD

#### Medication

No drug is specifically licensed for the treatment of BPD. People with BPD often experience co-morbid mental illness, with lifetime prevalence of depression and anxiety disorders being particularly high. It is important that co-morbid illness is recognised and treated when it occurs.

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<sup>19</sup> World Health Organisation, *The Right to Health*, Office of the United Nations High Commissioner for Human rights, 2008.

National Institute for Health and Care Excellence developed a quality standard, Qs88<sup>20</sup>, which noted:

‘No drugs have established efficacy in treating or managing borderline personality disorder. However, antipsychotic and sedative medication can sometimes be helpful in short-term management of crisis (the duration of treatment should be no longer than one week) or treatment of co-morbid conditions.’

Some health boards in Scotland have developed local guidance in this area. NHS Highland’s ICP for personality disorder advises:

‘No drugs are licensed for the treatment of personality disorder in the United Kingdom (UK) and evidence for efficacy of drug treatment is scarce... Medication should be avoided as the primary or sole treatment of personality disorder.’<sup>21</sup>

Despite this, the majority of people with BPD responding to us said they found medication helpful, with around a quarter telling us that it was not helpful.

Medication to help with symptoms of anxiety and insomnia, especially during a crisis, were reported as particularly helpful.

*“I need medication – I am past the stage of trying without it; I would be hospitalised immediately.”*

*“Medication is trial and error and can take a long time. Medication for anxiety, sleep and controlling symptoms gets you stable and can take the edge off what can be a huge thing, getting you to a place where you are able to function again.”*

In response to our survey, 75 consultant psychiatrists answered our questions about prescribing. The most commonly prescribed medicines were antidepressants, antipsychotics, and then anxiolytics (anti-anxiety medications). Mood stabilisers and hypnotics (sleeping tablets) were less frequently used.

A number of GPs commented negatively on the use of medication and highlighted the importance of providing psychological therapies:

*“Treating patients with antidepressant medication without giving them the diagnosis and the knowledge that medication will not always/often help is a disservice.”*

*“I think it’s important for diagnosis to be made early so that the appropriate non pharmacological support can be given - not a condition that responds well to medication but patients seem to end up on multiple complex medication regimes for both physical and psychological symptoms.”*

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<sup>20</sup> National Institute for Health and Care Excellence (NICE) *Personality Disorders: borderline and antisocial*, Quality Standard [Qs88], pp. 27, 2015. <https://www.nice.org.uk/guidance/qs88>

<sup>21</sup> NHS Highland, *Personality Disorder - Integrated Care Pathway (PD-ICP) (7.1)*, 2015.

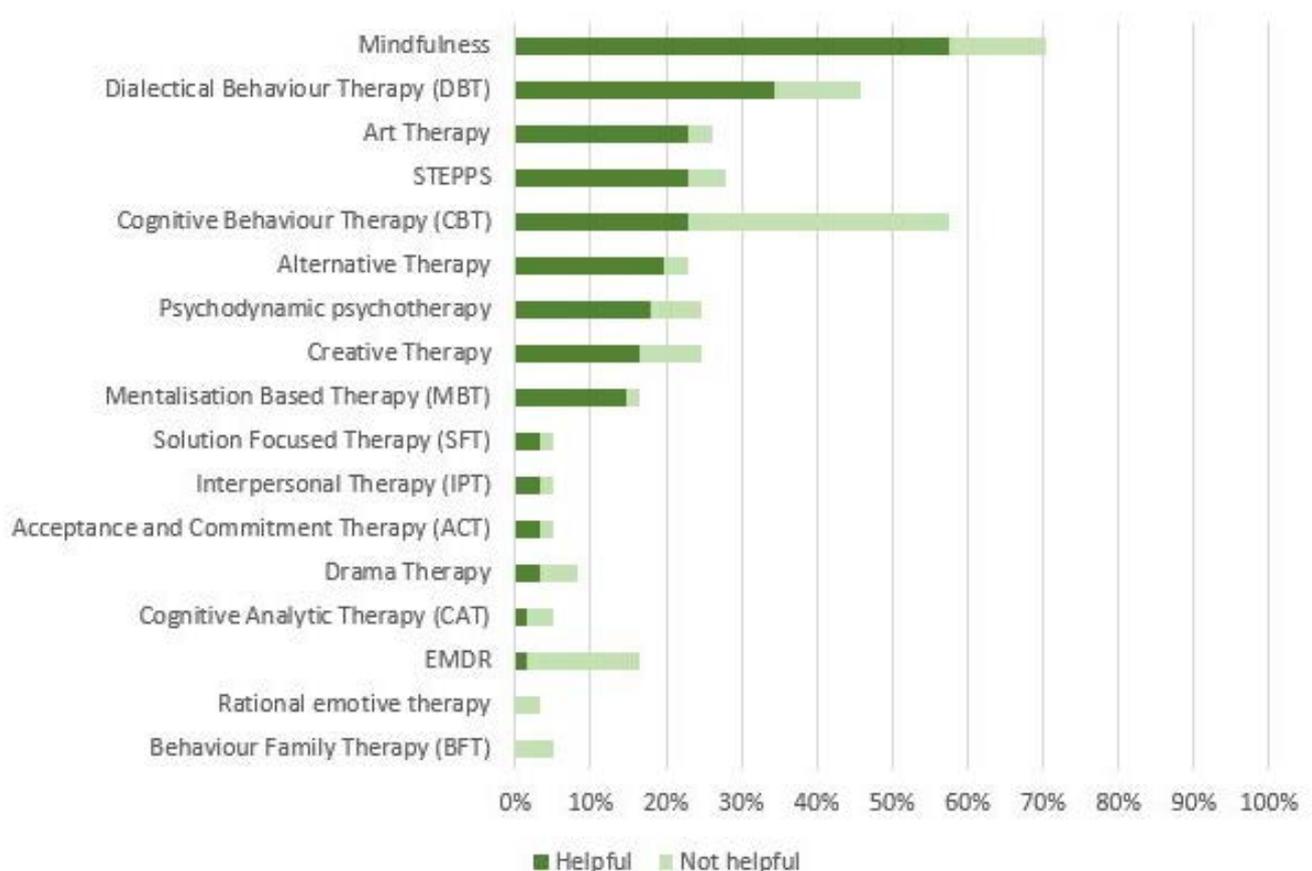
## Psychological Therapies

Psychological therapy is considered to be a first-line treatment for people with BPD. A number of therapies have been developed for the condition, including Dialectical Behavioural Therapy (DBT) and Mentalisation Based Therapy (MBT). These approaches are among those that have shown some efficacy in treating the symptoms of BPD. Systematic reviews suggest that more research is needed in this area<sup>22, 23</sup>.

NHS Education for Scotland set out a 'matrix' to guide health boards in their planning and delivery of evidence-based psychological therapies<sup>24</sup>. This matrix provides information on the range of therapies, on the strategic planning of them and of the supervision and training required to support the delivery of these therapies.

Sixty-one people told us that they had received some kind of therapy.

Figure 1. Types of therapies received (% , n=61)



<sup>22</sup> I. A. Cristea, C. Gentili, C. D. Cotet, D. Palomba, C. Barbui and P. Cuijpers, *Efficacy of Psychotherapies for Borderline Personality Disorder: A systematic review and meta-analysis*, JAMA Psychiatry, vol. 74(4), pp. 319-328, 2017.

<sup>23</sup> J. M. Stoffers, B. A. Vollm, G. Rucker, A. Timmer, N. Huband and K. Lieb, *Psychological therapies for people with borderline personality disorder*. Cochrane Database Systematic Review, 2012: 8.

<sup>24</sup> NHS Education for Scotland, *The Matrix A Guide to Delivering Evidence-Based Psychological Therapies in Scotland*, 2015. [www.nes.scot.nhs.uk](http://www.nes.scot.nhs.uk)

In [Figure 1](#), STEPPS is an abbreviation for Systems Training in Emotional Predictability and Problem Solving. EMDR is an abbreviation for Eye Movement Desensitisation and Reprocessing.

Other types of therapies included equine therapy, schema therapy, safety and stabilisation, person-centred therapy, hypnotherapy and psychotherapy.

*“There has been little impetus to provide psychological treatment, until my last crisis, following an admission. I had schema focused therapy which has been very helpful. If I had psychological treatment in a more timely way, my admission might have been avoided.”*

*“When I eventually accessed trauma therapy, I had treatment for 14 months. My life improved and if I need ‘top up’ I can get this to stop the crisis hitting harder.”*

*“Having spent many years seeing psychologists etc, DBT has been an eye-opener and a lifesaver. It’s the only thing that has made a tangible difference to my understanding of myself and has shown me ways to manage this condition better.”*

However, not all comments were so positive.

*“I’ve not received or been offered any of the therapies that are on this form. And yes, that frustrates me immensely.”*

*“I was horrified when they offered me CBT via the telephone.”*

Local Delivery Plan Standards are priorities that are set and agreed between the Scottish Government and NHS Boards to provide assurance on NHS Scotland performance. In relation to access to psychological therapy, the current standard is that 90 per cent of patients commence treatment within 18 weeks of referral. In the quarter ending March 2018, the Scottish Government reported that 78 per cent of people were seen within 18 weeks<sup>25</sup>.

Most people we consulted said they waited between 13 weeks and six months for their therapy to start, and that after treatment, some were referred on to another service.

*“There is a one year waiting list for STEPPS – you should be able to get straight on it.”*

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<sup>25</sup> <http://www.gov.scot/About/Performance/scotPerforms/NHSScotlandperformance>

## **What we were told by staff**

Many of the GPs and consultant psychiatrists surveyed also spoke about psychological therapies.

Psychiatrists generally reported having a range of therapies available locally, whether within their own mental health teams or from dedicated psychology services, with CBT, MBT and DBT among the most commonly mentioned. Positive outcomes were described with psychological therapies, particularly when patients had been given the diagnosis and offered interventions at an early stage.

*“Early diagnosis and appropriate psychological treatment from experience has better outcome and more likely success.”*

*“Patients with BPD/EUPD can often make use of psychological therapies and make significant behavioural changes. They can learn to manage emotions with treatment too.”*

However, inequity of access to psychological therapies and long waiting times for psychology were stated as common concerns:

*“Lack of appropriate psychology access and clinician time to make effective changes.”*

*“I have found impressive outcomes from DBT; unfortunately, this is not offered where I currently work, but I am hopeful this will change in time.”*

Whilst dedicated psychology services were valued, it was also suggested that community mental health teams (CMHTs) would benefit from more skills in delivering therapies:

*“Integrate ‘psychological therapies’ services into mental health – a general mental health service that can’t deliver psychological therapies is not fit for purpose.”*

The importance of considering trauma was also raised:

*“BPD is not necessarily a chronic disorder. It is important to think about co-morbidities including trauma and treat those, as well as supporting the person on pathways that facilitate reflection and emotional regulation.”*

*“Longitudinal key working with acceptance that trauma, which is at the core for most individuals given a label of BPD, is everyone’s business.”*

## **Admission to hospital**

It is generally accepted that long hospital admission for people with BPD should not be a mainstay of treatment. Supporting people to develop the skills and tools to manage their symptoms in the community is a central part of therapeutic programmes and working towards recovery.

Brief periods of inpatient care can be indicated when risks are significant and cannot be safely managed in the community or in situations where use of the Mental Health Act is required. Some health boards offer people with BPD the option of respite admission for crisis.

Often people with BPD we spoke with agreed that prolonged hospital admissions were not the solution, but that brief planned admissions could be helpful.

*“It’s not appropriate as a long term place, but even if just for 24-48 hours.”*

*“The main thing is safety, peace, asylum, being looked after.”*

*“Sometimes you still need others to take responsibility... Sometimes you still need a place of ‘asylum’ to be taken out of the situation when you feel suicidal.”*

Some people shared negative memories of inpatient care and their fears of the consequences of hospital admission.

Others spoke about experiences of detention in hospital under the Mental Health Act. Some felt this had kept them safe when they were refusing treatment and were unable to make safe decisions for themselves:

*“Capacity is a strange one because when you’re in crisis you can lie... Your judgement is clouded, the BPD takes over when you’re in crisis.”*

*“Being sectioned is scary, having your freedom taken away like that, but professionals should err on the side of caution because BPD has one of the highest suicide rates.”*

A few people in Dumfries and Galloway had a crisis plan which allowed for a brief admission, up to 48 hours, which they could choose to use when they needed it and they found this helpful.

### **Mental health legislation**

We carried out a small sample limited review of the use of mental health legislation in Scotland in relation to BPD and this can be found at [Appendix Two](#).

## Support and staying well

*My volunteering, informal support and part-time employment all involve mental health and I use my lived experience in a positive way. This is a vital part of staying well for me as it allows me to take what I saw as a useless and worthless existence for 20 plus years of my life and get something positive out of it for me and those I support.*

### Rights

People have the right to services to support their well-being and social development through the local authority, to have community care needs assessed and assessed needs met. These rights reflect the Social Work (Scotland) Act 1968, Article 26 UNCRPD, right to habilitation and rehabilitation, and Sections 25-26<sup>26</sup> of the Mental Health Act.

### What people told us at consultation

We were told services that help people cope with stress form an important role in keeping people well, but these services are difficult to access or not available at all in some areas.

### What we then asked

We asked people with BPD what kind of treatment and support they had. We were keen to hear if supports such as employment services, peer support, further education and volunteering were also accessed and what role these played in helping individuals stay well.

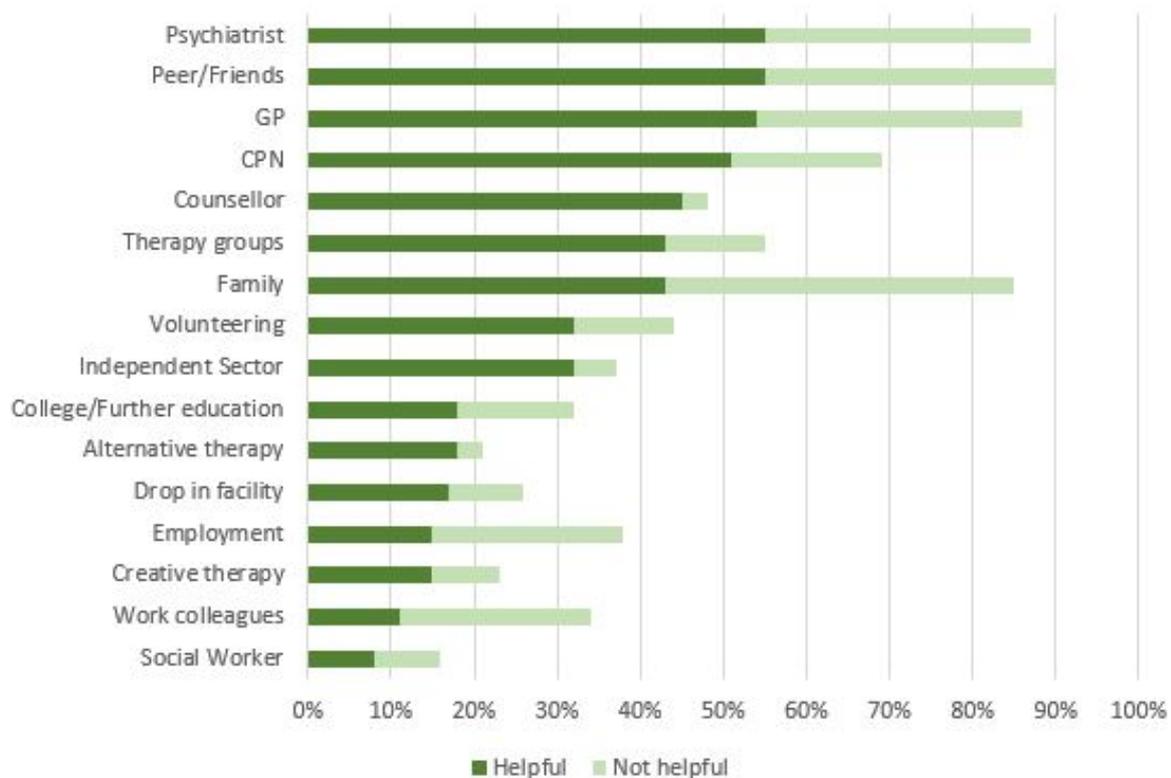
We asked staff working in mental health services what access they had to supports for people.

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<sup>26</sup> Sections 2-27 of the Mental Health Act relate to local authority functions, provision of services, care and support services. Section 26 relates specifically to services designed to promote well-being and social development.

## What people with BPD told us

[Figure 2](#). Forms of support received (% , n=65)



Over half found their psychiatrist, GP and CPN to be helpful, but not everyone had access to a CPN, with around a quarter that did not.

### GPs

People with BPD largely regarded GPs to be amongst the most helpful professional support in their lives. However, both people with BPD and GPs themselves reported a wide range of attitudes towards and experiences of the relationship.

At large GP practices, people identified particular GPs who they felt cared, were respectful and listened to them; in preference they sought them out for support for their mental health, choosing to see other practice GPs for physical health problems only.

Likewise building up a relationship with a trusted GP, perhaps with a longstanding family GP helped. Some people with BPD felt a lack of primary care support, where there were perceived discriminatory attitudes from GPs.

*“It helps to have a GP that has an understanding of BPD. We had one before that was doing psychiatry, now we don’t have one who understands it. It makes you more resistant to seeking help.”*

*“Good GP, very understanding, if it wasn’t for her I wouldn’t be here.”*

People with BPD valued GPs having information about their condition and treatment plan.

*“I’ve found the more information I’ve given them, the better they’ve treated me... Sharing a copy of my care plan meant they know more about me.”*

We consulted GPs for their views and received 119 responses to the online GP survey. The majority said they had more than weekly contact with people with a diagnosis of BPD, with almost a quarter saying they saw people with BPD at least once a day. Most of those surveyed indicated they did not feel confident managing patients with BPD.

Only half of GPs surveyed felt supported by mental health services. The need for better support from mental health services was the most frequently made comment, with many expressing frustration at trying to get support for their patients who have BPD.

*“It would also be helpful for CMHTs to take more interest in these groups of patients as a team approach, often left to crisis intervention with primary care taking the majority of the responsibility.”*

*“We struggle to get appropriate ongoing treatment for this group of patients.”*

*“BPD/EUPD are not considered as mentally ill so neglected by mental health services.”*

If appropriate supports were in place, GPs indicated they could better manage the care of patients with BPD.

*“They should ideally have an easily accessible key worker who knows them and their personality/behaviours well and can support patient/GP in reacting to the perceived current issue.”*

*“Many people appear to be misunderstood in primary care and their challenging, emotional behaviour is often thought to be attention seeking or manipulative.”*

A few GPs reflected on the complexities experienced both by patients and doctors in the face of these challenges:

*“Traditional models of GP consultation are very unsuited to BPD and high risks within this of creating more harm than good - 10-minute consultations can easily lead to our own stress reactions/frustrations being displayed; restricts the important aspect of shared communication with key supports; and can, all too readily, result in unhelpful referrals or inappropriate prescribing.”*

Other GPs took time to grapple with the challenge of providing care and treatment to this patient group with limited resources, and competing interests for services and funding:

*“Many of these patients are managed in general practice by individual GPs who are prepared to put in the time and effort to provide a supportive, consistent approach. It is not recognised or supported by the wider health and social care system. With less GPs there are soon going to be gaps in services for these patients.”*

The need for more support for GPs in managing people with BPD was identified by many:

*“We would hugely value support in the management of these patients. Many remain undiagnosed as waiting times/availability of specialist services are so limited.”*

*“I honestly think that because we have traditionally been more available than other services, we have been the fall back option for these patient when in crisis. As demands on our time are ever increasing, it has become increasingly apparent that perhaps a new model for these patients should be sought as I feel we are not really the most appropriate people to be seeing these patients as medical therapies rarely work. Access to psychological therapies is very poor. This would help. Local CPN and mental health services are extremely stretched as well.”*

Most GPs surveyed said they would be interested in receiving training about BPD and several commented on the need for better training:

*“Greater understanding of these issues - through training - especially for primary care.”*

*“Support in training - even if just to avoid pitfalls would be helpful. Should be more emphasis on training around BPD within our undergraduate and postgraduate training. Newly trained GPs come through with little or no knowledge of BPD.”*

### **Child and Adolescent Mental Health Services**

Borderline personality disorder is often not formally diagnosed before the age of 18 and there has been much debate about the diagnosis being made during adolescence. The NICE BPD guidelines are inclusive of ‘young people (under the age of 18) who meet the criteria for the diagnosis’, recommending the involvement of Child and Adolescent Mental Health Services (CAMHS) in the assessment and treatment of young people with BPD.

Although we did not meet with young people for the purpose of this themed visit, adults with BPD often reflected on their earlier care during adolescence. A number of themes emerged: not being given a diagnosis before the age of 18 was described as confusing, and abrupt and poorly coordinated transitions from CAMHS to adult services was described in some cases.

*“I was an inpatient at 16 years old and had contact with CAMHS. It took me two years to get a diagnosis. I was told a lot of other things which didn’t make sense e.g. emotional dysregulation.”*

*“I was told that I could not be given a diagnosis when I was in CAMHS as I was too young, but staff should communicate with and explain why you have this diagnosis.”*

*“I only moved from the CAMHS service to adult services and within one month I had a diagnosis of BPD.”*

Child and Adolescent Mental Health Services psychiatrists participating in our survey commented on difficulties around diagnosis and the challenge at times of accessing appropriate supports. However, they also expressed optimism about recovery for young people:

*“In CAMHS tends to be a formulation around relationship styles/patterns and emotional regulation. On a few cases, when the diagnosis might be very clear and the young person is approaching 18, a formal diagnosis with written, verbal and internet information might be given, but it is rare to give a formal diagnosis.”*

*“I work with young people who are under the age of 18 and we discuss about having borderline personality traits which can respond to treatment, containment and risk management.”*

*“I am always optimistic given the young age of the patients I work with. Things generally feel hopeful as the difficulties tend to be less entrenched. It can be very difficult to identify community supports which is a major issue.”*

### **Community Mental Health Teams**

General adult CMHTs currently provide the majority of support for people with BPD. This is usually through support from CPNs, outpatient psychiatry appointments and support from allied health professionals, such as occupational therapists (OT). In many teams, CPNs are trained in a psychological therapy and can offer additional therapeutic support. In other areas psychology services provide psychological therapies, either individually or in groups.

Psychiatrists and CPNs were rated as some of the most helpful supports by people with BPD. However, when we consulted people about their experiences, accounts of CMHT support varied widely. Some had very positive experiences of support, whilst others had found it difficult to access help, or when they did, they found some professionals discriminatory due to their diagnosis.

As with people's experiences of GP services, a central theme was the importance of establishing trusting and mutually respectful relationships with professionals.

People talked honestly about the challenges of developing trusted therapeutic relationships, with some describing the difficulties of engaging and the tendency to reject support, something widely acknowledged as being a potential barrier to supporting individuals with BPD:

*"I was offered a CPN but when I'm not well I sack them... I had two good CPNs who were always there for me, even when I sacked them. It took about five years to accept help, I kept withdrawing then going back."*

Perseverance and a consistent approach from professionals was valued in helping people to gradually accept help:

*"No matter what I present them [psychiatrist and CPN] with, I get a consistent and steady response."*

*"No matter how many times I mess up they're still there."*

*"My current psychiatrist has been my doctor for almost 12 years and has been an amazing support to me and kept me alive."*

Others were less positive about their experiences:

*"Psychiatrist and CPN not helpful, have no faith in them, don't handle me well... only interested in increasing medication but don't offer anything else."*

As with GP accounts, difficulty in accessing services was not uncommon:

*"I found there is a lack of help and services are so limited and that there is no treatments I have been offered."*

*"I've been very lucky living in a catchment area with great resources. At my previous address, care was chaotic with high staff turnover so I had no continuity. Having stability and the help of not just a CPN but also an OT has really helped to stabilise my mental health."*

When we asked psychiatrists what model of care they thought should be used for people with BPD, the majority said care and treatment primarily managed by general adult mental health services, with the support of specialist personality disorder services.

Very few opted for care by specialist personality disorder services alone or CMHT support alone. Less than half said they had access to a local specialist personality disorder service.

A particular challenge highlighted by psychiatrists was the lack of supports available for those with severe and complex difficulties, such as co-morbid mental illness, substance misuse and severe trauma:

*“I am concerned that therapies do not target this severely disabled group.”*

Keeping this group in mind was important in developing services:

*“Being careful not to develop care pathways based on those with milder/moderate impairment – the most severely affected get left out.”*

Most psychiatrists spoke positively about the potential for improvement and recovery in BPD, but emphasised the need for services to be appropriately resourced and access to evidence-based therapies being made available. The need for social supports was seen as important in not ‘over-medicalising’ care.

We found that attitudes of psychiatrists towards people with BPD were less stigmatising than among other groups we surveyed. We looked at the words each staff group used to describe their experience of treating patients with BPD. Psychiatrists tended towards more positive associations, such as ‘rewarding’ and ‘interesting’.

When we consulted staff delivering therapies, we asked what worked well:

*“Providing an individually tailored package of support which is tailored to individual need and not based on diagnosis.”*

*“A clear, consistent, bounded approach, relating to the individual’s level... Understanding of the individual’s way of operating.”*

When we asked about what works less well, they said:

*“We tend to work nine-to-five and a lot of the services the council provide are not designed for people with a mental illness let alone BPD/EUPD. Packages of care can be charged, which inevitably is a disincentive for many people.”*

*“We can respond in a chaotic way to people with EUPD and don’t always present united as a team when there is contact. A person sometimes has contact from different team members which can be confusing. I think we sometimes react too protectively, and are not bounded and clear enough about what someone’s own responsibility is, or we are not clear to the client about what we can and can’t deliver/provide.”*

*“We need a personality pathway to formalise current practice. The assessment process needs to be improved across the boards to improve quality of traits assessments and formulations that can then inform treatment plans.”*

We wanted to know what would improve their service and they said:

*“Increased staff to ensure sustainability of therapeutic activity and to address the development and training of the wider staff group. Increased access and availability of training and post training support to embed knowledge and skills – specifically understanding the diagnosis, attitudes and values, managing boundaries and risk.”*

*“Improve communication. Unsure of what the strategy is for people with EUPD in NHS.”*

*“On-going education of professionals to counteract residual pejorative view of personality disorder and access to training.”*

### **Specialist Personality Disorder Services**

Whilst the treatment and support of people with BPD is mainly offered by generic mental health teams with the support of primary care, the provision of specialist services has been recommended in a number of key UK documents over the last 15 years.

National Institute for Health and Care Excellence guidance states ‘mental health trusts should develop multidisciplinary specialist teams and/or services for people with personality disorders. These teams should have specific expertise in the diagnosis and management of borderline personality disorder’.

The recent survey carried out by the Royal College of Psychiatrists in Scotland<sup>27</sup> found that almost three quarters of Scottish health boards do not have a designated lead for personality disorder at the present time. Only two health boards (Greater Glasgow and Clyde and Highland) reported having specialist services for personality disorder, with Dumfries and Galloway having a dedicated consultation service.

We included visits to patients and professionals in health boards where specialist personality disorder services are currently provided.

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<sup>27</sup> Royal College of Psychiatrists, *Personality Disorder in Scotland: Raising awareness, raising expectations, raising hope*, August 2018.

## **Case study**

The 'Emotionally Unstable Personality Disorder Service' in Dumfries and Galloway offers a model of how a small team are delivering specialist support across a large rural area. The service runs on an education and consultation model and the team view their main roles as up-skilling and changing attitudes towards people with EUPD.

They do this by running workshops for professionals from statutory and third sector services. The team have so far provided teaching days for NHS staff, including primary care and A&E, social workers, housing workers and the police.

The team offer additional consultation and advice to colleagues who are managing complex cases. Although the team do not carry out therapeutic work themselves, they support mental health staff in working with people with EUPD.

Funding was provided to train CPNs within Community Mental Health Teams in Structured Clinical Management (SCM) for EUPD. This provides CPNs with the skills to support people with EUPD through this recovery model. The team are providing training and supervision to the community teams, to deliver SCM in their local areas. The aim is to train all CPNs in Dumfries and Galloway by 2019.

An important role of the service has also been supporting patients and staff with positive risk taking, which helps to reduce lengthy inpatient stays.

The team have also worked with inpatient staff to pilot planned admissions for a small number of people with EUPD, who are clinically assessed as requiring extra support when in crises. Based on individual need, a number of admissions are agreed over a set time period, which is regularly reviewed. This allows a person who feels in crisis to have a brief respite admission to a general adult ward (usually for a maximum of 48 hours) if they need it. The individual chooses when to use their allocated days, allowing them ownership of the process.

## Case study

The Coping and Succeeding (CAS) day service in Inverness was highlighted as particularly positive. This service has been developed over five years by the specialist personality disorder team in Highland, with service user involvement at every step. This co-production model is highly valued by participants, who described the service as having ‘a genuinely collaborative approach. The service offers a structured, time limited programme for a small group of people who have completed other stages of a phase-based therapeutic approach. It is the stepping-stone to moving on from mental health services.

There was general agreement about the ‘sense of community’ offered from the group. The team are linking up with the University of the Highlands and Islands and other organisations to provide educational opportunities for CAS members. Links with the Forestry Commission and other local outdoor and voluntary organisations are providing opportunities for recreation and potential future employment. These developments are still in their early stages but show promise.

## Other supports

We asked about support from a counsellor and of those who did have a counsellor, around half said it was helpful.

*“I work with a counsellor. We talk about my symptoms and how I’ve been feeling. I’ve seen a psychiatrist twice this year, been to groups and been referred by my CPN for other treatments and therapies.”*

Both the NHS Highland ICP<sup>28</sup> and the recently published consensus statement ‘Shining Lights in Dark Corners of People’s Lives’<sup>29</sup> say that some people with BPD will benefit from specific interventions to enable meaningful personal, interpersonal and social progress to occur.

Around a third told us that they had contact with an independent sector organisation, most felt their contact with these services had been helpful. Drop-in facilities were limited, but reported as very helpful.

*“There was nothing available in this area so I set up a user-led peer support group.”*

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<sup>28</sup>[www.nhshighland.scot.nhs.uk/Services/Documents/Personality%20disorder%20service/Complete%20NHS%20PDICP%20Part%201%20-%20Text.pdf](http://www.nhshighland.scot.nhs.uk/Services/Documents/Personality%20disorder%20service/Complete%20NHS%20PDICP%20Part%201%20-%20Text.pdf)

<sup>29</sup> The Consensus Statement for People with Complex Mental Health Difficulties who are diagnosed with a Personality Disorder, *Shining lights in dark corners of people’s lives*, 2018.

<https://www.mind.org.uk/media/21163353/consensus-statement-final.pdf>

*“I got really great support from Penumbra’s self-harm project – the combination of the approach that the service takes, along with the staff attitudes, makes this such a good service – I owe them my life.”*

*“When I’m down, I go to Falkirk and District Association for Mental Health if I hit crisis.”*

Self-management empowers people with mental health problems to lead their own recovery and providing the skills, strategies and knowledge to do this promotes improved self-management.

Most told us that self-management strategies, being taught skills to cope and finding strategies to manage suicidal thoughts were helpful areas to be supported in. Gaining these skills helped people cope with the symptoms and problems associated with BPD.

### **What people told us they wanted from services**

We wanted to find out if people had been informed about the range of specialist services, and therapies or treatments that have developing for BPD in the last few years. About half said that what they knew had been helpful.

Whilst the majority found support following contact with mental health services, both general and specialist services, was key to staying well, finishing a course of psychological group or individual therapy could be a challenge; it left a gap and many people said there were fewer opportunities for them.

Where services were not easy to access or responsive this created an immediate barrier. For example, particular referral criteria could leave people feeling excluded.

People told us they were looking for a consistent response, good communication and information, and a clear plan on how they could begin to work through their issues with support and ultimately live their lives. They also spoke of primarily looking for mainstream services that were accessed by others in their communities and not always specialist resources.

*“Social groups – something with a non-health or clinical basis would be good.”*

A sense of identity and being able to be involved in meaningful activity was important. People having a sense of responsibility, obligation or responsibilities in life can be highly influential in bringing about positive change and helping them stay well<sup>30</sup>.

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<sup>30</sup> Terry and Cardwell, *V Understanding the whole person*, Revolving Doors Agency 2015 (Check this reference)

## **Employment, education and volunteering**

Those who were employed, or engaged in further education or volunteering found it helpful. However, half of the people we spoke to were not engaged in any of those activities.

Having a job gave an overall sense of routine and structure to life and helped significantly in staying well. However, sharing issues with colleagues could be difficult, especially with managers for fear of stigma and discrimination in the work place. On occasion, the overall negativity of the experience and stress could lead to leaving the world of work completely.

Volunteering added routine to people's lives; helping to distract from their own concerns.

*"My volunteering, informal support and part-time employment all involve mental health and I use my lived experience in a positive way. This is a vital part of staying well for me."*

*"It's important to have a purpose, after DBT, I have two jobs but I don't tell my employer about my diagnosis."*

We heard that accessing funding for full-time education was difficult and required individual support.

## **Benefits and welfare reform**

Some people with BPD were keen to discuss the issue of financial stability and the problems and stresses associated with living on benefits. Although not exclusive to the diagnosis of BPD, there appeared to be added barriers for them: a misunderstanding of BPD and associated stigma when people were faced with the benefits process, both from the Department for Work and Pensions and when getting assistance from professionals to achieve a claim. While a sense of financial security was important, the process to achieve this was often dreaded and contributed to people becoming stressed and more unwell.

*"Navigating the benefits system was a challenge, I could not have done it without the Citizens Advice Bureau."*

The main barrier was the difficulty of obtaining benefits and filling in forms to obtain benefits<sup>31</sup>.

There was a tension between the idea of recovery and the sense that the idea of living on benefits somehow went against this, a struggle whilst having to acknowledge the need for financial assistance.

*"I feel like a fraud, but having benefits makes a huge difference."*

## **Family and friends**

The support of family and friends, and having an informal network often kept things in perspective, particularly if there were dependent children, providing a particular focus to stay well. However, explaining the diagnosis to family members could be very difficult. It was difficult to make sense of their own emotions and behaviours and could be problematic to explain this to others.

*“It’s difficult to explain your mental health to family, they don’t really understand depression never mind BPD.”*

In contrast, contact with family was more limited for people who had had adverse childhood experiences and poor family relationships. People also did not want to add to the burden of care that they felt family members already had to face far too often.

## **Recovery and peer support**

Recovery is a term that has been used for a number of years, but has seen progression in Scotland with the advent of the Scottish Recovery Network (SRN) in 2004 and a strong emphasis in Scottish Government mental health policy.

The SRN is an organisation designed to raise awareness and promote the issue of recovery. It aims not just to place recovery at the centre of people’s lives, but also develop this into mental health practice and ongoing policy. Discussion with staff at SRN highlights that recovery is a highly individualised and personal experience and is unique to each person. They therefore do not offer specific support for people with BPD, but choose not to identify people by their diagnosis.

The concept of recovery was one which some people with BPD that we spoke to sometimes found difficult to expand on; rather they viewed their progress as a lifestyle change or a means of finding new ways and mechanisms to adapt and cope with their own issues. For a few, comments were made that, as BPD had been explained to them by professionals as an intrinsic part of their make-up, change and the potential for recovery might be limited.

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<sup>31</sup> Citizens Advice Scotland, *Living at the Sharp End and Burden of Proof*, 2017.

*“There is very little focus on recovery or positive hope.”*

*“I don’t get the recovery thing, I’m always going to have BPD.”*

We were able to establish that for many people we spoke to, outside of professional services, finding a distinct way of coping needs to be a priority. This was especially important if local services were not flexible to change or readily available. Supports identified by people in this chapter are a key part of individual recovery for people with BPD. What we found however, is that both mainstream services and community alternatives are in short supply and continue to be difficult to access. The stigma and discrimination that people feel is also a barrier to recovery.

*“I just want help to develop hope and skills to cope but not have the ‘expectation of recovery’.”*

### **Peer support**

A peer support role is one where a relationship of mutual support between people of similar life experiences offer each other a connection and understanding. This can take several forms. For example, it can be an informal relationship that has developed between people over time and formed a supportive function. This may be a naturally occurring individual or shared group experience. In addition, peer support can be provided by the specific role of peer support worker; a worker who has had personal experience of mental health problems and is trained and employed to work in a formalised role with others and assist in recovery.

There have been a number of these posts developed in mental health services over the last few years. However, there are still relatively few employed peer support workers across the country (80). The people we spoke to had little experience of the role, nor had this been suggested to them by professionals.

It was encouraging to note that a number of the focus groups we attended did evidence naturally occurring peer support. Supportive relationships were emerging between individuals attending specialist groups, and we are aware that some people would continue to support each other once the programme had finished.

A few people we spoke to said that peer support could be something that might also assist in staying well. In some areas people can access a peer support group developed by people with lived experience. ‘Serenity’ in Inverness and ‘Beyond the Border’ in Dumfries were mentioned by their members as providing valuable support. However, most were not aware of peer support services in their areas.

*“A peer support group would be really good - it would provide a helpful social contact.”*

## **What we were told by staff**

Staff told us of the challenges that they face in coordinating good support for people with BPD. We spoke to both specialist BPD services and CMHTs and they identified a range of solutions and resources that they felt could assist in maintaining the health and well-being of people with BPD. A number of these focussed on additions or changes to existing services, including effective team working, increase in staffing and resource, and having a clear national strategy and care pathway. It is interesting to note that they contrast with the statements made by people with the diagnosis, who, although looking for accessible, flexible mental health services, are also pointing out that support needs to be seen more broadly than only in health settings.

Consultation with the Adult Support and Protection (ASP) West of Scotland Practice Network has indicated that a number of people with BPD have been referred into the ASP framework, particularly at times of crisis. Despite this, interventions can be short-lived and people are often directed out of the framework. Members of the network felt that meaningful interventions and services could be in short supply for people with the diagnosis and the response differs across the country. Additional comments centred on the high level of risk that was often associated with these referrals.

It is worth noting that Sections 25 to 27 of the Mental Health Act impose duties on local authorities to provide care and support services for any person with a mental illness and who are not in hospital. This includes personality disorder. In addition they are tasked with providing services which aim to promote well-being and development. This should include services which provide social, cultural and recreational activities and assist with training and employment opportunities.

## **Case study**

The Rivers Centre is NHS Lothian's specialist service for people of all ages affected by psychological trauma. It offers an open, accessible service and is based in a community library setting. This provides a discreet way for those who visit the service to get support for their mental health, away from the traditional clinical setting.

It was developed in consultation with users about what they would want their services to look like and how they should operate. The Rivers Centre puts the individual at the heart of everything they do and aims to make sure that people get the right help, at the right time. A self-referral system is used so there is no appointment system. Four mornings a week an advice service is in operation; people can either call ahead or attend in person.

When someone visits the centre, the first experience they have is contact with highly skilled staff who then undertake a short assessment of between 20-30 minutes. This is to discern the immediate needs of an individual.

After the assessment, input can range from giving advice, to referring to other services in the independent sector. This care is identified by link workers who assist in matching the most appropriate service for each individual.

The Rivers Centre is a public social partnership working closely with their colleagues in health, social care and the third sector. Currently the centre has 25 partners who they can refer people on to such as Rape Crisis, Victim Support and Penumbra.

There are no exclusion criteria for the Rivers Centre and no discharge policy, although they are not an emergency service, they offer people a multifaceted approach to help them deal with trauma.

## Crisis and A&E

*Since I have created my crisis plan with my psychiatrist things have went well with the crisis team and others who deal with me in crisis, but before that it was an awful experience.*

People with BPD experience difficulties in regulating their emotional states. Stressful situations and experiences can often be a trigger for crisis. Supporting people with BPD when they are in crisis is a key part of their care and treatment. Assessing and managing risk is an essential part of supporting people, as self-harm and suicidal tendencies are a core feature of the condition.

The recent Royal College of Psychiatrists report states:

‘Evidence based therapies all include collaborative crisis planning as one of their core components, as this is generally considered to be an important tool in empowering people to develop skills to manage their own distress.’

A crisis plan is a plan that the individual develops with medical and support staff detailing what they should do and who they should contact when a crisis arises.

### **Rights**

Everyone has the right to participate in putting together a care plan and risk or safety plan. This reflects the principles outlined in Article eight of the ECHR and the Patients’ Rights (Scotland) Act 2011. The right to information about crisis and out-of-hours services reflects Articles two and three ECHR duties to prevent risk to life and inhuman or degrading treatment.

### **What people told us at consultation**

People with BPD talked about the absence of service response, the difficulty in having their situation taken seriously, staff attitudes and the lack of access to hospital beds. They said they would often go directly to A&E departments for assistance rather than go to a GP or CMHT. Some felt they had been dealt with well, especially by CMHTs.

### **What we then asked about**

We asked what could trigger a crisis and what response was most helpful. We also sent an online questionnaire to A&E departments across the country.

## What we were told by people with BPD

People gave us some insight into their lives when crisis arises. Of these, the majority told us they had at least one episode of crisis in the month prior to answering our questionnaire. The most commonly mentioned trigger for crisis was negative attitudes from other people, followed by trauma, family issues or lack of support from services.

People mentioned many ways of coping in crisis situations. Some told us they withdrew from family, friends and usual activities and would try to deal with the situation alone. Others would seek help from services. People described the common symptoms of increased suicidal thoughts, urges and impulsivity during a crisis.

Only a minority of those we spoke with spoke about having crisis plans, but the majority of those who did have them found them helpful.

*“I have a crisis/safety plan but don’t use it much now. Used it often in the early days. It’s full of skills that I use regularly.”*

*“I now have a crisis plan and that helps, this was circulated to all parties that work with me.”*

Around a third of psychiatrists said their team always developed crisis plans with patients.

People sought help in a crisis in a variety of ways: by contacting their mental health worker or local crisis response team, speaking with their GP, calling a helpline or attending A&E. People also had experience of contact with the police due to concerns about their behaviour or safety during a crisis.

We heard mixed experiences about the support people received from mental health services when in crisis. Crisis services were not always found to be helpful:

*“Crisis services are awful, they don’t take you seriously, they just offer distraction techniques which are no good in crisis... they say go for a relaxing walk or take a bath.”*

*“It is very difficult to get proper support when in crisis. Saying things like ‘this will pass’ doesn’t help. Neither does people thinking you are attention seeking. Even with a management plan, when I am in crisis it does not get followed even though I wrote it when I was in a good place. It clearly states when I hit crisis what I am like, what I will say and how I need supported.”*

A few people mentioned advance statements and liked the idea of using these, especially if they could state their wishes about what should happen to their children if they were in crisis.

As people become more able to manage their crises, the majority reported that they used skills they have learned in the past to assist in recovering from crisis.

People spoke of how important it was to have professionals who didn't reject or discharge them at times of crisis, but instead persevered. Being supported by professionals who know you well was highlighted as being beneficial:

*"CPNs invaluable... important for them to know you when you're well, so they can help you when you're unwell."*

*"My therapist is helpful – doesn't try and fix me but takes me seriously and helps me get help when I need it in a crisis. They have helped me build a crisis folder and taught me to 'calm the harm'."*

*"Preventing crisis would be helpful. Knowing what the signs are, knowing what my crisis is like, when it comes, when it goes, and being able to try as many avenues as I can would help."*

### **What we were told by staff**

General practitioners and psychiatrists surveyed also spoke about crisis management. GPs described a range of experiences in accessing crisis support for their patients. Where supports were available this was valued:

*"Unscheduled care team have been very helpful."*

*"Crisis management via our home intensive treatment team is prompt."*

However, difficulties in accessing crisis support were also common:

*"When patients are in crisis there are often frequent appointments and calls which have to be dealt with without any support to the GP or patient."*

*"These patients often bounce between us and third sector services with little help from secondary care when a crisis arises."*

*"Availability of support and crisis support could be improved."*

One theme repeatedly highlighted by GPs was the importance of information sharing and the value this had in supporting their patients with BPD. Good communication and collaborative working was also identified by psychiatrists as key to improving crisis care:

*“Joined up, attachment focused working between crisis teams, CMHTs, primary care and psychological services.”*

*“Serious engagement with general hospitals to ensure fair treatment of self-harm and suicide attempts.”*

## **What we were told by services**

### **NHS 24**

The NHS 24 111 service provides urgent health advice out of hours, when GP practices are closed. The advice covered includes mental and physical health concerns.

NHS 24 report that people with a BPD diagnosis will generally attend A&E in crisis rather than contacting NHS 24 in the first instance.

They highlight that there could be improved communication between services and cited GP electronic systems not being accessible by NHS 24. In some health board areas, instead of having to refer individuals to GPs for follow up, information can be sent directly to CPNs in community teams for follow up.

A small percentage of calls to NHS 24 about self-harm and suicidal intent are passed directly on to the police for follow-up. The police may attend the person’s home and take them to A&E for further assessment.

NHS 24 are aware that around two thirds of calls they receive in connection with BPD are from, or about, people already known to services. The availability of wider information that could be gleaned from shared crisis plans would improve this support.

Currently NHS 24 are working collaboratively with police and the ambulance service on developing a pathway for unscheduled mental health services that will compliment locally based services.

## Police Scotland

Police Scotland is divided into 13 divisions covering the whole of Scotland. Each division has a Risk and Concern Hub which is responsible for incoming calls. The source of these calls varies considerably, from concerned members of the public to friends, relatives and other professionals. In an out-of-hours situation, people with BPD may come into contact with the police in this way, particularly if they are at risk and in crisis.

We know from our monitoring role that the police are in regular contact with people when in crisis with their mental health. Legally, the police are required to notify the Commission of any person held under a Place of Safety order (Section 297 of the Mental Health Act). This is when a person who they believe may have a mental illness and is in immediate need of care and treatment is found in a public place. The person can be taken to, and detained, in a Place of Safety for up to 24 hours in order to be assessed by a doctor and for any necessary arrangements to be made in relation to their care and treatment. For further information please see our latest report on the use of Place of Safety orders in Scotland<sup>32</sup>.

People with BPD told us that their experience was less formal and, although they did have contact with the police and were accompanied to A&E departments, they did not always feel supported:

*“Most of my support comes from the police and out of hours, I get more support from the police than other services. Mostly they are understanding and gentle, in general if it is the local bobby they will come back to check or give you a phone call to see if you are all right.”*

*“The police can be very good and helpful but individual officers vary greatly – some are very helpful and compassionate, some are not.”*

*“I think there should be a separate emergency service for mental health as we use up a lot of police and ambulance time because there aren't the right resources to help us.”*

Some people spoke about police officers lacking awareness about BPD and felt that this could be improved on. We are aware from contact with Police Scotland that mental health awareness training is available in some divisions with the aim of improving this across the force. We were also told about an initiative in Carlisle where police officers, out of uniform and trained in mental health, respond directly to crisis calls.

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<sup>32</sup> <https://www.mwscot.org.uk/media/431345/Place%20of%20safety%20report%202018.pdf>.

An additional response open to the police is to make a referral to the local authority under the Adult Support and Protection (Scotland) Act 2007. This legislation requires local authority social work departments to then make inquiries or fuller investigations if concerns exist. This occurs where they feel a person meets the legal criteria and may be at risk of significant harm. Consultation with the ASP West of Scotland Practice Network has indicated that a high number of ASP referrals are received by local authorities across the country in this way.

Emotional harm is often identified and potentially could apply to someone with a diagnosis of BPD. The concept of harm is widely defined, but emotional harm can be identified and potentially could apply to someone with a diagnosis of BPD.

### **Distress Brief Interventions**

Distress Brief Interventions (DBIs) are a relatively new way of supporting people in distress.

The DBI approach has emerged from the Scottish Government's work on the suicide prevention and mental health strategies. It arose out of people in mental health distress presenting to frontline services including Police Scotland, A&E, GP practices, ambulance and social work services, and receiving an inconsistent response. This was particularly the case in out-of-hours services where people would present in crisis.

The aim of the programme is to provide a framework for improved inter-agency working across a range of settings, interventions and community supports. The shared goal of providing a compassionate, connected service will mean better engagement with those in distress and that people will become involved with services for a longer period of time, leading to improvements in their own mental health.

Distress Brief Intervention is a time limited and supportive problem-solving contact with an individual in distress, involving a two tier approach in terms of response. Level one is provided by front line staff, such as A&E or ambulance staff, who will have initial contact with the person when they present. They will deliver the first response to the issue, which should be focussed and demonstrate compassion. Level two is provided by trained staff 'who contact the person within 24-hours of referral and provide compassionate community-based problem solving support, wellness and distress management planning, supported connections and signposting for a period of up to 14 days.'<sup>33</sup>

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<sup>33</sup> <http://www.dbi.scot/aim/>

All staff will have been trained to a specific level. Currently there are four services operating across Scotland: Aberdeen Penumbra, Inverness Support in Mind, Scottish Borders Joint Mental Health Service and a Lanarkshire project jointly hosted by Health and Social Care Partnership North Lanarkshire and South Lanarkshire Health and Social Care Partnership.

Distress Brief Intervention is not specifically targeted at people with a diagnosis of BPD, but many people with BPD will present at non-specific mental health services at times of crisis and out of hours.

Whilst recognising that a short term intervention, with a distinct ending is not always best practice for people with a BPD diagnosis, the DBI model does offer an empathic response and short-term continuity, both requirements in the longer-term support and care of people with BPD. In addition, this input may complement the longer-term care of the person with BPD. It should not replace any existing mental health input, but where these services are in short supply, the DBI programme will be able to identify and highlight local gaps.

The DBI programme is still at a relatively early stage and none of the people with BPD that we spoke to had had contact with this service.

### **Accident and emergency departments**

We received many comments about the experience of using A&E departments. Although some were positive, the majority of comments described a negative experience for those who used the service.

Most told us they were reluctant to use A&E departments and if they did, this tended to be in relation to episodes of self-harm or overdose of medication. Many expressed feelings of guilt at using the service but felt they had no other option. Apart from immediate physical treatment, A&E was not best placed to meet their needs:

*“A&E services don’t care, they make you feel like a time waster.”*

*“Hospital staff were very business-like; there to get you physically well and on some occasions I was seen by a psychiatrist or the liaison team and they just discharge you which I just find appalling – with little or no support – it puts a hell of a lot of pressure on my carer.”*

Occasionally people told us about A&E attitudes they found discriminatory:

*“Attitude made it worse... dismissive, accusatory and unhelpful.”*

The importance of good communication between A&E and mental health services was highlighted to us by several people with BPD:

*“Assumed mental health team would know via A&E when I had attended, but they didn’t communication issues between services.”*

*“In A&E they think you are making up your physical health symptoms. You are told ‘It’s all in your head’.”*

### **Information from A&E staff**

We received 110 responses from A&E staff across the country to our online questionnaire. The responses were from 93 medical staff and 17 nurses.

Most respondents told us they personally see people with BPD at least once a week in A&E. People were often brought to the A&E department by the police who were concerned about the behaviours of the person. The most common reason given by staff for presentation of people with BPD at A&E was self-harm or overdose.

Most A&E staff could refer to liaison mental health teams and around a third also referred to crisis teams and in-patient services. Difficulties accessing prompt mental health support was, however, a frequent criticism:

*“Mental health services are not available 24 hours a day. There are large gaps in local evening cover and slow work rate of assessment teams. Failure of local mental health teams to appreciate the pace and rate of emergency department workloads.”*

*“I often call psychiatry and am met with frustration that I have not managed the patient better, but I don’t have access to all the information regarding their engagement with psychiatry. I have to go on the face value of what the patient tells me or what I can see from previous attendances.”*

About half indicated they felt confident in dealing with people with BPD, medical staff reported feeling slightly more confident than nurses.

We asked respondents to highlight three words that best described their experience of treating people with BPD. The word most used was frustrating.

Only around a fifth of respondents had received any training in relation to BPD and a third had undergone training for self-harm/suicide management. We were told that some of this training had been a long time ago, as part of basic professional training:

*“Teaching led by liaison consultant psychiatrist with case examples.”*

*“Local teaching by psychiatric department and psychiatric study days.”*

*“Liaison nurses run study days.”*

Most respondents were interested in further training in these areas, with around a third being very interested to learn more.

Staff questioned whether A&E was the most appropriate place for people with BPD to be seen; the environment was noisy and busy, staffing levels were insufficient and cases often took up a lot of time and resource. It was felt that A&E could deal with the acute medical and physical aspects of presentation but not the underlying issues. An acute assessment or crisis service were suggested to be more appropriate:

*“A&E is not the place to assess such individuals; it is loud, chaotic and such patients do not do well in such environments.”*

*“I am aware that many come to the emergency department because we are always open. However it is not the best environment. The busy emergency department is not a pleasant or safe environment for someone with emotional distress and our staffing levels do not support the level of supervision often required.”*

*“This group are challenging because the emergency department has little to offer them. We can treat the overdose or stitch up the self-harm but ultimately we do next to nothing for the underlying problems. I would like to see an outside of emergency department service for these patients, rather than repeated attendances.”*

*“An acute assessment area at the local psychiatric hospital, where many could be better assessed in a more suitable environment. At present they are all directed to the emergency department if a crisis team is not immediately available. There has been an initiative to have the police contact crisis rather than bring to people to the emergency department, but use of this seems to be variable.”*

Accident and Emergency staff had several thoughts on how to improve care and treatment of people with BPD. They particularly wanted to be able to access information in care plans/crisis plans:

*“Locally we have access to management plans for patients with complicated psychiatric issues. These plans are excellent and very thorough, often explaining the background to the patient, the best approach when interacting with them as well as effective strategies. Unfortunately with a high turnover of junior staff, they often do not have the confidence of their assessment and still engage with Crisis Assessment and Treatment Service to discuss cases.”*

*“Treatment plans on the portal to advise how best to manage if they present - what support have they been offered and how engaged have they been.”*

*“If we knew more about them and who they had seen, even that day or hour, what plans and support were in place, we could help provide a consistent approach.”*

Staff wanted improved support from mental health services when people with BPD presented at A&E:

*“Better support from mental health services and colleagues when asking for advice/referring patients to them.”*

*“Not to withdraw all support from other services leaving the emergency departments to pick up the pieces in the out-of-hours period.”*

*“They should be able to access the mental health services rather than turning up in an emergency department.”*

*“Psychiatry teams should be more engaged in the process, especially during the initial presentations when the diagnosis has not been made.”*

*“More specific community support rather than having to resort to A&E in times of crisis.”*

### **Case study**

A small group of nurse practitioners in the mental health liaison service in Elgin, Moray, have been supporting A&E colleagues for some time by offering regular training about aspects of mental illness that they might encounter when treating patients who visit the department.

A person with lived experience of BPD approached one of the nurse practitioners with a suggestion that they both collaborate on a project to ascertain the attitudes of A&E staff towards patients who present with self-harm issues.

They surveyed staff and identified that they felt unskilled in supporting people with BPD who presented to A&E in crisis. Patients with BPD were also asked about their experiences in A&E. The staff predominantly described their experience of this patient group negatively, finding them ‘challenging’.

They requested further training and a study day was developed. An important part of this was service user presentation on how it felt to have BPD. The feedback from A&E staff was positive, with a strong impact on changing attitudes and with many expressing a desire for more people with lived experience of mental health problems to be invited to contribute to future training sessions.

## Stigma and discrimination

***BPD still seems a little-known and very misunderstood condition, even among medical professionals. More widespread awareness and understanding, coupled with early intervention and provision of DBT is essential if those of us with the condition are to stand an optimal chance of leading a fulfilling life.***

See Me (Scotland's national programme to end mental health stigma and discrimination) defines stigma and discrimination in the following way:

'Stigma is a negative perception attached to a certain characteristic, it is a form of prejudice and as such stigma is often rooted in fear and misinformation. Different mental health problems are often stigmatised in different ways. Public stigma refers to the negative attitudes and beliefs held by the general public towards people with mental health problems. People connected to people with mental health problems, e.g. family member or friend can sometimes experience stigma by association. This can negatively impact upon the mental well-being of both the individual and those around them.

'Self-stigma, which is the internalisation of negative and often stereotypical beliefs or attitudes, can lead people into believing that they are incapable of things such as getting a job or maintaining a relationship. This can result in the individual withdrawing, feeling frustrated, angry, experiencing low self-esteem and lack of confidence in their future. As a result many are at risk of defeating their own personal goals and ambitions.

'Structural stigma refers to the rules, policies, and practices of social institutions that arbitrarily restrict the rights of, and opportunities for, people with mental health problems.

When a person is treated less favourably in an institutional setting, such as the workplace, due to a stigmatised characteristic, this is discrimination. Stigma and discrimination are closely interlinked.

### **Rights**

It is a basic principle of the NHS, reinforced by Article eight of the ECHR (the right to respect for private and family life) that all patients, whether in the community or in hospital, have the right to be treated with respect, dignity and compassion. The Equality Act 2010 gives everyone the right not to be discriminated against on the grounds of protected characteristics that include mental illness and BPD.

## **What people told us at consultation**

Stigma from the public towards people with BPD was the most frequently raised concern. When in crisis, the attitude of staff could be stigmatising and unhelpful, particularly A&E staff.

Many felt that there is a shortage of safe places and services, and they weren't taken seriously. People often disliked the terms BPD and EUPD. They resented the assumption of staff that they had the skills to cope with distress and experienced poor responses when asking for help with suicidal and self-harming behaviours.

Many felt the loneliness and isolation they experienced was sometimes because of a profound self-stigma that made them avoid relationships with other people. People reported that the closure of community facilities, such as drop-in centres, led to a growing lack of places to meet other people. Some felt contributing to society was vital to their sense of well-being, but prejudice from other people made it hard to take part in activities.

## **What we then asked**

We asked about the attitudes and stigma they might have experienced from different groups of people, settings or stages of assessment and support.

## **What we were told by people with BPD**

The majority said they had experienced stigma as a result of their diagnosis and reported varying experiences with different groups; generally finding the attitudes of police and their own GPs helpful, but reporting mixed experiences in relation to social workers, psychiatrists and community mental health services.

*"I do not disclose my own previous diagnosis. I am aware that, although most professionals would not let this cloud their judgement or impression of me as a professional worker, there are others who would view me differently were I to mention this."*

The stigma and negative attitudes from family and friends and the wider public was mentioned. Family stigma varied; some family members did not understand the condition, others lacked the ability to deal with people when they were in crisis.

*"I keep myself well; my family will be helpful up until I really start showing symptoms of a major mood swing in which case they are not helpful at all."*

Friends could also act in similar ways, finding it hard to understand or accept the condition or behaviour of their friends when unwell, and in some circumstances actively avoiding people or stopping the friendship completely.

People with BPD reported a widespread lack of understanding of the condition by the public, which often came across as negative attitudes towards them and the diagnosis.

*“BPD is much stigmatised and they see us as attention seeking and manipulative, but really we are just in pain and can’t help ourselves.”*

### **Feelings of self-stigma**

Self-stigma is complex and can be bound up with reflections on past behaviour, as well as the opinions of others, and can cause some people to have very negative feelings about themselves. People reported feelings of self-stigma which included the effect of having been ‘sectioned’ (detained under the Mental Health Act) in the past, feelings of shame about having the diagnosis or about the actions the condition can sometimes lead people to.

People with BPD reported that they had acted in negative ways as a result of self-stigma. The main effect was not feeling able to talk about their diagnosis.

*“I rarely talk about my diagnosis except to my family or present psychiatrist/CPN for fear of being misjudged by others.”*

It also prevented people from seeking help or being open about thoughts they felt would lead to negative reactions from professionals, and could prevent people from raising complaints when they felt they had been poorly treated.

*“It is difficult to accept support at times because I often feel a burden or unworthy of support.”*

Successfully challenging self-stigma led to increased confidence. Peer-led activities, such as providing training in BPD, or volunteering could lead to positive experience and enhance self-esteem.

### **Attitudes of professionals**

Research undertaken in the UK looking at the attitudes and views of mental health nurses indicates that people with BPD are often viewed more negatively than those with other psychiatric diagnoses, and generate less sympathy amongst professional staff.<sup>34</sup>

People with BPD reported difficulty with the attitudes and understanding of health professionals, with some people feeling that many professionals lack both an understanding of the condition and an ability or willingness to see them as people in their own right.

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<sup>34</sup> D. Markham, *Attitudes towards patients with a diagnosis of “borderline personality disorder”: social rejection and dangerousness*, *Journal of Mental Health*, vol 12, pp. 595–612, 2003.

People said they struggled to feel heard when seeking help and could feel that their experiences were dismissed by professionals, especially when professionals first became aware of their diagnosis. They often feel judged by professionals and some reported that they were seen in pejorative ways; for instance as trouble makers or attention seekers.

An issue that was raised by some was the difficulty of getting help when they clearly felt that they needed it. The refusal of help was sometimes seemed to be communicated in a hostile and dismissive manner.

*“There is still much stigma attached to having a BPD diagnosis - a psychiatrist at a hospital I was transferred to recently told me 'We don't treat people like you' and discharged me after I was transferred there from my own authority, in crisis, as no bed was available.”*

*“I don't get taken to hospital soon enough because they don't like BPD people in wards so I deteriorate until the police are involved and I'm attempting suicide, and even then my CPN and psychiatrist don't want to admit me so I have to take myself to A&E in a state.”*

We were told that some staff had difficult attitudes and prejudices about people with personality disorder. These were hurtful and upsetting to the people concerned.

Sometimes frustrations were perceived as a desire to punish people for their actions.

Discrimination in employment was mentioned by some people and included workplace bullying, loss of work and inability to get back into the labour market.

### **Discrimination generally**

Some people reported that they thought they had been discriminated against as a result of their diagnosis. This was mainly in the workplace but also included issues around access to grandchildren, education, benefits and services. A small number of people said that they either were not believed when they tried to challenge this or felt their concerns would have been dismissed because of their diagnosis.

The behaviours exhibited by some people with BPD were viewed as challenging by many of the staff who responded to our survey. It is not possible to say that this is due to stigma and discrimination but we did hear of a lack of willingness of some staff to work with people with BPD.

A small number of staff and one psychiatrist held very strong views that people with BPD were attention seeking, manipulative, dangerous and likely to make complaints. This seems to confirm some of the views that people with BPD themselves reported experiencing from professionals.

It is important that there is wider training of general and specialist staff that includes looking at the values and attitudes that they hold about people with BPD, showing live examples of recovery in many different forms, skills training in what to say and do, having a recovery focus and challenging the sometimes pejorative attitudes held by some professionals towards people with BPD<sup>35</sup>.

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<sup>35</sup>[https://www.mentalhealthcommission.ca/sites/default/files/qualitative\\_model\\_report\\_feb\\_2015\\_0.pdf](https://www.mentalhealthcommission.ca/sites/default/files/qualitative_model_report_feb_2015_0.pdf)

## Carers

*When she went missing I had no idea who to contact or call, she goes into crisis and will now phone me or her support worker. Her support worker is amazing. She can talk to her about things she will not tell me. I cope much better knowing she has the support worker now.*

### Rights

Everyone has the right to agree how much they want family and friends involved in their care and support, have their carer involved, and their views and caring role considered when determining the need for support and services. This reflects the Carers (Scotland) Act 2016<sup>36</sup> and Article eight of ECHR, respect for private and family life.

### What we asked about

We asked what carers thought kept their relative or friend well, what level of support they received and what might help in the future.

### What carers told us

We received completed questionnaires from carers and spoke directly to the families of five people with BPD. All described themselves as being dissatisfied with the diagnostic process and all described difficulties for their relative in getting a diagnosis. The families felt excluded from the process, that their opinions were disregarded and they were given no advice on how to help.

*“All the psychiatrists I have spoken to appear extremely reluctant to change the diagnosis, going by what they read in notes instead of getting to know her.”*

*“I don't understand it. Even though we were there at the assessment they didn't include us.”*

Families reported great stress and anxiety when their relative was unwell, went missing and they could not find out if they were safe.

Staff can often have difficulty with confidentiality issues at these times, understanding the value of carer involvement whilst maintaining their common-law and professional duty of confidentiality to their patient.

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<sup>36</sup> The Carers (Scotland) Act 2016 Act came in to effect on April 1 2018 to ensure better and more consistent support for carers.

If the person with BPD wishes no disclosure, these wishes must be respected, but staff should regularly revisit this decision. Careful consideration is needed on how the carer can still be offered support and general information, especially if the carer is to be responsible for ensuring the service user is safe and well at home.<sup>37</sup>

*“No one told me anything. None of the doctors would speak to me because it was confidential. I didn't have a clue. I was given no assistance, no support, no one would speak to me, and no one said a word.”*

*“I am her mum - she could have just said 'they are here and safe' - just a hint that they were there.”*

Carers are usually the first to be aware of a developing crisis. Often at times when professional help has not yet been established or is unavailable. They are often best placed to notice subtle changes in the person for whom they care, and usually the first to notice the early warning signs of a relapse.<sup>38</sup>

Getting support was a great relief for some, especially in a crisis situation. Although this was not universally available, and negative and unhelpful attitudes were upsetting for families:

*“They won't admit to hospital because of BPD. They refuse to deal with it. They seem to think it is not real, it is made up - they see it as someone seeking attention.”*

Those who did manage to link in with carer support groups found them very helpful.

Comments from carers on how to make some positive change included: more collaboration between families and mental health teams, a sensible approach to confidentiality and a better understanding of BPD as a genuine condition allowing appropriate support to be put in place.

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<sup>37</sup> Mental Welfare Commission for Scotland, *Carers and Confidentiality*, Good Practice Guidance, 2013.

<sup>38</sup> Carers Trust Scotland, *Carers Included: A Guide to Best Practice in Mental Health Care*, 2013.

## Appendix One

### Key

Most-more than 80%

Majority - 56 to 80%

About half - 45 to 55%

Minority - 20-44%

A few - less than 20%

Very few - less than 10%

## Appendix Two

### Mental Health Act analysis

Most of the time when people become unwell they will agree that they need treatment, but sometimes people are unwilling or unable to agree to treatment. The Mental Health Act sets out when and how people can be treated, taken into hospital against their will, what their rights are and the safeguards which ensure these rights are protected.

The Mental Health Act applies to people who have a mental disorder; this means any mental illness, personality disorder or learning disability, however caused or manifested.

The Commission has a duty to report on the use of the Mental Health Act in Scotland and we produce regular reports about our statistical monitoring. We check that all relevant paperwork is correct. We look closely at the use of detention. Latest figures from 2016/17 show that mental illness accounts for the vast majority of people detained under the Mental Health Act.<sup>39</sup>

Mental illness alone accounted for most (89%) of new short term detention treatment certificates in 2016-17, mental illness with personality disorder accounted for a further five per cent of these detentions. Two per cent of these detentions related to a diagnosis of personality disorder (PD) only. The rates of people with PD alone detained under this type of order have changed little over the past 10 years.

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<sup>39</sup>Mental Welfare Commission for Scotland, Mental Health Act monitoring report 2016-17, pp. 27, 2018.

We undertook further work to examine detentions that included PD to see if there were any common themes arising. We selected a random day in March 2017 and identified all Mental Health Act orders open on that day (point prevalence) where PD was mentioned in the criteria for detention.

We looked further at these orders and eliminated those where there was associated mental illness or learning disability. This resulted in 16 detentions under the Mental Health Act and 10 detentions under the Criminal Procedure (Scotland) Act 1995, where PD on its own was the criteria for detention.

We looked at each individual case; we reviewed the detention form completed and looked for information on the reason for admission and the type of PD identified.

From this limited review of individual cases and the paperwork we received, we concluded that there did not appear to be inappropriate use of mental health legislation in relation to these people with borderline personality disorder (BPD) alone.

There may though be occasions we are not aware of, when it may have been appropriate to use detention under the Mental Health Act but it was not used.

### **Mental Health Act**

Of the 16 detained under this Act, two were male and 14 female. BPD/Emotionally Unstable PD was given as the diagnosis in 12 cases. The remainder were organic, dissociative or mixed aetiology PD.

Age range was predominantly 45-64 (three under 25).

Except for one short term detention certificate (up to 28 days), all were detained under either a compulsory treatment order or a community based compulsory treatment order. Reasons given for the need for detention related to severe self-harm or suicidal thoughts. Only one was a first episode of detention, all the rest had a history of detention.

### **Criminal Procedure Act**

The demographics in this group were quite different. Of the nine detained under this Act, all but one were male. There was only one case where Emotionally Unstable PD was given as the diagnosis, others included organic, dissociative, anti-social, paranoid, narcissistic and mixed PD.

Seven were aged 25-44, one 45-64 and one aged 65-84.

All were involved in serious offences resulting in admission to hospital. Three were subject to compulsion orders, three to compulsion order with restrictions and two were on a transfer for treatment direction from prison to hospital. Five were first episode admissions to hospital.





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