Borderline Personality Disorder: Stigmatisation experiences of accessing and participating with frontline services in England.

Donna Maria Bradbury

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Abstract

Borderline personality disorder (BPD) is one of the most stigmatised of all psychiatric diagnoses. Frontline service professionals regard this diagnostic group as challenging, manipulative, time wasters, a drain on services and attention seekers which results in people with the diagnosis being subject to stigmatising and negative attitudes, which is also reflected in people receiving unequal care and support or exclusion. The stigma associated with this diagnosis remains as the catalyst in creating barriers to accessible care, life quality and the continuation of discriminatory practices. The current research presents the experiences of individuals with a BPD diagnosis in accessing and participating with frontline services in England. The current research focuses on investigating stigmatisation in frontline services and provides recommendations for reducing such stigmatisation.

This qualitative research was conducted using a social justice constructivist grounded theory approach. Semi structured narrative interviews were carried out with a total of eleven participants in varying locations across England. The data analysis identified five main themes: stigmatisation and awareness, the power of language, service provision, professional control and reclaiming power and identity. The findings evidenced that stigmatisation, negative attitudes and exclusion of people with a BPD diagnosis was experienced throughout physical, mental and public protection services. This study makes a direct contribution to this area of research from the lived experience perspective.

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For mum, I love you.
23rd July 1949 – 22nd July 2022

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Declaration

I declare that the work in this thesis was carried out in accordance with the regulations of the University of Gloucestershire and is original except where indicated by specific reference in the text. No part of the thesis has been submitted as part of any other academic award. The thesis has not been presented to any other education institution in the United Kingdom or overseas.

Any views expressed in the thesis are those of the author and in no way represent those of the University.

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Chapter 1. Introduction

This research explores the experiences of people with a diagnosis of Borderline Personality Disorder (BPD) in accessing and participating with frontline services in England. It will explore whether attitudes towards this diagnostic label can result in social and service exclusion and lead to those with a diagnosis of BPD to self-exclude due to the negative beliefs held by professionals. The term BPD is used throughout this study to reflect the participants own language in describing their diagnosis. The undertaking of this research was prompted by witnessing the negative and stigmatising attitudes and practices towards people with the diagnosis in a variety of frontline service settings.

Academic and research literature pertaining to the BPD diagnosis has been consistently biased in excluding the experiences, views, and voices of individuals with the diagnosis. Knowledge of BPD is generally taken from the experiences of professionals within the health and social care sector rather than people with a diagnosis of BPD (Smith and Cashwell, 2011; Maranzan, 2016). However, professionals' interactions with those who have the diagnosis are most commonly at times of emotional crisis and help-seeking giving an unfair representation of this diagnostic group. A crisis is defined as risk of harm to self or others and inability to function normally in everyday life that requires additional support (Rethink, 2020). Mental health crises are considered a complex phenomenon and there are contradictory definitions of them, each of which entails ideas about how and when support is needed (Lyons et al., 2009; Burns-Lynch et al., 2014; Klevan, Karlsson and Ruud, 2017). Not everyone will experience a mental health crisis with these clinical indicators, and those that fall outside of these categories which are nonetheless overwhelming and devastating for people are generally less well known and taken less seriously by mental health services (Lakeman and Fitzgerald, 2008; Lyons et al., 2009; Tobitt and Kamboj, 2011).

The exclusion of lived experience from the literature reinforces the negative perceptions and narratives surrounding the diagnosis, stereotypes abound, for example that people with the diagnosis are manipulative, destructive whirlwind, challenging and attention-seeking (Woollaston and Hixenbaugh, 2008; McGrath and Dowling, 2012; Warrender, 2015). To counteract the exclusion and minimisation of people with a diagnosis of BPD the current research sought to explicitly gather the experiences and views of people with BPD to address this unequal balance.

This chapter will provide a brief overview of the diagnosis, symptomology, causation factors and the stigmatisation of this label and negative attitudes by professionals towards the diagnosis. The overview of the diagnosis is taken from the medical model perspective, that professionals would be taught during training, and from the information available to someone wanting to find out more about BPD. The reason for this is to highlight and explore the discriminatory and stigmatising language used to describe the diagnosis. The dominance of the medical model in relation to mental health fuels the negative perceptions and stigmatising behaviour towards people with a BPD diagnosis (Johnstone, 2014). The medical model perspective is explained in more detail in chapter five and leads into the theoretical development of the Dominant Identity Status Model outlined in chapter seven.

Personality development

Casey and Kelly (2007) suggest that the human personality is difficult to define. However, personality theorists such as Jung (1963) Erikson (1980) and Rogers (1961) see it as the foundation upon which characteristics such as emotional patterns, behaviours and cognitions are developed which enable day-to-day living. Our personality develops in the early stages of childhood and is moulded and shaped by emotional, physical, and social experiences (Garvey, 2018). Personality development is also linked to the physical development of the child and adolescent brain, with a particular focus in the literature on the pre-frontal cortex, the area of the brain which is implicated in personality expression, cognitive behaviour, decision making and moderating social behaviour (Starcevic and Filipovic, 2018).

Research suggests that two major changes take place within a child's brain before and after puberty which are thought to contribute to fine tuning neural networks in the frontal cortex (Vizard, 2008). Environments in which children have negative emotional, physical, or social interactions and experiences can increase the probability or risk for the disruption of the natural development of the brain and personality (Garvey, 2018). For the healthy development of brain circuits and personality, children require positive and negative learning experiences. The lack of such experiences can result in a decrease and miswiring of brain circuitry (Garvey, 2018).

The impact of environmental effects demonstrated by the Bucharest Early Intervention Project (BEIP) (2020) longitudinal study on children institutionalised from birth in Romania, determined that a lack of healthy experiences that stimulate growth resulted in deficits of brain development. The children’s physical and cognitive growth was stunted and delayed, and their brain activity was altered compared to non-institutionalised children (Nelson et al., 2007; Tierney and Nelson, 2009). The disruption to brain and personality development can lead to the development of psychological conditions and disorders such as Attention Deficit Hyperactivity Disorder, anxiety disorders, attachment disorders and neurodevelopmental disabilities (Schore, 2001; Petchel and Pizzagalli, 2011). Children who have early experiences of trauma, victimisation or adverse events that increase emotional stress responses for periods of time are at an increased risk of psychopathology, which is the manifestation of behaviours or experiences suggesting mental illness or psychological impairment in adulthood including the development of a personality disorder (Roberts et al., 2008).

Overview of Borderline Personality Disorder

Accurate descriptions of emotional disorders, personality disorder and BPD can be found as far back in history as ancient Greece (Tasca et al., 2012). During the Victorian era mental illness became more socially recognised and the term lunatic became embedded as the description of a person with a mental disorder, but the term also had connotations of dangerousness and immorality (Crocq, 2013). The recognition of mental health conditions has become more accepted and understood in society, but the personality disorder diagnosis remains linked to such connotations within society, media and frontline services correlating personality disorder as dangerous, risky and violent (Markham, 2003; Nash, 2006; Ring and Lawn, 2019).

The term BPD was first used by Adolph Stern in the 1930s to describe patients held in a lunatic asylum who appeared to be more severely disturbed than the more usual neurotic patients experiencing psychosis (Wirth-Cauchon, 2000). BPD was first introduced by the American Diagnostic Statistical Manual of Mental Disorders (DSM) 111 in 1980, with the World Health

Organisation releasing their classification of mental and behavioural disorders the ICD-10 in 1992 (BPD Community, 2017). Since then, BPD has become the most common of all the personality disorder diagnoses in psychiatry (Johnstone, 2000; Shaw and Proctor, 2005).

A personality which is considered 'disordered' by the psychiatric establishment is primarily defined as an enduring pattern of behaviour and experience that deviates from the structural expectations of one's culture, is inflexible and pervasive with the general onset in adolescence or early adulthood leading to impairment or distress (DSM-5, 2015). Patterns tend to be stable and encompass multiple domains of behaviour and psychological functioning. Frequently, but not always they are associated with varying degrees of subjective distress and problems in social functioning and performance (DSM-5, 2015). Personality disorders are described as deeply ingrained with maladaptive patterns of behaviour which are generally recognised by the time a person reaches their adolescence and continues into adulthood (Casey and Kelly, 2007). There are twelve types of personality disorder listed in the diagnostic manuals which are clustered into three groups; while each personality disorder has different symptomology the ones in each cluster share characteristics as outlined in the table below.

Cluster A – odd or eccentric	Cluster B – dramatic, emotional or erratic	Cluster C- anxious or fearful
Paranoid	Anti-social	Avoidant
Schizoid	Histrionic	Dependent
Schizotypal	Borderline	Obsessive-compulsive
	Narcissistic	

Table 1 Clusters of Symptoms according to Diagnostic Criteria

The two remaining personality types are personality change due to another medical condition (Brain injury, Dementia, Alzheimer's, Parkinson's, Stroke, cancer – brain tumour etc) and Other specified personality disorder and unspecified personality disorder.

BPD is grouped in Cluster B classified as one of the erratic, emotional and dramatic personality disorders which predominantly presents as displaying a pervasive pattern of instability in relationships, negative core beliefs, identity, self-image, and affect. Emotionally Unstable Personality Disorder is considered as equivalent to BPD and is used within the ICD-11 (2019).

People with a diagnosis of BPD can experience chronic feelings of emptiness and are likely to become involved in unstable and intense relationships repeatedly causing emotional crises to avoid and reduce feelings of abandonment. Symptoms and features of BPD, with increased impulsivity and risk- taking behaviour can increase in early adulthood (Lieb et al., 2004; Stepp, 2012; Scott, Stepp and Pilkonis, 2014; Fertuck, Karan and Stanley, 2016). People can adopt distress coping methods which can include, but are not limited to, non-suicidal self-injury, suicidal ideation and risk-taking behaviours such as unprotected sex or sexual promiscuity, drug and alcohol abuse and eating disorders (DSM-5, 2013; Rosenstein et al., 2018; ICD-11, 2019). Comorbid diagnoses are also very common for those with the diagnosis, which can include, but again is not limited to, other personality disorders, body dysmorphia, anorexia nervosa, bulimia, obsessive compulsive disorder (OCD), mood/anxiety disorders, Asperger's, post-traumatic stress disorder (PTSD), and complex PTSD (c-PTSD) (Distell, Trull and Boomsma, 2009; Lubke, 2014; Biskin, 2015).

BPD is one of the most academically and scientifically researched of all the personality disorder sub-types with much debate on whether the symptomology places it in the category of a personality or mood disorder (Kulacaoglu and Kose, 2018). However, there are marked differences between personality disorders, which involve long term patterns of thoughts and behaviours that are unhealthy and inflexible, and mood disorders which have episodic periods of extreme sadness or euphoria (Parker, 2014). Support to reclassify the condition from a personality to a mood disorder is weighted by the fact that markers of emotional dysregulation are highly comorbid with depression and bi-polar disorder as well as affective instability being a core feature of the conditions (Morna and Crawford, 2013). PTSD and complex PTSD (c-PTSD), which has additional symptoms to PTSD affecting emotional control, is supported for inclusion in the reclassification of BPD. PTSD and c-PTSD frequently occur in people with the diagnosis with a range of between 30-79% having developed PTSD/c-PTSD due to trauma in childhood (Cacowski, Neubauer and Kleindienst, 2016; Ford and Courtois, 2021).

1. Chronic feelings of emptiness
2. Affective instability
3. Fear of abandonment
4. Identity disturbance
5. Impulsive behaviour
6. Inappropriate anger
7. Recurrent suicidal or self-harm behaviour
8. Suspicious or out of touch with reality
9. Unstable and intense interpersonal relationships

Table 2 Core Symptoms Associated with BPD

Due to the co-morbidity of PTSD/c-PTSD and BPD, some members of the psychiatric community suggest that BPD should be identified as a delayed form of PTSD/c-PTSD to accurately reflect symptoms as well as being less stigmatising than the BPD label (Furnham and Dadabhoy, 2012; Ford and Courtois, 2021). Studies have shown that women with comorbid BPD and PTSD/c-PTSD show more severe symptomology and poorer general functioning with increased non-suicidal self-injury, impulsivity, suicidal ideation and admittance to hospital. It should be noted however, that not everyone with a BPD diagnosis has experienced trauma (Rusch et al., 2007; Leichsenring et al., 2011; Cackowski, Neubauer and Kleindienst, 2016).

Diagnostic criteria of BPD

Clinical diagnostic assessment for BPD in England is made using the ICD-11 diagnostic manual (WHO, 2019) or the DSM-5 (American Psychiatric Association, 2013). The diagnostic assessment includes an historical and present-day exploration on the four different domains of BPD symptomology which include: affectivity – influenced by or resulting from emotions; interpersonal functioning – interaction and relationship with others; impulse control – maintain self-control, urges and behaviours and cognition to determine whether they meet a set number of specific criteria for a diagnosis to be made. Both diagnostic manuals use the same criteria for diagnosis; the DSM requires a minimum of five out of nine diagnostic criteria’s to be met, whereas the ICD requires a minimum of three criteria.

A full explanation of each of the diagnostic criteria for BPD taken from the DSM-5 can be found in Appendix 1. The ICD-11 which was released in 2019 by the World Health Organisation and approved at the World Health Assembly, however the earliest that it can be officially used is January 2022. The ICD-11 contains changes to the personality disorder diagnosis and abolishes Emotional Unstable Disorder (EUPD) as a sub section of the emotional mood personality disorder. BPD and the other personality disorder types will now be classified as moderate to severe.

The DSM-5 received a mixed reception prior to its release in the UK and the USA in 2013 and was largely criticised for employing a top- down approach to mental health conditions which tried to diagnostically fit people to conditions (NHS, 2019). The British Psychological Society (2016) stated that any classification system should take a bottom-up approach that centres on a person's experiences, problems, symptoms or complaints which treats the person, not a disease. The DSM-5 was also criticised for lowering diagnostic thresholds for multiple disorder categories, which could lead to inappropriate medical treatment amongst vulnerable populations or people with everyday worries being misdiagnosed and needlessly treated. Particularly how the revision of personality disorders was not supported by empirical research and increased the pathologization of normal variations of human behaviour (Society for Humanistic Psychology, 2016). Wakefield (2013) proposed how it could make a higher frequency of people being misdiagnosed particularly in those displaying borderline psychopathology leading to a diagnosis of bi-polar disorder or major depression (Limandri, 2012; Corradi, 2015). The DSM-5 has since been updated with the release of the DSM-5-TR (2022) text revision in March 2022. This release has not altered the diagnostic specifications for BPD.

The diagnostic assessment is generally not carried out before the age of 18 years old with the DSM-5 or 16-17 years of age if using the ICD-10. The diagnostic manuals conflict in relation to the age at which someone can be assessed for the diagnosis which means that diagnosing before a person has reached adulthood (18 years old) raises concerns due to the appropriateness of the diagnosis in a period of major developmental transitions – physically, psychologically, and socially. During this period adolescents commonly experience emotional instability, identity issues, moodiness and sensitivity to rejection which are also defining features of BPD. The DSM-5 does however allow diagnosing BPD under the age of 18 if symptoms are persistent and pervasive and not limited to a particular developmental stage or other mental disorder with symptoms being present for at least 1 year (Videler et al., 2019). The lowering of the age of recognition of BPD in childhood or adolescent years has been argued for (Biskin, 2015; Bozzatello et al., 2019; Wertz et al., 2020) in order to implement psychological interventions before patterns of maladaptive behaviours become entrenched, making treatment in later life more difficult and challenging as well as reducing the rates of suicide attempts and suicide ideation (Miller, Muehlenkamp and Jacobson, 2008; Biskin, 2015; Chanen, 2015; Fonagy et al., 2015).

Hessels et al. (2018) argue that personality disorders should be considered as a lifespan developmental disorder with precursors of symptomology in early life and thus diagnosing BPD in young people should be considered legitimate. Chanen and McCutcheon (2013) suggest that BPD would be better described as a disorder of young people considering the greater prevalence of symptomology that occurs during puberty and subsequent steady decline during each decade in adulthood (Samuels et al., 2002; Ullrich and Coid, 2009). The National Institute for Clinical Excellence recognises and acknowledges the presence of BPD in individuals under the age of 18 and advises treatment and intervention when needed (NICE, 2009) and Mehlum et al. (2018) suggests early detection and diagnosis provides early intervention, treatment and a reduction in the economic burden to society from the high use of health services. However, diagnosing at an earlier age in the UK is a controversial subject with reluctance amongst the psychiatric community (National Collaborating Centre for Mental Health, 2009) due to concerns about the transience of maladaptive traits in young people, as the personality has not yet fully developed, and the stigma that is associated with the diagnosis (Ayodeji et al., 2015; Winsper et al., 2015).

Generally, the most common clinical dilemmas are that the condition can be over-diagnosed, under-diagnosed or misdiagnosed due to the similarity in presenting symptomology and affect mainly with bi-polar disorder (Ghaemi, 2014; Webe-Alamah and Wolgamott, 2014). Diagnostically, BPD is often misdiagnosed or diagnosis is delayed due to shared symptomology with conditions such as bi-polar disorder, anxiety, depression and c-PTSD. However, Parker (2014) suggests that differential diagnostic markers can be implemented through identification of mental health conditions present in an individuals' history. For example, bipolar disorder rarely presents in childhood but tends to emerge in late adolescence or early adulthood, in contrast to BPD which tends to be evidenced by symptoms of emotional dysregulation from childhood and evolves rather than having a distinct onset as in bipolar disorder.

Symptomology

The central feature in the aetiology and development of BPD is emotional dysregulation, defined by a marked reactivity, variability of mood and insensitivity. Disturbed emotional processing encompasses fast and intense emotional and reactive responses to stimuli or triggers; individuals characteristically have an increased emotional arousal generally with a range of dysphoric affects aligned with strong and rapid mood reactions in combination with limited impulse control (Chenard-Poirier and Biskin, 2013; Paris, Scherpiet, 2014; Scott, Stepp and Pilkonis, 2014).

Individuals with a diagnosis of BPD will often switch between negative and positive emotional states which are interpreted as characterising people, objects, situations and themselves as either all good or all bad to protect themselves from fear or anxiety of potential abandonment, betrayal or loss of trust (Houben et al., 2016). This is known as emotional switching, referring to sudden and drastic changes of emotional states from good to bad, positive to negative and vice versa, and is thought to be a common defence mechanism for those with the diagnosis (Beck and Freeman, 1990). Switching is the concept of dichotomous thoughts where the world, people and feelings are observed and evaluated as either good or bad with nothing in between reflecting the black and white thought processes of the diagnosis (Beck and Freeman, 1990). Emotional switching can be chaotic and distressing for those experiencing it. Switching can influence how they see themselves or how others view them, an unstable self-structure, self-loathing, and difficulties with self-other differentiation (Skodol et al., 2011; Houben et al., 2016). People with a BPD diagnosis often have an erratic self-view with a poor understanding of their own personal qualities and poor definition of the psychological boundaries between themselves and others (Bender and Skodol, 2007; Beeney et al., 2016).

The state of switching can also include feelings of omnipotence, emotional hypochondriasis, passive-aggression and acting without regard of the consequences and projective identification (projecting feelings onto someone else, then manipulating that person to respond with the same feelings that have been projected onto them) (Houben et al., 2016). However, research into whether emotional switching is a prominent factor of the diagnosis has produced inconclusive results, indeed Santangelo et al. (2014) and Houben et al. (2016) found no differences in overall changes of emotional intensity between individuals with diagnoses of BPD, PTSD and bulimia nervosa. In contrast, Trull et al. (2008) found that those with a BPD diagnosis, or those with comorbid diagnosis of BPD and PTSD, displayed a higher intensity of emotional switching specifically related to intense feelings of sadness and fear. Therefore, emotional switching is not conclusively identified as a prominent factor of the diagnosis.

Individuals with a diagnosis of BPD can have a repeated disturbance in identity with feelings of chronic emptiness, alongside fluctuations between the idealisation and devaluing of those around them, serving a self-verification function which can feed into the negative viewpoint they have of themselves (Valentiner, 2014). Those with the diagnosis, have an inability, at times, to distinguish or recognise attributes or traits particular to their own identity or sense of self and because of this, they can adopt the traits of those around them as a mechanism for grounding themselves. This lack of identity or sense of self as opposed to others without the diagnosis can lead to unpredictable responses when interacting with others (Freeman, Stone and Martin, 2005).

Impulsivity

Impulsive behaviour is classed as another core feature of BPD symptomology and can take various forms in its presentation, for example spending, substance abuse, binge eating, risk taking behaviour that puts individuals in harm’s way such as risky sexual practices (primarily by women) (Kulacaoglu and Kose, 2018). Although impulsivity is not a predominant symptom in all people with a BPD diagnosis, it is implicated in a range of health risking behaviours. Meade and Sikkema (2005) research into risk-taking behaviours of people with severe mental illness contracting HIV/Aids, found that those with a BPD diagnosis were at the greatest risk of contracting HIV. Some individuals with a BPD diagnosis who have experienced sexual abuse are also reported to have a greater number of sexual partners and a higher risk of experiencing further sexual violence or being persuaded to engage in a sexual encounter

(Sansone and Sansone, 2011a). Due to emotional dysregulation, alongside chronic feelings of emptiness and loneliness, people with the BPD diagnosis seek out others who are willing to engage in intimacy to find an escape that negates the emotional discomfort (Mangassarian, Sumner and O'Callaghan, 2015). Additionally, Crowell, Beauchaine and Linehan (2009) and Cooper, Venta and Sharp (2018) argue that childhood impulsivity may also be a factor in the development of BPD symptomology.

Dissociation and Dissociative Identity Disorder

Dissociation is a mechanism involved in a division within the personality to give psychological protection, detachment from and containment against traumatic or stressful events as well as a way of escaping or avoiding physical or psychological threats (Brand and Lanius, 2014; Mosquera, Gonzalez and Leeds, 2014) and provides a way to regulate emotional distress by disrupting memory and feelings of difficult psychological and biological experiences (Dorahy et al., 2015). Individuals with a BPD diagnosis can use a feature of dissociative defence described as splitting to avoid conflict or create conflict with others (Ntshingila et al., 2016). Research suggests it may occur in at least 80% of those with the BPD diagnosis (Al-Shamali et al., 2022) and can present in a variety of forms such as amnesia – loss of memory; derealisation - altered perception or experience of the external world; depersonalisation – feeling detached from one's body (Winter et al., 2015).

Various authors (Low et al., 2000; Stiglmayr et al., 2008; Fonagy, Luyten and Strathearn, 2011; Kruger et al., 2014) have identified that a large majority of individuals with BPD have experienced trauma. Childhood trauma, insecure and disorganised attachment from, and lack of, parenting have been identified as predictors of dissociation validated by clinical and non-clinical research (Brand and Lanius, 2014). Dissociation has close associations with emotional neglect, stress, suicidal ideation, PTSD, and non-suicidal self-injury. Briers and Rickards (2007) and Weiss et al. (2013) identified that some individuals with historical trauma experienced simultaneously occurring disassociation, emotional dysregulation, and negative emotion.

Sar et al.'s (2003) study of 240 people with a BPD diagnosis identified 64% of them had comorbid Dissociative Identity Disorder (DID) suggesting a strong correlation between the two conditions. The symptomology of BPD and DID share similarities for example fluctuations in identity, emotional states, impulsivity, unstable relationships, self-harm and suicide ideation, and in some instances DID can in fact be a secondary effect of BPD (Lauer, Black and Keen, 1993; Brand and Lanius, 2014). Recognition of dissociation disorders and symptomology awareness has increased but remains underdiagnosed or unrecognised clinically (Korzekwa, Dell and Pain, 2009; Brand et al., 2016), in part because DID is seen as controversial within the mental health community with some clinicians doubting the existence of such a disorder (Zieligman et al. 2016).

Suicide Ideation and Non-Suicidal Self-Injury

Suicidal behaviour is commonly associated with the BPD diagnosis (Cukrowicz et al., 2008; Soloff et al., 2012) with 10% of those diagnosed taking their life over the duration of their illness, at a rate almost fifty times higher than the general population. This means this diagnostic group is one of the highest at-risk for suicide completion. Other research suggests that 50% of individuals with a BPD diagnosis will have at least one serious suicide attempt and will have at least three suicide attempts during their lifetime (Oquendo et al., 2003; Paris, 2004; LeGris et al., 2012; Knafo, 2015; Ntshingila et al., 2016). There is a higher propensity towards suicidal behaviour to manage and reduce negative emotions. Suicidal ideation and attempts appear to be more pronounced in the early stages of the disorder, particularly for those in their twenties, where there is also a higher risk for suicide when the diagnosis is comorbid with other psychiatric conditions (Paris, 2004). Bilsen (2018) suggests that younger people are more vulnerable to mental health problems and that numerous factors such as personality characteristics, family structure and specific life events can increase the risk of suicide.

Suicidal behaviour develops to communicate emotional distress and pain to others and to negate negative emotions (Manning, 2011). There is a higher incidence of unemployment, low quality of life and unstable intimate relationships amongst people with a diagnosis of BPD, that creates a negative sense of self and making suicide a tempting alternative (National Collaborating Centre for Mental Health, 2009). Paris (2004) also suggests psychosocial and biological risk factors can also impact recurring suicidal behaviour and ideation. Factors identified that increase the risk of suicidality are impulsivity, co-morbidity of other mental health conditions such as depression and anxiety, previous suicide attempts, drug and alcohol use and unstable emotions and interpersonal relationships (Paris, 2017; Carballo et al., 2020).

The definition of self-harm in England (NICE, 2012) is an act intended to harm the body without suicidal intent and can present in many forms including skin carving, blood- letting, burning, and ligaturing, skin picking, ingestion or insertion of foreign objects, head banging, lacerations, binge drinking, substance abuse, restricting food intake and self-scratching (National Self Harm Network, 2008; Turner et al., 2008; NICE, 2012). Self-injury is used as a grounding strategy, to establish feelings of being in control or to re-associate from a dissociative state (Linehan, 1993; Hawton, Zahl and Weatherall, 2003). The act of physical harm refocuses unmanageable psychological pain to a physical entity (Stänicke, 2021). Non-sucidal self-harm is a strong predictor of completed suicide (National Self Harm Network, 2008; Turner et al., 2008; NICE, 2012).

Self-harm is most common around adolescence. A primary influence on non-suicidal self-injury and suicidal behaviours is the inability to effectively regulate emotion (Stepp et al., 2013; Winchester, 2015). Linehan (1993) proposed that self-injury is itself an addictive behaviour that functions to reduce feelings of dysphoria and negative mood/mindset to manage psychological distress. The purpose of self-injury is often used to inflict self-punishment to inflict retribution for a feeling, thought or behaviour and manage feelings of not being worthy, good enough, anger at oneself, sadness, feel in control, reduce and manage suicidal thoughts and not to cause or want death (National Self-harm Network, 2008; Stänicke, 2021). Self-harm is described by various names such as para suicide, self-mutilation, deliberate self-harm and episodic and repetitive self-injury (Horton et al., 2014). Many of these descriptors hold and evoke negative connotations because self-harm is deemed predominantly as a mental health issue and considered a deviant practice of emotion management which is not socially or culturally accepted (Gunnarsson, 2022). Self-harm and stigma have a strong association which tends to arouse strong emotions amongst professionals and society (Gratz, 2001; Lamph, 2011). It is highly associated with BPD and comorbid PTSD in adolescents and adults although rates of self-harm can decrease in adulthood (Chapman, Gratz and Brown, 2006; Andrews et al., 2019; Colle et al., 2020). Non-suicidal self-injury is often present before formal diagnosis of BPD is made, with onset prior to the age of twelve years (Ayodeji et al., 2015). Therefore, self-harm may be considered as a precursor to a diagnosis (Chapman, Gratz and Brown, 2006; Walker, 2009; Moran et al., 2012; Wilkinson, 2012; Ayodeji et al., 2015; Klomek et al., 2016). Skin cutting and multiple forms of self-harm are suggested as most commonly used in females with BPD (Klonsky, 2007a; National Self Harm Network, 2008; Lamph, 2011; Ludascher et al., 2015; Turner et al., 2015; Vaughn et al., 2015; Naoum et al., 2016). In the DSM-5, BPD is the only psychiatric condition which has non-suicidal self-injury as a main criterion for diagnosis even though recent research has linked it to other conditions such as other personality disorders, anxiety and depression (In-Albon, Ruf and Schmid, 2013; Zetterqvist, 2015). The strong association between BPD and self-injury can lead to assumptions that those who engage in self-harming behaviour have BPD, with people being diagnosed even though they do not meet all the required criteria for the diagnosis (In-Albon, Ruf and Schmid, 2013).

There is a higher incidence of self-harm behaviour in females with BPD accounting for 60-90% of those diagnosed using self-harm behaviour to cope with emotional stresses through the release of endorphins and to regulate negative feelings (Klonsky, 2007b; Zanarini et al., 2008; Niedtfeld et al., 2010; Naoum et al., 2016). Self-injury is also used as an act of self-validation and mastery over one's feelings by reducing those feelings (Kleindienst et al., 2008; Edmondson, Brennan and House, 2016). Self-injury can emerge in times of intense rage or temporary episodes of depression which is a common characteristic of BPD and can become a repetitive cycle reinforcing negative feelings leaving people feeling alone and isolated (Kernberg, 1986; Marriott, 2011; Edmondson, Brennan and House, 2016; Naoum et al., 2016). The act of self-harm is associated with a significantly increased risk of suicide and death from physical illness, and it is suggested that around 10% of people who self-harm will take their own life within 10 years from the first time they self-injure (Skegg, 2005; Schoppmann, Schröck and Schnepp, 2007; Butler and Longhitano, 2008; Karman et al., 2015; Butler, 2016).

While non-suicidal self-injury can provide short term relief from emotional distress it can lead to negative long-term consequences of repeated self-harm and becomes a maladaptive emotional regulatory strategy and a form of emotional avoidance to manage and control negative feelings (Chapman, Gratz and Brown, 2006). It can also invoke feelings of guilt and shame and socially isolate individuals from their family and peers (Gunnarsson, 2021;

National Alliance on Mental Health, 2022). The lack of understanding by professionals of the act of self-harm prolongs the feelings of shame and guilt which increases the dependence on the behaviour to regulate or diminish negative emotions (Chapman, Gratz and Brown, 2006; Long, Manktelow and Tracey, 2013; Liu, 2017).

Causative factors

What causes BPD has been a long- standing debate amongst professionals and scholars with varying hypothesis proposed including child development experiences such as traumatic physical and sexual abuse or neglect, separations or bereavement, witnessing domestic violence, maternal inconsistency and unstable parenting in early childhood, genetic susceptibility and neurobiological dysfunction, (Cartwright, 2008; Biskin, 2015; Hall and Riedford, 2017).

Childhood Trauma

People with a BPD diagnosis report a higher prevalence of childhood trauma which suggests that behaviours and symptoms may be a direct result of the experiences of early life abuse (Everett and Gallop, 2001; Ball and Links, 2009; Chanen and Kaess, 2012; Berenz et al., 2013; Luyten, Campbell and fonagy, 2020). Childhood sexual abuse has been repeatedly linked to the development of BPD and studies by Zanarini et al. (2004) and Cackowski, Neubauer and Kleindienst (2016) compared sexually abused BPD patients with and without PTSD and found that childhood sexual abuse predicts the severity of BPD symptomology including non-suicidal self-injury, affect dysregulation and dissociation. However, according to Leichsenring et al. (2011) there is no association between traumatic childhood experiences and psychopathological changes in adolescence/adulthood and Kulacaoglu and Kose (2018) argue that childhood trauma is not a prerequisite for the development of BPD.

Research into childhood trauma has shown that it has a profound effect on emotional regulation, response to life events, social interaction and interpersonal relationship development, and functioning of impulsive and self-destructive behaviours (Van der Kolk, 2005). Exposure to trauma in childhood can mean children can experience diverse states of consciousness (disassociation, depersonalisation, derealisation, amnesia, and flashbacks) and has been linked to a variety of the personality subtypes such as BPD, anti-social, narcissistic, histrionic, and schizotypal (Van der Kolk, 2005).

However, BPD is suggested as the most likely out of the personality disorder subtypes to be associated with childhood abuse. As well as BPD, childhood sexual and physical abuse is associated with other psychiatric conditions in adolescence and adulthood such as schizophrenia, anti-social personality disorder (ASPD), PTSD, panic disorder, depression and substance abuse (Shrivastava et al., 2017).

Early childhood attachment

Childhood attachment and early-stage relationships influence development of the self, the personality and psychological processes that protect people from the stressors of day-to-day life (Maj et al., 2005; Mosquera, Gonzalez and Leeds, 2014). One cannot discuss childhood attachment without reference to Bowlby's (1973) theoretical framework of attachment, attachment behaviour is defined by Bowlby (1973) as an instinctual inclination to seek out safety from an individual that exudes protectiveness in situations that can be deemed fearful or dangerous and in which feelings of vulnerability are triggered. Bowlby (1973) suggested that separation from the mother, referred to as 'maternal deprivation', or primary caregivers, could result in psychological and physical problems and adolescent delinquency.

Early childhood patterns of attachment then affect how information and emotional responses are processed throughout life (Van Der Kolk, 2005). Secure attachment is the healthiest form of attachment where a child feels protected and can rely on their attachment figure at times of need and distress (Simmons et al., 2008). Secure attachment ensures a child feels secure and understood which enables for the optimal development of a child's nervous system and, as the child matures, it can aid a healthy self-awareness, ability to regulate emotions, empathy, trust and healthy relationships (Bowlby, 1973). Children learn to emotionally communicate with their primary caregivers before they can talk and the emotional availability between the caregiver and child contributes to a secure attachment, emotional regulation, a sense of self and healthy peer relationships (Vallotton, 2009). Children who develop secure attachment with their care givers learn how to describe and communicate their emotions and formulate efficient response strategies to restore emotional safety and control at times of distress producing an optimal safety and security equilibrium (Van Der Kolk, 2005). Children learn to regulate their behaviour through the anticipation of responses from their care givers and this interaction allows them to construct internal working models of the cognitive and affective characteristics of primary caregivers (Bowlby, 1973; Van Der Kolk, 2005). Good stable care in childhood can mitigate against psychopathology such as BPD or stress related disorders (Beck et al., 2017; Ball Cooper, Venta and Sharp, 2018).

Conversely, insecure attachment can be defined as a lack of consistent love and affection in childhood causing anxiety and fear of rejection and abandonment (Van Durme, Braet and Goossens, 2015). People with a BPD diagnosis who had early insecure attachments have difficulty in developing a stable sense of self (Aaronson et al., 2006). A lack of emotional availability in the caregiver-child relationship creates an invalidating environment and constitutes a risk factor in the development of BPD (Trupe et al., 2016). If the caregiver responds inconsistently to the child's feelings of fear or distress, and is unresponsive, abusive or negative then the child will be unable to regulate their emotional response back to the optimal safety and security equilibrium (Van Der Kolk, 2005).

Van Dijke and Ford (2015) and Aaronson et al. (2006) specifically identified insecure attachment styles in childhood as possible risk factors for developing a personality disorder and thus attachment theory has become an important framework for some in understanding the processes of emotional regulation. Difficulties of attachment are often prominent aspects of personality disorders and in particular BPD, with unstable relationships and intense feelings of abandonment and loneliness (Levy, 2005; Gunderson and Lyons-Ruth, 2008). In an extensive review in the 1990s of attachment styles in people with personality disorder Fonagy et al. (1996) used the Adult Attachment Interview (Kaplan and Main, 1984) for assessing people's strategies for identifying, preventing and protecting the self from perceived dangers. Results showed that 92% of clinical patients with a BPD diagnosis presented with insecure attachment. The disturbance in a stable sense of self (identity) can result in extreme attachment symptomology such as Dissociative Identity and false detachment in relationships to test a partner's commitment to them to reaffirm the feeling of stability and safety (Perry and Cooper, 1996; Aaronson et al., 2006).

Other factors, such as familial dysfunction and parental psychopathology, can result in childhood attachment deficits and in deficits in the ability to identify mental states in themselves and others (Bateman and Fonagy, 2004; Sansone and Sansone, 2007). The typical family environment of an individual with BPD is considered to be chaotic, highly conflictual and lacking in caregiver support (Laporte and Guttman, 2007). Familial environments which may be chaotic or where there is caregiver violence or substance abuse invalidates and does not meet the needs of the child (Golomb et al., 1994), delegitimising children's emotional expression which could result in internalising feelings and issues that can include social withdrawal, selective mutism, depression, anxiety and obsessive-compulsive behaviours (Lui, Chen and Lewis, 2011). The result is a failure to find adaptive ways of regulating emotion as well as self-invalidation of one's own experiences and avoidance of emotional experiences reducing the capacity to identify and modulate such experiences (Moorey et al., 2006). This can result in coping behaviours such as self-injury to manage and regulate negative emotions. As a result, attachment deficits between the caregiver and child impair social cognition or the capacity to think of the self in relation to behaviour, thoughts and feelings (Sharp et al., 2016).

Familial relationships characterised by a lack of empathic interactions or controlling attitudes that limit the child's autonomy (Laporte and Guttman, 2007; Kaehler and Freyd, 2009; Oltmanns et al., 2012) may also contribute. Even the 'perfect' family environment, one which exerts high demands and pressures upon a child and cancels out any show of negative emotion or which promotes self-control and individual achievement, can invalidate the child if they have difficulty in controlling emotion and regulating behaviour (Musser et al., 2018).

Separation from caregivers is common leading to unmet needs or feelings of invalidation and ignored communication. The role of invalidation has received much support in the aetiology of BPD symptomology with caregiver criticism and poor distress tolerance positively associated with the diagnosis (Cheavens et al., 2005; Sturrock and Mellor, 2014; Gill, Warburton and Beath, 2018). The impact of invalidation can vary by caregivers' gender with male caregivers being less emotionally available and whether from the primary caregiver (usually the mother) or other caregivers contributing to the invalidating environment (Cinamon and Rich, 2002).

Reeves' (2010) research found no association between invalidation and development of BPD symptomology and research results are usually taken from subjective self-report measures with can be influenced by mood state, accuracy of memory and impression management at the time of completion (Mauss et al., 2005; Chapman et al., 2010; Cheavens and Heiy, 2011). Therefore, unless the constructs of caregiver invalidation can be thoroughly researched with a greater number of subjective accounts to provide certainty, then a solid argument of invalidation as a causative factor is unclear.

Rutter's (1981) studied a group of adolescent boys to see if there was a relationship between early separation and anti-social behaviour. Rutter found that when the children returned to a stable environment, they became less inclined to anti-social behaviour. Shaffer and Emerson (1964) were also critical of Bowlby's theory and believed that multiple attachments were possible and did not only relate to the mother. Moreover, Levy (2005) suggests that although there has been empirical support for the connection between attachment and personality pathology, the relationship between attachment styles in childhood and personality disorder remains unclarified due to other potential factors which could include genetic predispositions, family stressors and environmental factors. Additionally, the development of internal working models of the self and the child's attachment figures may leave them vulnerable to life's stressors and trauma experiences (Levy, 2005).

Linehan's (1993) Biosocial Theory of BPD suggests that it is primarily a disorder of the ability to regulate emotion caused by interplay between emotional vulnerability emerging from invalidating childhood environments, caregiver inconsistency, caregiver over-protection/involvement, environmental influences and biological vulnerabilities. The theory proposes that there is a singular broad dysregulation across the spectrum of emotional response resulting in heightened emotional sensitivity, inability to regulate intensity of emotional responses and a slowed return to the emotional baseline. The Biosocial Developmental Model (Crowell, Beauchaine and Linehan, 2009) extends Linehan's Biosocial Model towards a lifespan perspective in which emotional dysregulation and impulsivity are hypothesised as occurring independently and sequentially with risk factors of caregivers who are inconsistent in support of the child resulting in impulsivity (particularly in high-risk environments) with the inability to refrain from displaying extreme emotions. Over time, coping behaviours can emerge increasing the risk of BPD symptomology and disrupting positive healthy social development (Winsper, 2018). It must be noted however, that being in a negative or unsupported family environment which does not validate a child's need, does not necessarily predict the development of BPD symptomology in children (Musser et al., 2018).

Genetics and Brain abnormalities

This is an area of development for BPD research based on neurological perspectives (Vollm et al., 2004). Genetics and abnormalities of the brain have been suggested as risk factors for BPD with growing evidence supporting a genetic vulnerability to having BPD, however no specific genes have been identified as a possible cause (Siever et al., 2002; Kendler et al., 2008; Leichsenring et al., 2011). Biogenetics has shown an association between genetic factors and adverse childhood experiences in the development of the condition, and it has been shown that diagnosis is five times more likely with first degree biological relatives that have also been diagnosed with BPD (Lieb et al., 2004; Webe-Alamah and Wolgamott, 2014). Twin studies based on the DSM-IV criteria showed rates for BPD of 35% and 7% in monozygotic and dizygotic twin pairs suggesting a genetic effect in the development of the condition (Torgensen et al., 2000; Siever et al., 2002; Lieb et al., 2004). Genetic analysis of personality disorder traits identified four main factors (emotional dysregulation, unstable sense of self, unstable cognitive functioning, unstable interpersonal relationships) which suggests that overall heritability rates of BPD is estimated at 47% (Lieb et al., 2004).

Neuroimaging techniques provide evidence to support the theory of neurobiological functional disturbances in understanding and the regulation of emotion, stress responses and affect (Newman, Harris and Allen, 2011). Research conducted on rates examining the link between neurobiological dysfunction and early development trauma demonstrated that a prolonged exposure to trauma and stress led to a loss of neurons in the hippocampus and amygdala associated with emotional regulation, impulsivity, an increase in internalising and externalising behaviours, depressive symptoms and cortisol secretion (McEwan and Sapolsky, 1995; Newman, Harris and Allen, 2011). The hormone cortisol is secreted acutely or chronically dependent on the level of stress experienced and has several systemic effects (Bremner, 1999). If cortisol levels are chronically high for a prolonged period it can damage the hippocampus, cause long-term deficits in memory, cause Addison’s disease (Adrenal insufficiency which can cause anorexia, hypoglycemia, fatigue, muscular weakness and mimic psychiatric disease) and Cushing’s disease (over-production of cortisol which can influence mood changes, depression, memory loss and physiological risks) as well as being associated with psychiatric symptoms of anxiety, irritability, and depression (Packan and Sapolsky, 1990; Bremner, 1999; Ten, New and Maclaren, 2001; Musselman and Nemeroff, 2004; Pfennig et al., 2005). Abnormalities in hippocampus and amygdala function have been associated with psychiatric disorders such as depression and post-traumatic stress disorder.

Additionally, altered functioning of the hypothalamus-pituitary-adrenal (HPA) axis has been linked to suicidal behaviours, suicide ideation and completed suicide (Ribeiro et al., 1993; Nemeroff, 2004; Pfennig et al., 2005). Suicidal behaviour is a core symptom of BPD. Neuroimaging of the brains of individuals with a BPD diagnosis consistently highlight areas of deficit in the brain regions, primarily the frontolimbic area and reductions in the volume of the amygdala, frontal cortex, and hippocampus, that affects impulsivity and emotion regulation. These key structures have been suggested to be the underpinning mechanisms in the pathophysiology of BPD (Rossi et al., 2014). Findings during controlled tasks show that hyperactivity in the amygdala and insula with a decrease of frontal lobe activity are involved in the processing of emotionally aversive stimuli (O’Neill et al., 2015). The HPA axis will mobilise various parts of the body in a response to physical or emotional stress through the release of various hormones to release stored energy or increase cardiovascular function. Empirical research and clinical features of reactive stress have suggested that the HPA axis does not function normally in individuals with a BPD diagnosis and may account for the maladaptive responses of stress such as suicide, non-suicidal self-injury instead of a functioning co-ordinated response by the HPA axis and the sympathetic nervous system (Zimmerman, 2009). The sympathetic nervous system has a fundamental role in maintaining physiological homeostasis of the cardiovascular system and response to dangerous or stressful situations known as the flight, fight or freeze response (Bracha, 2004; Seravalle and Grassi, 2022)

The HPA axis has also been identified in the relationship between individuals with a BPD diagnosis and trauma and the release and balance of serotonin (Skodol et al., 2002; Cattane et al., 2017). The serotonergic system involves itself within a wide range of behavioural, biological, and psychological functions. The serotonergic transporter gene (5-HTT) is recognised as an identified gene link for the BPD condition suggesting the role it plays in emotional regulation, impulsivity, and suicide ideation. Over reaction and responsiveness of the HPA axis in individuals with a prolonged history of BPD with childhood abuse evidentially supports developing theories of an existing relationship between early traumatisation and an increase of HPA axis function in adulthood (Lieb et al., 2004; Ni et al., 2006; Soloff et al., 2014). In support of such theories, clinical studies have determined that experience of early childhood stress contributes towards the risk of developing psychopathology and neuroendocrine abnormalities (Zimmerman and Choi-Kain, 2009).

However, Leichsenring et al., (2011) argues that these findings are unclear as to cause, effect, or whether they are an epiphenomenon of the disorder. To be identified as a risk factor it is suggested that abnormalities should be present in the early stages of the disorder as adolescents with BPD features have been shown to respond to interventions (Chanen and McCutcheon, 2013). Childhood trauma or prolonged periods of exposure to other active stress have been causatively linked to neurobiological changes which are in some studies have been associated with the BPD diagnosis (Bandelow et al., 2010). Although it is known that trauma and stress in early childhood development can impact on the natural development of personality traits in adulthood, not all individuals who develop BPD have been exposed to trauma or stress (Schmahl, McGlashan and Bremner, 2002; Lieb et al., 2004) and not all individuals who experience childhood stress go on to develop BPD symptoms or other psychological problems.

Gender and BPD

BPD is predominantly diagnosed in females with a female to male gender ratio of 3:1 (Cartwright, 2008; DSM-5, 2013). As a result, the majority of research and subsequent literature on BPD is focused on women or does not consider gender differences with regards to impact, treatment, clinical presentation, life history, negative experiences and seeking help and support from services, due to the label (Johnson et al., 2003). Mental health is predominantly associated with weakness under hegemonic masculinity and the cultural norms of gender dictate that men display their masculine agency in strength, stoicism, and decisiveness (Johnson et al., 2012; Moss-Racusin and miller, 2016). Although men are diagnosed with the condition it is thought that they are less likely to seek help and support, or treatment (Bayes and Parker, 2017; Kulacaoglu and Kose, 2018). Sher et al.'s (2019) study focusing on gender differences and similarities of suicidal behaviour, aggression, and comorbidity suggest that men with the diagnosis may be more impaired than women. Studies on clinical, forensic and prison populations have found a high prevalence of men with the diagnosis, indicating that BPD is not a rare condition (Black et al., 2007; Wetterborg et al., 2015). Gender studies in forensic and prison populations have identified men as having a higher comorbidity rate with other mental health disorders. In the general population it is estimated that around 20% of men diagnosed with BPD also present ASPD (Grant et al. 2008). Literature on gender differences of BPD generally provide stigmatising and fear-based information for men with the diagnosis, suggesting that they are more likely to have higher lethality of suicide attempts or have repeated contact with the criminal justice system (Sher et al., 2019). This is of particular concern considering those recently given the diagnosis often seek information to understand the condition and are thus likely to be provided with a highly stigmatising description.

Available research on gender differences in diagnosis, generally coincide with studies into domestic violence, aggression and criminal justice (Hastings and Hamberger, 1988; Else et al., 1993; Dutton, 1994; Holtzworth-Monroe, 2000; Johnson et al., 2003; Sher et al., 2019). In terms of intimate partner violence, which has traditionally focused on males with BPD, a cross gender analysis study conducted by Hines (2008) gathered data from across sixty-seven universities around the world using the International Dating Violence Study, 2001-2006, Revised Conflict Tactics Scale (Straus et al., 1996) and the Personal and Relationships Profile (Straus et al., 1999). Results support the hypothesis that BPD positively predicts psychological, sexual, and physical intimate partner violence for both men and women perpetrators. Subsequent research has supported the hypothesis that both genders diagnosed with BPD are associated with violence towards their partners (Kuijpers et al., 2011; Mancke, Bertsch and Herpertz, 2015).

The gender divide in a BPD diagnosis has led to speculation as to whether the higher rate observed in women is reflective of sociocultural or biological differences between the genders

(Skodol and Bender, 2003). Shaw and Proctor (2005), however, argue that BPD is a gendered diagnosis and is the latest attempt to explain the ways in which some women resist and survive oppression and abuse, this time by describing behaviour as symptomatic of a disturbed personality. One plausible theory for the apparent gender disparity of BPD is that women generally undertake more self-harming behaviours and therefore engage more with acute services and mental health settings. Men, however, generally abuse substances and engage in the antisocial aspects of BPD and thus come into contact with drug and alcohol rehabilitation services and the criminal justice system more (Sansone and Sansone, 2011a). Research studies on aggressive behaviour in those diagnosed with BPD have shown that men have enhanced aggression compared to females displaying the more anti-social symptomology of BPD which is described as dysregulated anger and behavioural manifestations such as engaging in physical fights as well as higher comorbidity of substance use disorder (Howard, 2015; Hall and Riedford, 2017).

Men can often be clinically misdiagnosed; it is suggested that societal and clinician biases commonly hold beliefs that women are naturally more emotional whereas men's display of intense emotion can appear as anger and antisocial which results in an inaccurate picture of the true extent of the problem for men (Sansone and Sansone, 2011). Feminists have long argued that psychiatry is not an objective science as women have been historically situated on the side of hysteria and irrationality thus pathologizing them for their behaviour of conforming or failing to conform to social expectations of feminine passivity. Busfield (1988) suggests that the concept of mental illness is socially constructed and inappropriately applied to women by a patriarchal order as a means of social control. Sedgwick (1982) proposed that women who are given a psychiatric label are seen as victims whether by social order or as victims of a biased, sexist and unjust psychiatry in which women's distress and behaviour is seen as pathological rather than what they have experienced in an attempt to take control of their life.

Comparatively less is known about men with a BPD diagnosis (Goodman et al., 2013; Robitaille et al., 2017) although research into gender differences in BPD have also investigated sexual orientation and suggested that 16-58% of men diagnosed with BPD identify as homosexual (Paris, Zweig-Frank and Guzder, 1995; Reich and Zanarini, 2008). Higher rates of parental control and childhood sexual abuse were found along with decreased maternal affection in men diagnosed with BPD (Paris, Zweig-Frank and Guzder, 1995; Reich and Zanarini, 2008). Men with a diagnosis of BPD appear to have different comorbid diagnoses than women. Johnson et al. (2013) compared co-morbidities in 65 men and 175 women with BPD diagnoses and found that men were more likely to have co-occurring substance disorder, schizotypal, narcissistic and antisocial personality disorders whereas women were more likely to have comorbid eating disorder and post-traumatic stress disorder.

Stigmatisation of BPD

The diagnosis of BPD attracts a considerable amount of negative attention and is the most stigmatised out of all the personality disorders (Sheehan, Nieweglowski and Corrigan, 2016). Stigma and discrimination towards people with a BPD diagnosis mean they experience significant inequalities and exclusion, poor access to mental and physical healthcare, reduced life expectancy, loss of social status, increased rates of victimisation, poverty and homelessness and exclusion from education and employment (Bates and Stickley, 2014; Durcan, 2014; Wang et al., 2018; Henderson, Potts and Robinson, 2019). Media representations perpetuate negative stereotyping of people with personality disorders by exaggerating links with violence and dangerousness which leads to public fear and therefore people self-excluding from society (Foster, 2006; Pescolido, Manago and Monahan, 2019).

People with a diagnosis of BPD experience stigmatisation and negative attitudes from frontline professionals. In my experience of supporting and advocating for friends with a BPD diagnosis, I have witnessed how professional attitudes change once a diagnosis is disclosed. General practitioners have disregarded physical health complaints, repeatedly associating physical symptoms to mental health diagnosis; interrogating them on the validity of their medical need for an appointment as if they are wasting the doctor’s time, A&E doctors and nurses who have become uncaring and unkind in their attitudes and self-harm wounds being closed without anaesthetic. Mental health services have questioned or ignored the severity of a crisis, placing the individual under greater distress without any support because of the BPD diagnosis. The stigmatisation of this diagnosis has not lessened despite increased awareness that people’s distress is valid and can have devastating consequences for those who experience it.

People with the diagnosis are often stereotyped as manipulative, attention seeking or trouble (Gallop, 1988) and are the patients that psychiatrists dislike the most. Academic research by mental and health professionals repeatedly portrays individuals with BPD as challenging, threatening, manipulative or coercive towards professionals, there is training for professionals on how to protect themselves in interactions with people with BPD (Tredget, 2001). Research has consistently shown that this stigmatisation has not improved despite frequent mental health campaigns to end the stigma of mental health (Sheehan, Nieweglowski and Corrigan, 2016). Research on BPD is shown to be largely gathered from mental and physical health professionals, indicating strong reactions and negative attitudes, less empathy and care resulting in poor treatment of people in distress and need.

Gallop (1988) discussed the impact of stereotyping of people with a mental health diagnosis such as BPD, and its influence on how professionals react to the person even if they have not met them before or indeed anyone with a BPD diagnosis. Gallop (1988) also believed that expecting negative attitudes and experiences can also become self-fulfilling and influence a person's current attitude in preparation for interaction. That is, current attitudes can be based on the negativity they have previously experienced. Over thirty years ago, Lewis and Appleby (1988) conducted research into the attitudes of psychiatrists and trainees towards this diagnostic group and how these influenced their approach and effective patient treatment regardless of gender or class. They concluded that the BPD diagnosis carried enduring negative attributes, less deserving of care and more difficult to work with. Chartonas et al. (2017) research on the attitudes of psychiatry trainees towards patients with BPD, using the Lewis and Appleby questionnaire, found that negative attitudes towards this group have remained unchanged. The results identified that specific features of BPD such as impulsivity, self-harm, substance use, suicidal behaviour and disordered eating can cause negative attitudes in trainees. They concluded that most of these behaviours carry moral connotations which can challenge the social norms, provoke negative reactions triggering prejudice in clinicians.

The next chapter will review and evaluate literature pertaining to the topics that have been derived from the findings of the data. It will focus on the stigmatisation of those with the diagnosis and the impact it has on the social and service exclusion. In response to the challenge of the negative perceptions and stigma experienced it will review literature pertaining to the inclusion of experience led people within professional practice and organisational policy, how activist movements such as Mad Pride and the ‘service user’ movement grew to readdress the inequality and power that professionals and mental health services hold, but to also challenge for change and reduce stigmatisation. The explicit voices of people with the diagnosis in relation to frontline services has not been addressed in this context and the research that has been undertaken only focuses on particular areas of health and social care such as the nursing profession.

Chapter 2. Literature Review

Johnstone (2001, p.201) states that ‘People suffering from mental illness and other mental health problems are among the most stigmatised, discriminated against, marginalised, disadvantaged and vulnerable members of our society’. Sansone and Sansone (2013), Markham (2003) and Wahl’s (1999) and Horn, Johnstone and Brooke’s, (2007) research into professional’s attitudes and the experiences of people with the diagnosis evidenced negative attitudes and stigmatisation from mental health professionals. Negative and stigmatising attitudes are not only directed at individuals but influence service delivery and policy (Kealy and Ogrodniczuk, 2010). The literature on BPD is predominantly taken from a professional’s perspective rather than those with lived experience, reinforcing stigmatising beliefs and maintaining the stigma of mental health.

Findings from multiple research studies (see Aviram, Brodsky and Stanley, 2006; Martinez et al., 2011; Serra et al., 2011; Lopez et al., 2012; Hamilton et al. 2016) has revealed that rather than relying on the general populations or professionals’ opinions, beliefs and attitudes towards mental health, it is important to highlight the lived experiences of those with a diagnosed mental health condition in addressing the stigmatising perceptions and attitudes they experience. To understand the impact that stigmatisation has on those with a diagnosis of BPD, information must come directly from those with the diagnosis as they best inform research on questions of what stigmatisation is, what it does and how it is conveyed by professionals and others in society. Sharing their lived experience can provide opportunities to empower individuals, enhance their self-esteem and challenge inequalities that arise from stigmatisation (Ungar, Knaak and Szeto, 2016).

Stigma is the catalyst for discriminatory practices, structures and behaviours and is a primary barrier to accessible care, recovery, and life quality, in which people or groups are denied equality and treated differently because of their stigmatised status (Allport, 1954; Major and O’Brien, 2005; Ungar, Knaak and Szeto, 2016).

This first half of this chapter will present a review of the literature on the stigmatisation of mental health and the BPD diagnosis. It will discuss the varying types of stigmatisation including societal, structural, cultural, and internalised. Additionally, it will present the literature on how different forms of stigmatisation impacts a person with the BPD diagnosis, influencing frontline professional's perceptions and attitudes towards the diagnosis, social and service inclusion/exclusion, and the criminalisation of mental health. The second half of the literature review focuses on mental health activism and presents how dominant discourses in mental health influence professional's interactions with those with mental health diagnoses and have fuelled a challenge through activist movements and organisations to reclaim individual identity and dispel discriminatory discourses and narratives. Lastly, it will cover the challenge to stigmatisation of the BPD diagnosis through experience-led inclusion and training within services and frontline professionals.

The evolution of stigmatisation in mental health

Stigma, originating from the Greek word stigmata, relates to individuals who are said to wear a mark of shame because they have an identifying characteristic that is not in keeping with other members of their surrounding community or group (Overton and Medina, 2008). The first academic research of stigma was introduced by Goffman (1963) in his *Notes on the Management of Spoiled Identity*. Goffman defined stigma as possessing an attribute that makes one different from others, therefore discounting and discrediting them as a whole and usual person. He described how stigmatised people form a virtual social identity which is not matched by their actual one, when, in the eyes of society, they become dishonoured and disfavoured leading to them becoming outcasts.

Goffman's concept of stigma was born out of labelling theory (Becker, 1963) which describes attributing a negative label to an individual whose behaviour goes against the social norm. Goffman (1963) suggested three types of stigma: the abomination of the body meaning physical deformities which are more identifiable in today's society as a disability, self-injury scars or obesity; blemishes of character that are perceived for example as weakness, mentally ill, homosexual, criminal, addiction, and employment status; and the tribal stigma of culture, race and religion which continue down familial lineages to affect all members. The application of labelling theory to mental illness was first addressed by Scheff (1966) who argued that social attitudes were influenced by psychiatric diagnostic labels and the presence of negative attitudes towards these labels caused individuals to ingest deviant behaviour and exacerbate social rejection (Markham, 2003).

All three types of stigma outlined by Goffman (1963) are still evident in contemporary society. More recent definitions of stigma have adopted a social constructivist framework that challenges the existing views about individuals that have a mental health condition such as BPD and their consequences (Fine and Asch, 1988; Savin-Williams, 2005; Herek, 2009). For example, how beliefs or behaviours that are outside of the social norm can be viewed disapprovingly which then places such people into inferior statuses and negative regard (Corbiere et al., 2012). The social constructivist framework focusses on lived experience and the impact of stigma and places the onus on the stigmatisers which contrasts with Goffman's work which focused on the stigmatised, framing people as victims and thereby removing them of agency. Tyler and Slater (2018) argued that despite the understanding of stigma based on Goffman's work, a fuller understanding of stigma is needed to understand the role and function it plays in the cultural and political arenas and how it creates and maintains inequality and injustice. Since Goffman, the concept of stigma has evolved to encompass the macro and meso socio cultural structures and power. Currently several theories on the construct of stigmatisation exist, which include societal stigmatisation based on social identity, secondary label stigma and structural stigma, which will be discussed in turn.

Societal stigmatisation

Social Identity Theory (e.g. Tajifel and Turner, 1979) suggests people cannot hide their membership of certain groups of people who are stigmatised by characteristics that are different from 'normal' members of society. These might include race, religion, sexuality, self-injury scars, addiction, learning disability, physical disability or behavioural differences indicating a mental health condition or sense of self derived from being a member of a group that represents a psychological connection for support, self-value and represents normative identity. A person's social identity can be fundamental to an individual's self-concept and if their identity is evaluated negatively then this can become the lens through which they interpret and view all social experiences (Stets and Burke, 2000).

Collective membership of a stigmatised group provides social support, connections with others and a collective way to highlight, challenge and reject stigmatising attitudes towards mental ill health (Tajifel, 1970; Crabtree et al., 2010; Klik, Williams and Reynolds, 2019). The social identity of individuals with mental health conditions places them in a lower status minority group within society impacting upon their well-being and self-concept which can compound their mental health difficulties (Katz, Joiner and Kwon, 2002; Jackson et al., 2009; Schulze et al., 2010; Begeny and Huo, 2016; Klik, Williams and Reynolds, 2019). Public and social ignorance of BPD and the symptomology of the condition makes people with the diagnosis invisible, until coping strategies such as self-injury as emotional regulation mark the body making them visible and exposing them to stigmatisation.

However, mental health stigma can be better understood as an issue of social injustice particularly when lost opportunities are experienced by individuals primarily due to their mental health diagnosis (Corrigan, 2004). The social dynamics of power have been incorporated into understandings of stigma as a response from theorists, such as Erickson (1966) and Bourdieu (1987) who have argued that stigma is not about 'personal tragedy' but rather as the social oppression of variance. Phelan et al. (2008) describe oppression as a function of stigma, and Young (1992) suggests there are 'five faces' of oppression: exploitation, cultural imperialism, violence, powerlessness and marginalisation, although empirical data has yet to link stigma and oppression (Scrambler, 2011). Marginalisation is identified as a feature of social oppression resulting in the exclusion from vital resources, non-recognition as a valuable member of society, and negative attitudes from professionals resulting in the limitation of services in provision for this population group (Mullaly, 2007; Ward, 2009).

Forty four percent of people living in England do experience a mental health problem during their lifetime and ninety percent of them report experiencing stigma due to their mental ill health, therefore stigmatisation continues to be a major issue (Corker et al., 2016; Health and Social Care information Centre, 2015). Social and public identifications of 'mentally ill' people can produce significant harm through discrimination, stereotyping and prejudice against those labelled with mental illness. This can reduce life achieving opportunities, create psychological distress, cause people to socially exclude themselves and impact on seeking out services at times of physical need or emotional distress (Wahl, 1999; Corrigan and Matthews, 2003).

Historically, public attitudes towards mental illness have been negative; Mehta et al. (2009) identified that attitudes in England became even more stigmatising between 1994-2003. They proposed this trend implied that during this period and, despite mental health and anti-stigma campaigns such as ‘Changing Minds’ and ‘See Me’, there was an intensification of media coverage which have often associated mental illness to violence in part related to the reformed Mental Health Act (2007) which proposed extended powers in compulsorily detaining a person and introduction of the community treatment order. Following the national campaign Time To Change (2009), which targeted public behaviour, discrimination and stigma, Evans-Lacko, Henderson and Thornicroft (2013) examined longitudinal trends in mental health knowledge, attitudes and behaviour 2009-2012. Their research determined that there had been a positive improvement in public attitudes and behaviour towards mental health, but knowledge of mental health conditions showed no changes from data from a 1994-2003 study. This indicates that public awareness, perception, and attitudes towards mental health can be improved with anti-stigma campaigns.

Research has also helped develop anti-stigma campaigns such as Heads Together (2017) fronted by members of the Royal Family to end stigma around mental health. Stigma remains a detrimental factor in affecting the lives of those with a mental illness and is a significant barrier towards seeking and receiving healthcare. Evidence by the World Health Organisation (2002) and Pattyn, Verhaeghe and Bracke (2015) suggest that there is a large gender gap in seeking treatment, revealing that men can be more vulnerable to the experience of mental health stigma than women.

Stigma is not just a by-product of a society which highlights a lack of understanding of mental illness but is also extremely common among frontline professionals despite the ever-increasing push for mental health awareness and education within their respective fields all of which have a duty of care to treat, support and protect individuals (Smilt and Cashwell, 2011; Maranzan, 2016). Diagnostic labels can potentially lead to stigmatisation in one of two ways, by allocation of membership to a stigmatised group and/or by obtaining a label from a professional which then continues to be the main identifier of an individual (Corrigan, 2004). In the current climate of societal concerns about the rising cost of financial survival and economic flourishing, groups such as the mentally ill, disabled, homeless, drug and alcohol addicts, the elderly and social welfare claimants are seen as a parasitic drain with ever-increasing demands for resources (Klein, 2007; Tyler, 2013).

The BPD diagnostic label has shown to be highly stigmatised, research has repeatedly evidenced stigmatising attitudes and responses from professional organisations towards the diagnosis (Smith and cashwell, 2011; Maranzan, 2016). The label of BPD has become so stereotyped and stigmatised that it has become an exclusion criterion from provision of care by services and organisations resulting in explicit segregation (Koekkoek, Meijel and Hutschemaekers, 2006; Thornicroft, 2006; Warne and McAndrew, 2007; Ross and Goldner, 2009; Sulzer et al., 2016). The label BPD invokes such negativity that even clinicians are at times resistant to give this diagnosis to an individual for fear that the stigma will do more harm than good (Sulzer et al. 2016). In their study on patient-centred communication of the BPD diagnosis, conducted by interviewing thirty-two clinicians and patients ranging from psychiatrists and psychologists to clinical social workers and two BPD activists identified that clinicians used a variety of tactics to communicate mental health problems without directly giving their patients the diagnosis. This included identifying co-morbid mood disorders and PTSD as this was considered less ‘blaming’ than BPD and its symptoms. Clinicians justified this practice of non-disclosure by explaining that patients would be unhappy or resistant to the diagnosis anticipating that patients would be aware of the high level of stigma associated with the BPD label. Only 9% of the clinicians interviewed practised full disclosure with their patients (Sulzer et al. 2016). Sulzer (2015) argues that individuals with BPD or other psychiatric conditions can and do suffer from stigmatising attitudes, they are labelled as ‘difficult’ by professional services due to their higher use of services, issues with compliance and perceived failure to work to get better and lose their identity as a human being, being seen only through the lens of a psychiatric disorder and undesirable qualities such as unpredictability, violence, and dangerousness to others (Koekkoek et al., 2006). In reality, research has identified that the majority of individuals with BPD are more likely to be victims of violence than perpetrators and most often subject to violent assaults based on their vulnerability to mental health problems (Alexander and Link, 2003; Walsh et al., 2003; Corrigan, 2004; Angermeyer and Dietrich, 2006; Large et al., 2008; Raven, 2009; Durcan, 2014).

A few qualitative studies have explored individuals’ experiences with BPD, but it has not generally been the focus of their inquiry (Ramon, Castillo and Morant, 2001; Aviram, Brodsky and Stanley, 2006; Kealy and Ogrodniczuk, 2010; Black et al. 2011; Bodner, Cohen-Fridel and Lancu, 2011). Huggett et al. (2018) examined the views and experiences of participants from a local mental health charity and found that society operates a hierarchy of stigma. Physical health conditions were deemed less stigmatising and received more sympathy, whereas mental ill-health had higher levels of perceived dangerousness based on the diagnostic label.

Structural stigmatisation

To understand stigmatisation and its processes, it is necessary to comprehend the structural formation of stigma that exists. The structural concept of stigma (Hatzenbuehler and Link, 2014) recognises the process of stigma from a cultural perspective and its inner workings as a system within organisational structures. It is synonymous with institutional settings rather than elements emerging from the general social world. In this perspective, it is the rules of our society, codified through policies and law that unintentionally or intentionally disadvantage stigmatised people through the control and limiting of rights and opportunities. Social roles, institutions, and the systemic relationships between them should be considered to understand the role of structural stigmatisation (Archer, 2000; Corrigan et al., 2004; Krajewski, Burazeri and Brand, 2013; Rusch and Thornicroft, 2014; Ungar, Knaak and Szeto, 2016).

Structural stigma denies individuals entitlement to things that people who are considered ‘normal’ take for granted (Johnstone, 2001; The Mental Elf, 2018). Huggett et al. (2018) identified that institutions such as hospitals, prisons, councils, and the government exhibited structural stigma as evidenced by policies, procedures, and the cultures of these organisations. Huggett et al. (2018) participants who had self-reported experiences related to their mental health problems described how disability benefit assessments did not fully account for the gravity of mental health issues and participants stated that professionals had distanced themselves and lacked understanding.

Corrigan (2004) proposes that structural stigma involves four phases: firstly a cue or recognition that there are differences in an individual (for example, physical, observable or psychiatric differences resulting in social skill deficits; then stereotypes are activated amongst members of social groups (Corrigan, 2004; Lenhardt, 2004); prejudicial attitudes derived from group membership then lead to discrimination, which is a behavioural response and a negative emotional reaction that stems from attaching stigma to someone and evokes social distancing (Corrigan et al., 2001). Prejudice is suggested to be a defensive emotion against fear of being contaminated or embodying an irresistible wish to avoid contact with someone deemed offensive or unacceptable (Brockington et al., 2001; Corrigan et al., 2001). Societal beliefs about mental illness are profoundly ingrained and reinforced by fear, ignorance, and intolerance (Overton and Medina, 2008). Cognitive processes can distort social relationships leading to complete avoidance whereby the stigmatised person or group is excluded socially and from services (Blankertz, 2001).

Cultural stigmatisation

The Mental Health Foundation report (2019) on Black, Asian and Minority Ethnic (BAME) communities stated that in England and Wales nearly a fifth of people come from a BAME background. BAME communities repeatedly face societal disadvantage; they are more likely to experience poverty, higher unemployment, racism and contact with the criminal justice system, all elevating risk factors for the development of mental health problems (Rethink, 2020; Mental Health Foundation, 2022). The prevalence of specific mental health conditions vary markedly in BAME communities; south Asian women are more likely to experience anxiety and depression (63.5% compared to 28.5% of white women) and Afro-Caribbean men experience higher levels of psychotic disorders (3.1% compared to 0.2% of white men) and are more likely to be detained under the Mental Health Act (Memon et al., 2016; Rethink, 2020).

In the UK, BAME communities repeatedly experience inadequate mental health provision and care, with some services not reaching and engaging communities where there is specific need (Centre for Mental Health, 2020). Additionally, people within the BAME community have a deep mistrust of services based on previous negative experiences and are more likely to access care through the criminal justice system rather than the healthcare system (National Collaborating Centre for Mental Health, 2019b). The psychiatric establishment and diagnostic processes do little to consider cultural differences. Interacting with mental health services is often viewed as diminishing a person's cultural beliefs, exercising power over an individual and propagating the view that mental illness is something to fear, reject and avoid (Fernando, 2003; Chakraborty et al., 2010; Knifton, 2012). Narayanasamy (2015) suggests that psychiatric diagnoses are constructed within western cultures and others do not necessarily conceptualise mental health distress as an illness.

Cultural pressures, fear of stigma and stigmatising beliefs can impact members of the BAME community in relation to accessing support and treatment. For some, the expectation to maintain social status and moral standing is crucial (Mereush, 2012; Weerasinghe, 2012; Cooper et al., 2013; Rethink Mental Illness, 2020a). For many BAME individuals, particularly those with Sikh, Hindu, or Muslim heritage, religious leaders rather than mental health services are seen as the first point of contact and support (Rethink Mental Illness, 2020b). The medicalisation of distress is historically and culturally rooted within psychiatry and psychology-focused mental health systems with continued debates on the link between social control, psychiatry, and the medicalisation of emotional distress (Scheff, 1966; Foucault, 1967; Laing, 1967; Szasz, 1974).

Language can also be a barrier in seeking out support primarily when English is not the first language, although services provide interpreters, conveying feelings and emotions accurately can be difficult (Knifton, 2012). Studies conducted in the UK conclude that marriage concerns and familial reputations in their community feature heavily amongst mental illness in South Asian communities which prevent seeking support, and these are seen as creating widespread shame and blame not only for the person with a mental health condition but their immediate and extended family (Hatfield et al., 1996; Tabassum, Macaskill and Ahmad, 2000). Research literature has also identified that there is an excessive use of compulsory admissions and restrictive treatments for ethnic minorities which can be attributed to racial prejudice and fear amongst frontline professionals (Kapadia et al., 2022). A qualitative study conducted by Kang (2021), on the views of mental health inpatient staff in supporting and meeting cultural needs, found that staff would often mistake cultural beliefs for delusional symptoms of their illness and fail to enable people to maintain their religious beliefs for example fasting during the time of Ramadan. Despite some of the failings, non-BAME staff often sought guidance from BAME colleagues and educated themselves with resources that were available.

Culturally the BPD diagnosis is under recognised among ethnic minorities leading to a lack of engagement with services and support based on fear of social and personal stigmatisation (Hossain et al., 2018). It has been suggested that ethnic minority groups experience two-fold stigmatisation whereby racism in society and within mental health services adds to internalised and public stigma, both impacting upon help-seeking. The stigmatisation increases with a BPD diagnosis where people experience exclusion from services for repeated presentations, negative attitudes and have complex needs (Gary, 2005; Judd, Komiti and Jackson, 2008; Clement et al., 2014; Bhui, 2018; National Collaborating Centre for Mental Health, 2019a).

Social inclusion encourages the empowerment of people that facilitates autonomy, choice and decision making through supportive relationships both socially and professionally.

Internalised stigmatisation

Research identifies that individuals often internalise stigmatising thoughts making them feel that they are a less valued member of society (Corrigan, 1998; Holmes and River, 1998; Link et al., 2001; Link and Phelan, 2001; Ritsher, Otiligam and Grajales, 2003). Internalised stigma is a sequential three stage process and when applied to mental health produces the following sequence: awareness – the publics beliefs and attitude toward mental illness; acceptance of the belief system (agreement) and lastly to fully develop secondary label stigma and apply it to oneself (Corrigan, Watson and Barr, 2006; Corrigan, Larson and Rüsch, 2009). Secondary label stigma is a maladaptive process in which an individual accepts the prejudices applied to them or their mental health diagnosis and integrate this into their sense of self devaluing themselves, experiencing shame and withdrawing. Individuals may also hide the part of their identity as a person with a mental health condition to pass as a member of a non-stigmatised group (Barreto, Ellemers and Banal, 2006; Ragins, Singh and Cornwell, 2007). However, this can have negative psychological consequences, restricting one’s authenticity, and possibly reducing social interactions for fear of being discovered increasing feelings of social exclusion (Campbell, 1999; Barreto and Ellemers, 2003; Wood et al., 2008; BBC, 2011; Newheiser and Barreto, 2014; Easton, 2018).

The process of being labelled mentally unwell can influence individuals to conform to society's expectations of the label by unconsciously exaggerating behaviours associated with a condition (Wisdom et al., 2008). Secondary label stigmatisation which sees individuals maintaining secrecy about their mental health condition encourages self-initiated withdrawal and social exclusion (Winnick and Bodkin, 2008; Ray and Dollar, 2014; Klik, Williams and Reynolds, 2019). Internalised stigma and shame felt by individuals can contribute to compromising the early recognition of mental/physical health symptoms and actively avoid seeking support and treatment in times of need. This is in part attributed by the fact that professionals doubt the credibility of physical complaints and assume that they are specifically a symptom of a mental health condition (Corrigan, 2004; Ross and Goldner, 2009; Hogan, Reynolds and O'Brien, 2011; Rusch and Thornicroft, 2014; The Mental Elf, 2017).

Krajewski, Burazeri and Brand's (2013) cross-sectional study into secondary label stigma and perceived discrimination of those with a psychiatric diagnosis including personality disorder diagnoses, surveyed 796 members of mental health charities from (Croatia, Israel, Lithuania, Malta, Romania and Sweden). Participants had been under mental health treatment and identified as being a 'service user'. The study found 33% of participants experienced high levels of secondary label stigma and 67% of participants experienced high levels of social stigma, suggesting that secondary label stigma, devaluation, and conscious discrimination is common in the overall population of those with a psychiatric diagnosis. The level of secondary label stigma varied by participants' country of origin, for instance Croatian participants experienced more internalised stigma than those from Malta, Sweden, Israel or Romania indicating a difference in public attitudes and perceptions towards psychiatric illness. In summary, secondary label stigmatisation appears common for those with BPD due to the expectation of perceived social rejection.

Symptomology of BPD such as unstable interpersonal relationships, attempts to avoid abandonment and a negative state of self could explain secondary label stigma as well as expected rejection in social interactions (Latlova et al. 2013; Latlova, Prasko and Kamaradova, 2014; Winter, Koplin and Lis, 2015). Indeed, studies conducted by Rusch, Holzer and Herman (2006) and Grambal et al. (2016) investigated levels of secondary label stigma in patients with BPD and other diagnostic sub-groups (psychosis, affective or anxiety disorders) and concluded that individuals with BPD showed higher levels of secondary label stigma relating to self-efficacy, quality of life and self-esteem. Suicidality (including attempts), lower social support and a higher severity of psychiatric symptomology was shown to be strongly correlated in the association and impact of BPD and secondary label stigma (Perlick, Rosenbeck and Clarkin, 2001; Alonso et al., 2009; Livingston and Boyd, 2010; Drapalski, Luckstead and Perrin, 2013). High secondary label stigma results in lower functioning in social situations and evokes social maladaptation (isolation and exclusion) resulting in further discrimination and social stigma (Yanos et al., 2012).

The impact of stigma on social inclusion/exclusion

Social exclusion is described by Levitas et al. (2007) as the withholding or lack of resources, services, rights and goods that create an inability to participate in social, economic, cultural or political activities and relationships that are available to the majority of individuals in society, affecting quality of life and equity and social cohesion. Sayce (2001) proposed that social exclusion is connected to compounding problems of impairment, discrimination, diminished social role, lack of economic and social participation and disability. Factors that influence this are lack of status, unemployment, opportunity to establish a family, reduced or zero social networks, race, sexuality and other discriminators, repetitive rejection and the restriction of hope and expectation (Sayce, 2001).

Stigma may deny individuals opportunities and obtain the same chances as the rest of the population (Evans and Repper, 2000). Those diagnosed with BPD can and do experience social adversity, lack of support and a higher rate of mortality based entirely on the psychiatric label that has been given to them (Ismail, 2002). Stigma is known to compromise and compound mental health conditions and reduce the likelihood of achieving a level of recovery in living the life that people want (Rivera-Segarra et al., 2014; Cruwys and Gunaseelan, 2016). Mental health stigmatisation leads to exclusion and withdrawal from social functioning or seeking support or treatment from services and instils a sense of inferiority, a sense of shame and purposeful concealment of one’s state of mental function in particular a diagnosis of a personality disorder (Corrigan, 2004). Some mental health services have standard criteria for the access of services and exclude individuals who fall below the threshold set.

Societal knowledge of physical diseases is generally seen as beneficial to support and create understanding for individuals, but mental ill health is often disregarded (Mannarini and Rossi, 2019). Knowledge of mental health conditions has greatly improved and positively influenced the social perception of individuals. Despite this people with a psychiatric diagnosis often maintain secrecy about a condition or fear having to disclose their diagnosis due to the associated stigma (Angermeyer and Dietrich, 2006; Mannarini and Boffo, 2015; Mannarini and Rossi, 2019). Repper and Perkins (2001) suggest that for professionals to lead the way in facilitating inclusion, they should begin by analysing their own beliefs and attitudes towards those with mental ill-health, and only with the belief in rights and abilities of those they help and support can positive promotion and achievable social inclusion be achieved.

In attempting to confront the social exclusion of those with mental ill-health, and ensure fair access to treatment and support, the UK government have introduced policies such as *Personality Disorder: No longer a diagnosis of exclusion* (NIMH, 2003), *Breaking the cycle of rejection: The Personality Disorders Capabilities Framework* (NIMH, 2003b), Borderline Personality Guidelines (NICE, 2009a). However, these policies have not had the desired effect in addressing or reducing the issues that people with a diagnosis of BPD experience (Royal College of Psychiatrists, 2020). *Reaching Out* (Cabinet Office, 2006) acknowledged the barriers to inclusion, however the discursive language used in the document implies that excluded groups (such as those with mental ill-health) have failed their potential, failed to take opportunities, and do not benefit from accessing services because ‘their lives and engagement with services are too chaotic’ (Cabinet Office, 2006.p. 74.). According to Ward (2009) marginalising people by labelling as ‘the socially excluded’ maintains the stigmatisation of mental ill-health through constructing individuals as valued or devalued through discursive language; stigmatising labels imply inferiority of those labelled prompting self-exclusion from society. Despite such policies, personality disorder is an excluding label used to describe people who are predominantly classed as difficult, incurable, untreatable, unmanageable, frequent manipulators and self-harmers and are, in short, viewed as bad rather than ill (Wilstrand et al., 2007; Dickinson, Wright and Harrison, 2009; Winship, 2010; Karman et al., 2015; Latlova et al., 2015; Tyrer, Reed and Crawford, 2015).

Professional's perceptions and attitudes of Borderline Personality Disorder

People's relationships with professionals can be decisive elements in whether it helps or exacerbates a person's mental health distress (Ware, Tugenberg and Dickey, 2004; Denhov and Topor, 2012). Goffman's (1968) concept of stigma argues that mental health professionals possess superior insight regarding mental illness and subsequently will display empathy and sympathy as a result and are above the realms of exhibiting stigmatising behaviour or attitudes. Munro and Baker's (2007) research, suggests that Goffman's concept is flawed, and mental and physical health services are the sites of distressing and stigmatising experiences for individuals. The United Nations (2017) noted that 'Coercion in psychiatry perpetuates power imbalances in care relationships, causes mistrust, exacerbates stigma and discrimination, and has made many turn away from mainstream mental health services'. Professionals can and do stigmatise those with a psychiatric condition as regularly as the general population (Oliveira et al., 2020).

Despite the increased attention on underlying causes of mental health conditions and mental health stigma, individuals with a diagnosis of BPD continue to experience negative attitudes from professionals that have adverse effects on individuals and their support networks (Aviram, Brodsky and Stanley, 2006; Ahmendani, 2011; Bates and Stickley, 2013). Research on the negative attitudes and behaviours experienced by 'service users' indicates a worrying concern for those who access and participate with services, which appears to be apparent in all countries and cultures (Corbiere et al. 2012). Personal accounts by people with a mental health diagnosis and their families highlight how professional stigmatisation leaves them feeling stereotyped, patronised, shamed, incompetent making decisions, dehumanized and blamed for the way they are treated. One of the most reported complaints from individuals with a personality disorder relates to negative attitudes and intolerance from staff (Sukhera et al., 2017). Behavioural and reactive components of BPD symptomology evoke expectations in professionals which become a defining preconception of people with the BPD diagnosis with whom they have contact (Sheehan, Nieweglowski and Corrigan, 2014). Many professionals have developed the belief that individuals with the diagnosis of BPD will inevitably abusively target those that work closely with them and will continuously present with and display self-destructive behaviour and suicide attempts (Deans and Meocevic, 2006;

Munro and Baker, 2007; Westwood and Baker, 2010; Bates and Stickley, 2012; King, 2013; Gras et al., 2015; Sukhera et al., 2017).

The impact of negative interactions with professionals leads to individuals distancing themselves, rejecting treatment and not continuing with therapeutic programmes (Lewis and Appleby, 1988; Gallop, Lancee and Garfinkle, 1989; Aviram, Brodsky and Stanley, 2006). Stigmatisation of the BPD diagnosis has negative consequences that impact those on seeking support and treatment generally but also in times of crisis and the less social supportive networks are, the poorer the quality of life (Bonnington and Rose, 2014). Mental Health Today (2018) reported that BPD stigma, and in particular negative attitudes and avoidance of contact by professionals within A&E hospital departments, is the most common trigger for mental health crisis among people with the diagnosis (Latlova et al., 2015).

Accident and emergency departments are an important gateway for self-harm treatment and mental health patients struggling to manage. Nurses are generally the first medical professional that a patient meets when accessing assessment, triage, first aid and immediate psychological support. Nurses and healthcare professionals' attitudes and lack of empathy towards mental health and self-harm impacts care making decisions and delivery of care. In 2004, the National Institute for Health and Clinical Excellence released guidelines for the treatment of self-harm which included to offer analgesia throughout the treatment process. Commons Treloar and Lewis (2008) and Koning, McNaught and Tuffin (2017) when examining attitudes from mental health and A&E department staff towards patients with a BPD diagnosis who had self-harmed, highlighted that staff working in a mental health settings displayed more positive attitudes than A&E staff. Some of the negative views portrayed of patients with self-injuries included 'wasting the time and resources of the hospital' and an 'attempt to manipulate staff' and others around them (Koning, McNaught and Tuffin, 2017. p. 6). Previous research on the attitudes of the nursing profession towards patients with personality disorder traits, co-morbid diagnoses or enduring mental health problems and associated behaviours (e.g. demanding, uncooperative) found that such patients were deemed 'challenging' patients due to the refusal of mental health nursing staff's authority and therapeutic value (Stockwell, 1972; Armitage, 1980; Kelly and May, 1982; Breeze and Repper,1998).

The literature suggests that those branded in this way are inevitably denied the correct care and are avoided by other staff (Lewis and Appleby, 1988; Gallop, Lancee and Garfinkle, 1989; Colson, 1990; Wright and Morgan, 1990). These attitudes have been evident within general medical settings towards those who self-harm, resulting in hostility from nursing staff and perceptions that healthcare services and resources are being squandered and that such patients bring it on themselves, or are blocking hospital beds and not treated as a priority (Commons Treloar and Lewis, 2008; Conlon and O'Tuathail, 2012). Hostility towards those who have self-harmed has been recorded as resulting in more aggressive approaches and punitive behaviours including minimising or trivialising an individual's distress, shouting and humiliation, or being physically rough (Hopkins, 2002; McAllister et al., 2002; Thornicroft, 2006; Patterson, Whittington and Bogg, 2007; Wilstrand et al., 2007; Conlon and O'Tuathail, 2012; Karman et al., 2015; O'Connor and Glover, 2017). Markham's (2003) research on attitudes towards BPD and schizophrenia in relation to dangerousness and social rejection, employed a version of the Trute and Loewen (1978) social distance scale and the Link et al. (1987) scale to measure responses from healthcare assistants (HCA) and registered mental health nurses (RMN). Markham (2003) found that BPD patients were perceived as more dangerous by RMN's in in-patient settings.

Professionals are often cautious in the support they provide and can feel ill-equipped to deal with the emotional intensity that can manifest when supporting or engaging with individuals (Markham, 2003). This notion is reinforced by research showing that the chaotic nature and impulsive behaviours displayed at times of extreme distress, mean that professionals find it difficult to relate with these individuals and they view them as being misleading about the level of control they have over their own behaviour (Wahl, 1999; Ma, Shih and Hsiao, 2008; Woollaston and Hixenbaugh, 2008; Ross and Goldner, 2009; Westwood and Baker, 2010; Winship, 2010; Bodner, Cohen-Fridel and Lancu, 2011; Dickens, Lamont and Gray, 2016; Wang et al., 2018).

Healthcare is a key service that individuals with mental health problems will access, and one where there is a greater opportunity for them to be stereotyped and stigmatised. This can lead to exclusion and contravenes professional guidance on working with vulnerable populations (NIMH, 2003b; NICE, 2009; Ross and Goldner, 2009; Horsfall, Cleary and Hunt, 2010; Ungar, Knaak and Szeto, 2016). Bodner, Cohen-Fridel and Lancu (2011) identified that negative attitudes towards those with BPD come from professionals in less senior roles within healthcare settings confirming Eker and Oner's (1999) study that found that professionals in lower status positions held more negative attitudes compared to those with advanced professional training. However, younger healthcare students, females and those from ethnic minorities possess and display comparatively more positive attitudes towards ill mental health (Read and Harre, 2001).

Lyons, Hopley and Horrocks (2009) research explored the extent and nature of stigmatisation by healthcare professionals using postal questionnaires. Their data suggested that health and social care and mental health staff as well as generic service providers such as accident and emergency staff, social workers, hospital consultants and general practitioners overlooked physical problems due to an individual's mental health diagnosis. This research found a lack of respect and poor care including not listening to patients, physical abuse, being videoed without consent while unwell and ignoring the patient when accompanied by a carer and directing questions to the carer instead of the patient. Bonnington and Rose (2014) found that healthcare staff dismissed BPD as 'illegitimate' which resulted in a lack of understanding in the seriousness of people's distress. Raven (2009) suggested that many individuals with a BPD diagnosis feel blamed by services for having the condition when all they seek is acceptance. This highlights the level of stigmatisation and poor understanding of the BPD diagnosis amongst service providers and professionals.

Reducing the stigma within healthcare has become an important focus for advocacy, policy and practice. In response, contact-based approaches (direct interaction) have been recommended to situate a person with lived experience in the environment to educate as peers rather than as clients (Knaak, Modgill and Patten, 2014; Knaak et al., 2015; Ungar, knaak and Szeto, 2016). The available literature suggests that continuous education and supervision from a humanistic approach, with experience led inclusion and focusing on symptomology should be prioritised for frontline staff to reduce stigmatisation.

Mental health services

Professionals who work with and support people with mental ill health are in positions of power, trust, and influence. Mental health professionals have and portray stigmatising attitudes towards BPD more often than the general population (National Institute for Mental Health in England, 2003; Munro and Baker, 2007; Latlova et al., 2015). Mental health service professionals primarily believe that they are the 'experts' on mental health, with an authoritative power derived from the body of knowledge they are acquainted with (Hem, Molewijk and Pedersen, 2014). Many mental health professionals fail to account for the lived experience of an individual and the reality of the world they live in (Hem, Molewijk and Pedersen, 2014). Negative attitudes towards the BPD diagnosis held by mental health professionals working in a public health service were assessed in 2000 and 2015, Day et al. (2018) found that staff from the 2000 cohort voiced frustration at having to engage with individuals that they deemed disruptive, bad instead of mad and that they would actively avoid these individuals. The 2015 cohort used more treatment structures and routinely worked in multi-disciplinary teams which indicated a change towards using evidence-based treatments, BPD specific training, improving education and a removal of toxic working cultures.

Stigmatising attitudes by professionals have been well documented throughout literature and research, highlighting psychiatric staff's judgemental and stereotypical viewpoints which lead to unfavourable responses with less display of empathy towards patients with a BPD diagnosis (Ociskova et al., 2017). Indeed, despite Day et al.'s (2018) 2015 findings discussed above, the culture of stigmatisation towards personality disorders persists in psychiatry; trainee psychiatrists continue to have stigmatising beliefs and attitudes towards this diagnostic group (Lewis and Appleby, 1998; Chartonas et al., 2017; Dean et al., 2018).

Nurses working within a forensic psychiatric setting generally have negative perceptions of individuals diagnosed with a personality disorder with the emphasis more on the management and containment of symptomology rather than effective and continuous treatment and care (Mason et al., 2010). Mason et al. (2010) found that the diagnostic labels of mental illness and personality disorders determined how a patient would be 'managed' or whether they have a positive clinical outcome. Regardless of whether patients were placed on a low, medium or high secure units, nurses regarded these patients as challenging, compared to patients with other mental illness who were deemed more treatable and less of a management concern.

A personality disorder diagnosis can be used by psychiatrists to justify a decision not to admit a person in need onto a psychiatric ward or not to accept them for treatment. This practice leaves other frontline services, such as A&E departments and general practitioners, under severe pressure to effectively manage people in a state of crisis but not admitted to a psychiatric ward. As a result, stigmatisation can increase, including ‘iatrogenic stigma’ (Sartorius, 2002) which is defined as physician-created and caused primarily by an individual’s diagnosed illness or medical treatment such as psychiatric medication/ therapeutic support. It proposes that there are two interlinked constructs which are low expectations of prognosis and recovery as well as lowered expectations of character, attributes, and potential (Luigi et al., 2020).

Reynolds (2017) highlights the lack of understanding of the BPD diagnosis by professionals particularly GPs and lack of specialist service provision. They argue that very often GPs fail to identify personality disorder symptoms and have an even poorer understanding of BPD despite being on the frontline of healthcare services and repeatedly coming into contact with individuals with the diagnosis (Reynolds, 2017). One participant highlighted the negative, stigmatising attitude she received from her doctor who considered her frequent episodes of self-harming behaviour and suicidal ideation as manipulative and attention seeking rather than a period of mental ill health. Ali Strick who runs a grassroots mental health organisation, Arts Sisterhood, discussed how her GP stated that she ‘wasn’t ill, just a bad person…there is just a deep lack of care and understanding about BPD’ (Reynolds, 2017). This reinforces the notion that a personality disorder diagnosis is highly stigmatised and influences negative attitudes from professionals (Kendall, 2002).

Stigma and the criminalisation of mental health

Despite English policy generally providing investment and focus in dealing with individuals who pose the most risk of harm to the public, most people with BPD who happen to come into contact with the criminal justice system in fact do not pose risk to society (Centre for

Mental Health, 2015). However, stigmatisation can influence the interaction between the criminal justice system and mental illness whereby the criminalisation of mental illness can occur. This is frequently the case when the police, rather than mental health providers, are the first responders to an individual's mental health crisis where behaviour is deemed dangerous to themselves or society. Individuals with mental health conditions that encounter the criminal justice system have complex and multiple needs, with minimal services available or accessible to address these at point of first contact (Durcan, 2014b). Police officers have become the overflow outlet of mental health services to those in a state of severe crisis or at risk of harm (Campbell, 2020b). In 2015 it was estimated that 20-40% of incidents attended by the police dealt with mental health issues, and over the past five years at 41% has showed no change (The College of Policing, 2015; Campbell, 2020b). Twenty-three English police forces reported that the number of mental health related incidents police were called to attend to rose from 213, 513 in 2015 to 301, 144 in 2019 (Campbell, 2020b). The increase highlights that the mental health system is broken (Campbell, 2020b), and for some people, the police provide the only direct access to mental health services.

The Mental Health Act (2007), which covers England and Wales, gives the police powers to enforce removal of a person via Sections 135 and 136. Section 135 allows a magistrate to issue a warrant for the police to gain entry, by force if required, into a private dwelling to remove a person to a place of safety, for the purpose of an assessment if an approved mental health practitioner has reason or suspicion that a person is suffering from a mental disorder, is not capable of caring for themselves, is being neglected, mistreated or cannot be controlled. Section 136 allows the police to remove or keep a person at a place of safety without the issue of a warrant. A place of safety is considered a hospital, care home, police station or other suitable premises, and a person has no rights to appeal the decision of being taken or kept at a place of safety under section.

The Bradley Report (2009) identified reports of unlawful practice by police officers in the carrying out of Section 135 such as if they could not remove the person from a private dwelling, they persuaded the person who is at risk to go into a public space then applied Section 136. The forcible removal of a vulnerable person can evoke a sense of criminalising their mental health crisis and cause humiliation through having a visible police presence at their home and being removed in a police vehicle which adds to the stigmatisation of mental health, increases detention and incarceration (Corrigan, 2014; Durcan, 2014a). Lord Bradley's (2009) report, commissioned by the government, identified that the use of police custody effectively criminalised people for essentially having a health need, exacerbated their mental/state distress and in some cases led to death while in custody. The legislation in England permits those with a mental health condition awaiting a psychiatric assessment to be held in police cells for up to twenty-four hours (or extended to thirty-six in exceptional circumstances) without any requirement for review and despite not having committed a criminal offence (Department of Health, 2007; Her Majesty's Inspectorate of Constabulary, 2013). Liberty, one of the UK's leading civil liberties and human rights organisations, state that no other similar powers by police exist for individuals who do not have a mental health condition (Liberty, 2016).

The Centre for Mental Health (2014) published a report for the Department of Health and Home Office, from twenty-seven professionals, 'service users' and carers stakeholder events across England and Wales, on the use of Section 135 and Section 136. Professionals outnumbered 'service users' by 140-70. The report found that the use of police cells as a place of safety was becoming less normalised; however, for people under the age of 18, detention in cells was often the default option due to it taking longer in finding a place of safety and post-assessment beds compared to adults. Assessments were often carried out by an approved mental health professional (AMPHs) or doctors who held limited or no child and adolescent experience. The findings highlighted a notable difference in the treatment of white and ethnic minority 'service users' by police officers. Ethnic minority 'service users', who more commonly experienced the use of force at times of mental health distress, were more likely to be identified as dangerous, aggressive and a risk to others and were more likely to have a mental health assessment on entering the criminal justice system (Durcan et al., 2014). People from the BAME community tended to receive their first mental health assessment on entering the criminal justice system (Durcan et al., 2014).

Mental health professionals and those with mental health conditions have long voiced concern over the involvement of the police due to insufficient training in responding to situations of people experiencing a mental health crisis as it is not only stigmatising but can place individuals at further risk (Care Quality Commission, 2013; Lancaster, 2016; Cummins, 2017). Mclean and Marshall (2010) found police officers often felt they had inappropriate responsibilities forced upon them to deal with mental health incidents which often resulted in arresting individuals for their own safety, resulting in criminal records and the misuse of the mental health legislation. They also found that health services failed to provide adequate alternatives. Successive governments in England have created policies diverting individuals with mental health conditions away from the criminal justice system and into mental health services, however the Bradley Report (2009) showed that suitable diversion provision was disjointed and fragmented.

Police officer attitudes or procedures similar across many countries. For example, Martin and Thomas (2013) found police officers in Australia misunderstood and misused mental health legislation and believed individuals with BPD were exempt from receiving adequate alternatives and assessment under current legislation resulting in detention in police cells. Due to globally increased distress and fear of police involvement, incidents resulting in violence between individuals with mental ill-health and the police have been documented leading to mental health organisations such as Rethink, Mind and Amnesty International condemning methods used by the police to control situations particularly those that result in the use of tasers (Bather, Fitzpatrick and Rutherford, 2008; Corrigan, 2008; Mercer, 2012).

People with lived experience have questioned whether compulsory powers would be needed if people could easily access appropriate community services (Centre for Mental Health, 2019a). Her Majesty’s Prison Service has become a new unofficial psychiatric asylum providing a place of safety, care, and access to treatment (Centre for Mental Health, 2015). The prison population has a significant proportion of those incarcerated having mental illness, substance misuse and personality disorders (Centre of Mental Health, 2015). Most individuals with a personality disorder diagnosis in society are not nor have been offenders, but individuals with a personality disorder diagnosis account for 66% of the prison population, making it vital that the criminal justice system can respond to the needs of people with a personality disorder (Durcan, 2021). Poor mental health among the prison population is now normal, but still misunderstood and not catered for, which has added to the rates of self-harm (Centre for Mental Health, 2015).

Primary health care in prisons and in the community is failing those who are at most need of help and support and the result is the gradual normality of the criminalisation of mental health (Sampson, McCubbin and Tyrer, 2006; Centre for Mental Health, 2011; Moore and Tangney, 2017). Given the large number of people with a personality disorder diagnosis serving custodial sentences in England, the impact of stigmatising labels can be devastating resulting in many individuals repeatedly cycling through the criminal justice and social care system (Moore and Tangey, 2017).

Offenders with a diagnosis will continually experience societal exclusion and rejection from community services and criminal justice services with limited provision to address and support their complex needs (Durcan, Allan and Hamilton, 2017; Easton, 2018). In addition, social exclusion and withdrawal can drastically impact upon their mental health but also increase criminal and anti-social behaviour as a coping method (Skeem, Manchak and Peterson, 2011; Ray and Dollar, 2014; Centre for Mental Health, 2015; Durcan, 2016; Durcan, Allan and Hamilton, 2017; Cockburn, 2017; Easton, 2018).

Women receive more custodial sentences despite committing the least serious offences whereas men face custodial sentencing aimed at rehabilitative measures highlighting the power of society in upholding gender ideology of femininity and family (Parry-Crook, Oliver and Newton, 2000; Sheehan, McIvor and Trotter, 2007; Fossey and Black, 2010; Karston, De Vogel and Lancel, 2015; Women in Prison, 2015; Prison Reform Trust, 2017; Prison and Probation Ombudsman, 2017; Women in Prison, 2017Brown, 2021; The Times, 2021). In the prison setting around 20% of women will meet the criteria for BPD, supporting previous assertions that BPD is a gendered diagnosis (Wheatcroft, 2021).

The Corston Report (2007) highlighted that women were more susceptible to higher rates of mental illness, self-harm and suicide and those with a BPD diagnosis in prison are more vulnerable. The hostile punitive environment can be extremely traumatic leading to the use or exacerbation of self-harm and suicide ideation to manage the emotional distress caused by the experience of incarceration. Self-harm differs considerably between genders, rates of male self-harm approximate 570 incidents per 1, 000 whereas female rates, 675 incidents per 1,000 in prison establishments (Birmingham, 2003; Edgar and Rickford, 2003; Fossey and

Black, 2010; National Offender Management Service, 2015; Ministry of Justice, 2018). Many women prisoners have experienced childhood trauma whether physical, sexual, psychological or raised in domestically abusive households (Women in Prison, 2017). The regimented environment of prison can trigger re-experiencing features of abuse such as traumatic sexualisation, stigmatisation, powerlessness, and betrayal (Fossey and Black, 2010; Karsten, De Vogel and Lancel, 2015).

Showing vulnerability within a prison environment can be seen as a weakness which allows an individual to become an easy target for bullying and victimisation from other inmates but also prison staff (The Howard League for Penal Reform, 2016). Those that ask for help can be met with a lack of empathy and derogatory comments for example suggesting they toughen up and get on with it (The Howard League for Penal Reform, 2016). Prisoners that have experienced periods of distress and /or self-harm are regularly ignored, dismissed, or get no response from staff (Castillo, 2003; The Howard League for Penal Reform, 2016; Prison Reform Trust, 2017; Prison and Probation Ombudsman, 2017). Alternatives to a custodial sentence, such as Women’s Centres, community support organisations, increased mental health services and experience led support groups are the most productive options to keep people in the safety of their environments, family and friends and not ostracise them from society due to periods of mental distress, trauma and behaviour that does not fit the ‘normal’ representation of others (Rope, 2018; Forrester et al., 2020).

Upon release from custody, recognition and support for those with mental health by probation services shows a huge variance in the ability to identify mental health needs and those serving community orders (Centre for Mental Health, 2012). The identification and screening of mental health conditions among people is not adequately or effectively shared on the criminal justice route to put in place appropriate interventions (Criminal Justice Inspectorate, 2021). Considering this, the death rate of those serving court orders in the community increased by 40% from 2016/17 to 2017/18. (Ministry of Justice, 2018; Centre for Mental Health, 2019b). Misinterpretations of behaviour and negative perceptions based on the presence of a personality disorder diagnosis suggests a plausible theory as to why so many people end up in the criminal justice system and why stigmatisation and discrimination is so entrenched with a BPD diagnosis.

In summary, people diagnosed with personality disorders or serious mental health conditions continue to be defined as the 'difficult', 'problem' or 'unpopular' groups among frontline professionals. In response to the impact that a mental health diagnosis can have and the subsequent way a person can be treated, there has been a steady flow of mental health activist groups challenging the system, beliefs, practice, and treatment. The second half of this literature review will discuss the birth of the activist movement and how it continues to advance the future inclusion of 'experience led' insights within frontline services to educate and challenge stigmatisation, and the power and use of discourses in mental health.

The Service user/survivor movements

Mental health activism is a historically continuous endeavour to counter medical narratives of 'madness' and challenge discrimination and exclusion in society. The activist movement has repeatedly highlighted and fought to change the coercive practices of mainstream psychiatry and the reductionist models of mental health (Chamberlin, 1978; Morrison, 2005; Coleman, 2008). The first known evidence of group activism and advocacy in the United Kingdom was in 1845 through an organisation known as the Alleged Lunatics Friend Society, where members had been imprisoned in madhouses and subjected to degrading treatment (Hervey, 1986). For two decades this organisation campaigned for patients' rights; the rights to be involved in decisions relating to their care and imprisonment. The mental health advocacy movement of the early twentieth century promoted the American concept of mental hygiene which involved the art of preserving the mind against all incidents and influences calculated to deteriorate its qualities, impair its energies, or derange its movements (Hervey, 1986). In other words, the restriction or promotion of exercise, food, clothing and climate, laws of breeding, regulation of passions, emotions and opinions and the discipline of the intellect were all monitored to promote a healthy mind (Rossi, 1962). The mental hygienists who enforced this believed it to be a healthy lifestyle and, as an example, identified extra marital intimacy as a deviation and source of mental illness.

According to Crossley (2006) this conservative backbone to their discourse was viewed as progressive for its time; firstly, it deemed that mental ill health came from varying factors, including biological and social, and that improvements in the person's natural setting would diminish negative symptomology. Second, they believed that mental illness shared similarities with physical ill health and could be treated as just the same, which fought stigmatisation experienced in that period. Third, the promotion of prevention of mental illness with particular emphasis on childhood development and finally, the early detection and treatment of mental illness. In the UK, three groups advanced support of mental hygiene in campaigning for public education and patient well-being. These three groups joined in 1946 to become the National Association for Mental Health, which today is known as MIND (Rashed, 2019). People with mental health diagnoses fight for change and access to information and resources, options to choose from that meet the individual's specific need and decision-making power. Changes involve replacing the discourses of the medical model and professional narratives that are used to identify those with a psychiatric label (Chamberlin, 1997). Mental health activism and the emergence of 'user' movements empower others to speak out to challenge stigma, discrimination and inequality where encountered and is, according to Wahl (1999), enabling people to manage the effects of stigma.

The contemporary activist movement is generally noted to have started in the 1970s in the wake of numerous movements fighting for civil rights such as black power, women's liberation, gay pride, and disability at that time (Rashed, 2019). Interest in involving people in their own care and treatment gained strength from the political and philosophical critiques of traditional psychiatry emerging at the end of the 1960s in Europe, Canada, and the USA (Chamberlain, 1990; Geller et al.,1998). The birth of mental health activism was in response to psychiatry and psychiatric institutions particularly their use of forcible treatment such as detaining people without trial under therapeutic laws, Electro Convulsive Therapy (ECT) and tranquilisers (Pilgrim and Waldron, 1998).

Anti-psychiatrists, most notably Thomas Szasz, Ronald Laing, and David Cooper, voiced criticisms of mental health practices. Szasz (1960) argued that mental illness was a myth which gave legitimacy for state oppression of those deemed socially deviant under labelling them as a danger to themselves and others. Szasz, identified mental illness as a problem with living in the world, lacking purpose and meaning and social interactions. Laing (1965, 1967) believed that the application of a diagnostic mental health label to someone whose behaviour may seem unintelligible, gave others permission to wrongfully exercise power over them. Laing explored the medical concept of the schizophrenia label as he believed that people were not experiencing a 'breakdown' but rather a 'breakthrough' in culminating a 'new ego' and 'existential rebirth' and that these people required encouragement and guidance and not a psychiatric label. Cooper (1967, 1978) considered schizophrenia and, indeed, all mental illness, to be a crafted ploy to alienate the familial and social structures in the hope of obtaining a less alienating, autonomous, and recognised existence. He believed that the medical establishment was working as an agent of the state to suppress and oppress people. Anti-psychiatry ideas were radical, if not revolutionary, and were at times adopted by mental health activists to criticise the medical establishment and inspire them to join in the civil rights struggles of the 1970s (Rashed, 2019).

The 1970s saw the establishment of civil rights activism in mental health. Notable groups in the United States, included the Insane Liberation Front (1970), Mental Patients Liberation Front (1971), Network Against Psychiatric Assault (1972), and in the UK, the Mental Patients Union (1972). These were distinct from the earlier activist groups in that they excluded sympathetic mental health professionals and members were purely patients or ex-patients. According to Chamberlin (1990), one of the main figures in the American movement, this was because a group that allows professionals and non-patients eventually leaves its liberatory intentions and finds itself in a more vulnerable state of attempting to reform psychiatry which was not a part of their agenda. Those who self-organised in this way found that their perceptions of mental illness were vastly opposed to those of mental health professionals and excluding the latter avoided any form of dictatorship (Chamberlin, 1990). The agenda instead was to end psychiatry as they knew it, to cease forcible treatment and involuntary hospital detainment. Also on the agenda, was the aim to make a person's freedom of choice and consent a priority, and to reject the medical model and reinstate full rights and autonomy to mental patients, including the right to choose or refuse treatment, live life away from institutional settings and to challenge the media's negative perceptions of people with mental health conditions. These groups believed in a non-hierarchical and non-coercive replacement to the standard care and treatment and advocated for alternatives such as drop-in centres, self-help groups and retreats.

These initiatives showed how ex-institutionalised patients were aware of their situations and thus was referred to as consciousness-raising (Chamberlin, 1990). Adopted from the radical feminist wing of the Women's Liberation Movement, Consciousness-raising was a means of creating revolution by giving women the space to understand their oppression, redefine themselves and create new feminist identities by exploring their feelings, needs and desires outside of patriarchal definitions, often for the first time (Kravetz, 1978; Rosenthal, 1984; Bruley, 2013). Consciousness-raising occurs when people come together and share experiences and commonalities which helps them to reinterpret their identity by giving it a broader meaning and significance (Chamberlin, 1990). The mental patient's civil rights groups advocated for people to abolish the assumptions made by the mental health system, that they had an illness, and the medical establishment could cure them. By sharing their experiences, they came to believe that the mental health system had not helped them but rather, as Szasz wrote, they saw it as a form of social control by medicalising socially unwanted behaviour as an excuse to force people into more 'sane' and acceptable forms of behaviour. Chamberlin (1988, pp.70-71) argued that consciousness raising

> helps people to see that their so-called symptoms are indications of real problems. The anger, which has been destructively turned inward, is freed by this recognition. Instead of believing that they have a defect in their psychic makeup, they learn to recognise the oppressive conditions in their daily lives' (Chamberlin, 1988. pp. 70-71).

Chamberlin (1988) determined that people respond individually to the real problems faced in life, such as trauma, loss and inequality and these responses require empathy, care, and support rather than what she believed society had to offer through psychiatric drugs and mental institutions.

The service user movement took hold in the 1980s and has since gained impetus as a collective international force advocating for a person-centred humanistic approach to mental health lobbying national governments and global organisations (Wallcraft et al., 2003; Campbell, 2009; Bacha et al., 2020). In the early 1980s, UK user/survivor groups were building relationships with the media to promote their cause with the first television programme made by service/users/survivors broadcast on Channel 4 during the mental health season 1983 and called ‘We’re Not Mad, We’re Angry’. It critiqued the psychiatric system with personal experiences of treatment being shared with viewers.

In 1985, activists from the United Kingdom met with other activists across the world at the Mind/World Federation of Mental Health Congress in Brighton which outlined the possibilities for collective campaigning in the UK. Previous to this, voluntary organisations spoke on behalf of the mentally ill with a lack of coherency or sense of their wishes (Campbell, 2005). The few service user groups that did exist lacked funding and were underappreciated, accused of being radical and extremist in their ideas with nothing positive to offer (Campbell, 2005). Later that year the Annual Mind Conference took place in London as the first national event in which service ‘users contributed significantly to the conference programme’ (Campbell, 2005, p.73). 1986 the first national network for service ‘users’ involved in action was established known as Survivors Speak Out. Having organised the first national conference of ‘service user’ activists, other groups had started to form in England and join the collective fight which included Mindlink, the Nottingham Patients’ Council Support Group and National Voices, a service ‘user’ group within the National Schizophrenia Fellowship, now known as Rethink (Wallcraft et al., 2003).

This period started a shift towards a consumerist approach to the provision of healthcare and the viewpoint of patients in the UK as ‘users’ of services. This shift formed four significant ‘user’ networks that campaigned for change and challenged discrimination, and provided support and shared information: UK Advocacy Network (UKAN), a national network for service user led advocacy projects and local user forums developing national advocacy policy, information and support; Survivors Speak Out (SSO), initially formed for mental health service users and allies in the UK; National Voices Network, set up within Rethink to support those with a diagnosis of schizophrenia, de-stigmatise the condition particularly the myth of violence associated with it and The Hearing Voices network formed in 1988 offering a positive framework of development to manage with hearing voices and raise awareness.

However, for some the ‘user’ discourse was not favourable and a survivor discourse appeared accepting membership from non-patients and professionals to build genuine and honest partnership and inclusion in all aspects of service structure, delivery and evaluation (Campbell, 1992; Chamberlin, 1992). Through the 1990s and 2000s two trends continued: service user discourse and survivor discourse with a more radical tone and concern for human rights (Morrison, 2005). Ten years on from the birth of the service user movement in the 1980s, Sassoon and Lindlow (1995) highlighted that the voices of people from the BAME community were not being heard due to barriers that prevented them from speaking out. They proposed that high levels of oppression, high doses of medication, lack of transparent communication with service providers and fears of being sectioned influenced people to not share their opinions and experiences. In addition, the stigma of having an association with the mental health system could potentially be overwhelming to those already marginalised and in a vulnerable societal position.

In the United Kingdom today, the service user/survivor movement is nationally represented by the National Survivor/User Network (NSUN) which unites survivor and user groups/individuals across the country to strengthen their voice and aid with policy changes. Within the movements in the UK there exist a variety of stances on improving standards for those with mental health conditions in comparison to the ideals and goals of the early civil rights movement groups. Participants' voices (Wallcraft et al., 2003) raise differences on issues such as the justification of compulsory treatments and whether the movement is compromised by financial gain from pharmaceutical companies.

Debates surrounded the legitimacy of, or rejection of, the medical model in relation to mental distress and whether, activists who embrace the medical model have been unable to unshackle themselves from disempowering frameworks forced upon them by the mental health system. Additionally, some felt the movement had minimalised issues by forming alliances with the mental health system rather than focusing on civil rights (Wallcraft et al., 2003; Rashed, 2019). This is the fundamental contrast between mental health activism and endeavours to improve services and treatments. The goal of activism is to change the dominant view of mental health as a disorder of the mind preventing a positive identity and reform the elements of psychiatry that do not work (Rashed, 2019).

Discourses in mental health

Dominant discourses in mental health influence the way in which professionals interact with people with mental ill-health (Hamilton and Manias, 2007). Foucault (1985) suggested that discourses uphold and produce moral codes that construct right from wrong and truth from lie. They are important to discuss in this study as the language used about mental health holds power generating marginalisation of certain diagnostic groups. Discourses emerge out of and are embedded in relations of power within institutions like medicine. Institutions shape the production of discourses and knowledge, and this knowledge is legitimised whilst undermining people to maintain control over them (Cole, 2020). Once a discourse is embedded in society and institutions such discourses are continually reproduced as ideology (Cole, 2020).

Narratives work to create hierarchies and are a productive force that shape thoughts, ideas, beliefs, identities and interactions of people (Ringer and Holen, 2015). As such they fuel the continued stigmatisation of people with the BPD diagnosis. The discourses around people with the BPD diagnosis (that they are manipulative, dangerous, hard to work with etc) constructs a belief system about this diagnosis which labels every person with the diagnosis rather than seeing them as an individual. Cardano's (2010) study on narratives of mental health, interviewed members of the Hearing Voices Network and identified that their experiences were generally characterised by stigmatisation of mental health. Foucault (2005) demonstrated how mental ill-health and distress is conceptualised, given meaning and negotiated between people in specific ways. Narratives influence how a person can make sense of the difficulties they experience and understand themselves (Moses, 2009; Tucker, 2009). Individuals who access and participate with services use a range of strategies to manage and understand their mental health and distress. How this distress is interpreted is vital to what becomes available to them in relation to care and understanding they receive from services (Ringer and Holen, 2016).

Survivor Discourse

People's own definition of their mental ill-health and distress and experiences of services can allow them to draw from a range of discourses. For some people identifying as a survivor encapsulates their activist stand against the limitations placed upon them by the institution of medicine and to draw from anti-psychiatric discourse (Speed, 2006). The survivor discourse is the most associated with the anti-psychiatry movement of the 1960s and 1970s. The survivor identity is the creation of a collective identity that highlights survival from the harshness of the mental health system that results in future resistance to the medical aetiology and treatment of mental health. To survive is to emerge from various challenges and difficulties from internal or external sources relating to the condition that led them to be immersed in the system. The label of survivor tells a story of experience which for many has been forced confinement in the mental health system, coercive and unhelpful treatments, discrimination, and stigmatisation. Survivor indicates the distress and suffering experienced due to what others label as ‘mental illness’. Survivors discarded what they felt was an imposed identity as a ‘patient’ and redefined their own identity to portray strength and determination of their experience within the system. Pilgrim and Rogers (1999) suggest that ‘survivor’ characterises people who are hesitant to re/enter patient-hood. Instead, they state all people, wish to establish ‘credibility as ordinary people with rights of citizenship’ (Pilgrim and Rogers, 1999, p. 201). Campbell (1992) wrote that fundamentally the survivor identity is the voice of survivors, a voice which he believes is not respected by society or the psychiatric system. The activist movement favours the voice of survivors as a source of authority as Crossley (2004, p. 1477) states, ‘Listen to the voice of the user!’ ‘Let survivors and consumers speak out!’.

Survivors have adapted their experiences of mental distress and mistreatment into a form of cultural and symbolic capital (Rashed, 2019) in which the devalued status of the patient is reversed and endows people with the authority to speak authentically. The experience of both distress and treatment, stigmatised elsewhere, has become recognised as a valuable, perhaps superior knowledge base. Survivors have laid a claim, recognised at least within the movement itself, to know ‘madness’ and its ‘treatment’ with authority, on the basis that they have been there and have survived it (Bassman, 2001). They are experts of their own experiences and what it is like to be subjected to treatment in the mental health system and to experience stigma and discrimination in society.

However, Rashed (2019) proposes that the survivor discourse has not fully reversed the negative beliefs attached to the occurrence of madness which is reflected in the language used surrounding mental illness, disorder, and pathology. Crossley and Crossley (2001) argue survivor status can only be attained through active membership of mental health organisations and personal experiences of being part of an oppressed and exploited population. Critics of the survivor discourse suggest it has been used by the psychiatric establishment to construct victim-hood and woman blaming theories for abuse and imply victim personalities are dependent upon expert help and advice (Alcoff and Gray, 1993). The term implies resolution of traumatic experiences or a series of events, but the effects can be lifelong. It obscures the pain and distress whilst denoting triumph. While the survivor discourse has empowering effects for some, it has facilitated the re-emergence of dominant discourses of the medical model of mental health (Alcoff and Gray, 1993).

Service 'users'/'survivors' are now slowly being recognised as rightful and valuable partners in the developing and running of services (Together/NSUN, 2014). Service 'users/survivors' have established a foothold in many areas of health and social care services, which in the 1970s, when the civil rights movement was in full swing, would have been unimaginable. Demand for experience-led involvement from government and frontline services has been vitally important. Part of this has been due to the number of people that have spoken out shattering the silence and creating awareness, discussion, and greater social inclusion. People with mental health conditions were once visibly and verbally absent but are now influencing others to be recognised and counted (Campbell, 2005). Inclusion by physical and mental health services enables promoting the understanding of mental health diagnoses and distress, challenging stigma and discrimination, educating frontline professionals to leading mental health research (Thornicroft and Tansella, 2005; Tait and Lester, 2005).

Mad Pride discourse and mad pride

The Mad Pride movement initially developed across Europe, Canada and the United States from the psychiatric/consumer/survivor/ex-patient movement influencing mental health services and human rights awareness. Mad Pride started in the UK in 1997, when members of Survivors Speak Out, including the four founders (who each had first- hand experience of the mental health system) Mark Roberts, Simon Barnett, Robert Dellar and Pete Shaugnessy, split off to form direct action groups from not having their intentions to make positive changes taken seriously. It was an emergent wave of new activism and activists that thought engagement with mental health services and survivors/user's experiences and views were fed into governmental systems to be used and abused whilst leaving them powerless (Curtis et al., 2007). The movement attracted members who criticised the medical model framework and coercive mainstream psychiatric care and to change the beliefs and perceptions of mental illness (Schrader, Jones and Shattell, 2013; Rowland, 2015).

Mad Pride celebrates mad identity, and seeks to develop and empower mad communities, challenge discrimination and advocates for rights whilst reclaiming previous derogatory terms to identify themselves as nuts, crazy or psycho (Laverack, 2013).

> What is mad culture? Mad culture is a celebration of the creativity of mad people, and pride in our unique way of looking at life, our internal world externalised and shared with others without shame, as a valid way of life. We are already an alienated sector of society, in fact the most alienated sector of society…we need to create our own culture in which we feel comfortable.' (Sen, 2011, p. 5 in Rashed, 2019, p.19).

Mad Pride reverses traditional narratives of madness as illness and instead views it as a foundation for identity and culture. In coming together, people embrace their 'madness' to create solidarity and group identity through shared experiences of stigma, discrimination and the psychiatric establishment. The use of the term 'mad', when directed against someone, was once considered bigotry, but it has since come to represent an alternative to mental disorder. This follows the path of other movements seeking equality and civil rights in reclaiming identity and dignity relating to differentiation in individuals.

Mad Pride rejects the language of mental illness and disorder and the medical construction of it as a condition that requires treatment. It reclaims the language of madness to challenge the medical monopoly on labelling and reclaims the term 'mad' from negative connotations associated with madness/mental illness, instead promoting a more positive viewpoint (Schrader and Jones, 2013; Rashed, 2020). Mad Pride discourse refers to a range of experiences, moods, thoughts, and behaviours that do not conform to dominant medical and psychiatric constructs of what is normal, disordered, or ill. Rather than adopt the dominant construct, the Mad Pride discourse challenges the psychiatric 'experts' and posits that those who experience 'madness' are the experts (Liegghio, 2013; Menzies, LeFrancois and Reaume, 2013).

The Mad Pride discourse recognises, and is inclusive of, distress and disability associated with mental health conditions. Rashed (2019) proposes that there are three strategies to manage this: firstly, accepting the relationship between madness, and behavioural and emotional demonstrations of distress can be commonly attributed to social and interpersonal hardships including abuse, trauma, poverty, social inequality, and oppression, rather than the traditional viewpoint of human pathology or failings.

The second strategy proposes, in relation to disability, that mental illness is just a variant interpretation of the human experience and the ability to function in a world that is not setup to be inclusive of these variations. Lastly, acceptance that certain aspects of madness are distressing, for example hearing voices and dissociation, but these are the 'price' for acquiring the special gifts of madness. Jost (2009) describes the opinions of Will Hall, diagnosed with schizophrenia and founder of the Icarus Project, and his involvement with the medical establishment which led him to reject traditional concepts of mental illness. Hall fights to end the stigma of mental illness, but also that mental illness should not be framed as a disease or disorder to be suppressed or eliminated, but instead as a 'mad gift' to be accepted. Many, however, do not experience mental ill-health as a 'gift' but as demoralising and inherently negative which is further compounded by stigmatisation from others. Despite how much society becomes less stigmatising, mental illness will always have a detrimental effect upon the person (Jost, 2009).

Rowland (2015) writes that the Mad Pride movement has two very distinct extremes of activist goals. The first is the growing focus on self-help and patient centred care within the mental health arena in the hope of reducing stigmatisation. The other end of the spectrum is said to be more radical in its approach and is focused on winning human rights and alternatives for those labelled with psychiatric disabilities, and to challenge the international dominance of bio psychiatry (Rashed, 2019). Those that seek to achieve this target their political activism towards the biomedical structures and ideas and believe that the increased medicalisation in the treatment and study of mental illness has given power and sole authority to the psychiatric establishment in determining who is sane or insane. This creates and enforces a line of acceptable societal 'normality' which Thompson (1997, p.8) describes as ‘opposing twin figures that legitimate a system of social, economic and political empowerment justified by physiological differences’.

The efforts of the movement as political activists continue to question what they perceive as stereotypical representations within medicine and science. Identifying as ‘mad’ is not about an individual’s ‘intrinsic craziness’ according to Appiah (2010) but how a person positions themselves with respect to the social narratives of mental difference and diversity. Thus, to identify as ‘mad’ is to place oneself firmly within the complexities of social, biological, and environmental structures that struggle in the understanding of psychological pain and distress. But madness is not just an identity but a political stand of a marginalised and subordinated group seeking to reclaim and redefine madness. Mad Pride’s demands go further than civil rights equality and instead requires recognition of their differences and distinction of their identity to transform a society so it will restore respect and worth to people’s lives and identities (Rashed, 2019). This demand for change in the social construct of norms, beliefs and values lies on an equal footing for the demand of recognition voiced by other civil rights groups around sexuality, gender, and race. For others, Mad Pride allows them to be redefined as just mentally ill but instead in a way which celebrates their ‘unusual’ attributes. As an example of the redefinition of madness, the words of Debie (2013), taken from the opening speech of a Mad Pride event, demonstrate the position of mad activism,

> Mad Pride moves away from medicalising experiences under psychiatry to promote other sorts of framings. These mad positive approaches do not pathologize me. Instead of being seen as someone who is ‘sick’, I am seen as someone who diverges from our traditional narrow, exclusive, and discriminatory idea of ‘normal’. I need the world to be different so that I can thrive as the person that I am…Mad Pride sees mad people as a people and equity-seeking group similar to other marginalised populations. We are not just ‘individuals’ with an ‘illness’ (Debie, 2013, p. 7).

To influence professional and cultural change, the inclusion of lived experience or experts by experience in services and diminishing the use of service user-led labels by professionals has become even more important to change the old guard of mentality towards mental health.

Experience-led challenge to stigmatisation

Individuals who require support from mental health services and professionals in times of need can often find the experience stigmatising, exasperating, challenging and adding to their distress in an already distressing period (Fallon, 2003; Trevillion et al., 2022).

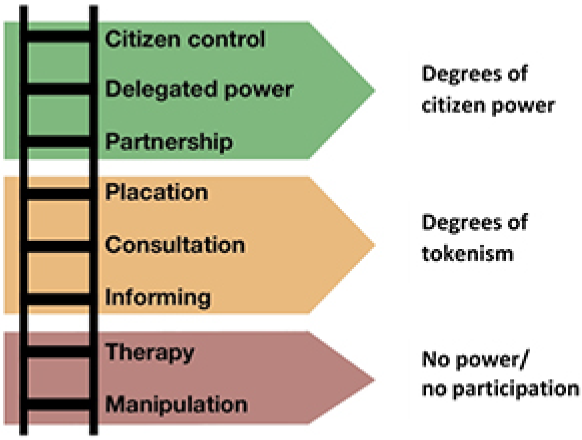
Farber (1993, p. 23) writes about the controlling nature of the system:

> In the mental health system anything less than total compliance is viewed as a threat. Any criticism of the mental health system is viewed as a sign of 'serious psychopathology'…In order to have any chance of escaping from the system, one has to confirm the definition given to one by one's captors: one must acknowledge that one is a mentally defective individual in need of psychiatric help and guidance.

As discussed, there has been, and is currently, an increased recognition that people with mental health conditions can and should actively contribute to the evaluation and planning of support services (Millar, Chambers and Giles, 2015; The Mental Elf, 2015). It is often the belief that people with mental health conditions are less advantaged and that inclusion is a vehicle for empowerment (Ochocka, Janzen and Nelson, 2002). Experience led inclusion is not a new concept and has been steadily increasing, albeit slowly, within frontline services in the UK. Experience led inclusion is conceptualised as an equal sharing of power and decision-making between the person and the service provider, with each bringing different and valuable assets and a recognition that both parties bring different knowledge and resources to the process (Cahn and Gray, 2005; Mayer and McKenzie, 2017). Individuals with lived experience of the mental health system and services have experienced it in ways professionals have not which means that their inclusion is inherently valuable. Health and social care providers can develop a better understanding through co-production in how these services impact upon people and realise the knowledge and credibility that experience led inclusion brings.

Opportunities through inclusion give people the means to share experiences with others and helps to identify similarities and practices which develop strategies of managing and maintaining good mental health. Inclusion ensures that mental health services, organisations and policies are shaped and led by those best placed to know what does and does not work for people who use mental health services. Meaningful involvement by those that use or have used services is becoming recognised as an indispensable element of mental health service delivery (Together/NSUN, 2014). When individuals are supported and equipped to deliver, check, and commission the services they and their peers use, those services show a vast improvement (The National Survivor User Network and Together for Mental Wellbeing, 2014). However, mental health advocates argue that the mental health system disempowers inclusive practices that stop people with mental health conditions from pursuing and reaching life goals (Corrigan et al., 2005). There is a real difficulty changing mental health services due to the structural and social inequalities that exist for those who have mental health conditions and access frontline services in England (Corrigan et al., 2005). Collective action is used to bring together members of a stigmatised group to challenge the existing status quo that impacts upon the equality and quality of life. However, as Hansen and Sassenberg (2011) suggest, strategies to implement social change can only emerge when people perceive the low status of their membership of a group as illegitimate. Williams and Lindley (1996) suggest that it is neither right nor just to expect those that have the least power within our society to make changes.

The voices of people with mental health conditions and those who campaign or speak for them still have limited influence and impact on policy (Hannigan and Cutcliffe, 2002). Although Chamberlin (1987) suggests that 'service users' don't necessarily have to work with service providers to influence change and challenge the hierarchy of power. If inclusion of 'service users' is to be utilised, and they are provided the opportunity to influence change, then it must be full inclusion to re-balance the inequalities between mental health users and providers. However, despite the growing presence of experience led inclusion, Hannigan and Cutcliffe (2002) suggest that service providers' inclusion of experience led input is tokenistic, while Scholz, Bocking and Happell (2018) state professionals only engage with people that are subservient to the status quo. Arnstein's (1969) 'Ladder of Citizen Participation', illustrates how varying levels of experience led service inclusion can be interpreted.



Arnstein, Sherry R. "A Ladder of Citizen Participation," JAIP, Vol.35, No. 4, July 1969, pp. 216-224

Figure 1 Arnstein (1969) Ladder of Participation

Inclusion implies equal participation in shaping mental health services. However, the limited inclusion of 'experts by experience' in services allows professionals to maintain control of the participation process and outcome (Milewa, Dowswell and Harrison, 2002; Broer, Nieboer and Bal, 2014). Within mental health care, negative power, restricting others' freedom, domination, control, and coercion is based on a hierarchical system with professionals at the top (Broer, Nieboer and Bal, 2014). Professionals are granted considerable power by virtue of their education and training which is concealed within professional organisations and their relationships with those accessing their services. Invisible power relations pose increased challenges to overcoming power imbalances. The power imbalance is produced at an individual level through their individual perceptions of their own power and that of others (Constantino and Nelso, 1995; Mason and Boutilier, 1996; Prilleltensky and Gonick, 1996).

Professional power and the medical model of mental health is explained by Lukes (1974) theory of the three dimensions of power and extends Dahl (1957) and Bachrah and Baratz's (1962) first and second dimensions of power. Describing how power is exercised and hidden, Dahl (1957) proposed the first dimension is power contained in and exercised by the governance systems of the ruling elite in society where the use of power is direct and is more likely to be trusted and obeyed. The second dimension (Bachrach and Baratz, 1962) covert power is not exerted by decision making but through setting agendas and the restriction of options. It is a more subtle form of power used within complex system. Lukes (1974) third dimension of power described power as manipulation of others' thoughts, so that what people think of being as correct leads to the acceptance of biased decisions without questioning whether it is right or wrong. Power can, therefore, be explained not as a possession, but rather as an exercise over control of others which does not promote positive productive action (Femdal and Knutsen, 2017).

Lived experience inclusion shifts attention away from the dominant paternalistic and institutionalised medical approach to mental health care (diagnosis, drug treatments and coercive interventions) towards a focus on empowerment, active participation, hope, self-determination, improving community services, promoting social inclusion and human rights (Price and Mullarkey, 1996; Gillespie, 2000; Nelson, Lord and Ochocka, 2001a; Nelson, Lord and Ochocka, 2001b; Beresford, 2003; Mancini, 2011; Slade et al., 2014). In addition, the World Health Organisation (2013) states that traditional psychiatric focal point on diagnosis should be replaced with person-centred care and inclusive participation. Juhila et al., (2014) suggest that we are in a transitionary phase moving away from professional control towards active experience led roles with associated rights and responsibilities, with professionals transforming their traditional role in new collaborative ones.

The World Health Organisation (1990) was the first to document the importance of the need to increase involvement of individuals autonomy in the decision processes of their own care. As a result, the NHS and Community Care Act (1990) formally required mental health 'service users' to be involved in service planning. Subsequently, policies in the 1990s, including *The Patients Charter* (Department of Health, 1991) and *Local Voices* (NHS Management Executive, 1992), took stances to make services aware and responsible to the needs of the patient. But rather than promoting patient's involvement in terms of partnership or participation, they conceptualised their involvement as consumers. Since the late 1990s, NHS modernisation under New Labour, formalised in policy via the NHS Plan (Department of Health, 2000) emphasised the government's commitment to creating a patient centred NHS with 'patients' voices at the forefront of care delivery and design and as a result, the Patient Advice and Liaison Service (PALS) emerged whilst the *Health and Social Care Act* (2001, Section 11) committed to the engagement of 'service users' in the evaluation and planning of services as well as opportunities for decision-making in treatment in all NHS organisations (Tait and

Lester, 2018). The Coalition government (2010-2015) then committed to experience-led inclusion in the *Equity and Excellence: Liberating the NHS* White paper (Department of Health, 2010) signifying the beginning of change to the way health services operated by promoting co-production and planned for the NHS to become more responsive to patients needs and wishes (Department of Health, 2010, p. 16).

Since then, inclusion in areas such as developing new models of care, policy formulation and service delivery have emerged with the expectation that it will become standard practice (WHO, 2008; Shaw, Rosen and Rumbold, 2011). The continued focus on social, empowerment and recovery focused models within mental health care, based on the promotion of inclusion and control over one’s own life, have become influential in policy and practice (National Institute for Mental Health England, 2005; Shepherd, Boardman and Slade, 2008; Department of Health, 2009). Barnes (2011) suggests that this key mandate for mental health education would bring change to service provision and practice, moving away from the traditional medical mental illness model. However, ten years later, as discussed earlier this has not occurred and stigmatisation and discrimination of/against mental ill-health and personality disorders have not changed; as Tait and Lester (2018) argue despite policy reforms and some good practice in a minority of services, experience-led inclusion within services is still limited and is rarely put into practical application, particularly for mental health service users. It could be suggested that service user choice has become a tool of political parties and a source of heated debate in the pursuit of power.

KUF training and co-production

Mental health professionals’ education is particularly identified as a positive and necessary strategy in reshaping the belief system surrounding mental health conditions, with a focus on personality disorders and breaking down negative and stigmatising attitudes (Happell, Moxham and Platania-Phung, 2010; Byrne et al., 2013). Simons et al. (2007) showed that previously, in the UK, mental health nursing had been at the forefront of ensuring positions within academic establishments for people with lived experience. As the largest professional group within health and social care, nursing professionals are in a position to influence effective and positive inclusion within their fields (Goodwin and Happell, 2007b). However, experience-led inclusion is yet to become an integral foundation in governmental policy on the professional education of nurses (Happell and Roper, 2009; Moxham et al., 2011).

There is growing evidence in support of the employment of experience led people within health and social care providers and educational institutions (Bennetts, Cross and Bloomer, 2011; Cleary et al., 2011; Lewis, Hopper and Healion, 2012). A national education programme (commissioned in December 2007 by the Ministry of Justice and the Department of Health), co-produced by Emergence, a user led BPD organisation and the Institute of Mental Health in Nottingham, aimed to improve the skills and capabilities of professionals working in social care, health, and the criminal justice system to deliver productive and effective services specifically for those diagnosed with a personality disorder (Davies et al., 2014; Ebrahim et al., 2016; Campbell and Craissati, 2018). The result was the *Personality Disorder: Knowledge and Understanding Framework* (KUF) offering different levels of training designed to support a variety of frontline professionals, increasing their understanding of personality disorder diagnoses, associated symptomology and gain practice-based knowledge of different working and support approaches (Personalitydisorder.org, no date).

KUF sought to challenge misconceptions about personality disorders, and specifically BPD by the co-production aspect of the training (Coodin and Chisholm, 2001; Krawitz and Jackson, 2007). Co-production is considered a positive way to illustrate ‘experience-led’ partnership and also facilitates in challenging stigmatisation, negative beliefs and stereotypes of people with a personality disorder diagnosis (Boyle and Harris, 2009). KUF is always delivered by two trainers, one with lived experience of a personality disorder and a professional (expert by occupation) that supports or cares for a person with the diagnosis (Davies et al., 2014; Ebrahim et al,.2016). The co-production model teaching structure enables people with a personality disorder diagnosis to authentically share their experiences to enhance the learners’. Furthermore, co-production enhances understanding between professionals, service providers and those who seek help and support, providing insight into each other’s experience and perspective of the personality disorder diagnosis, and can address difficulties that some people have with the diagnosis, and how those difficulties can be misinterpreted by professionals (Bateman and Fonagy, 2010). KUF training now primarily focuses on delivering training and support to frontline staff within the criminal justice sector.

Cooke, Daiches and Hickey (2015) found that ‘experts by experience’ co-delivering training alongside professionals felt valued and were seen as individuals and not ‘personality disordered’. Their participants, however, noted that this was achieved by supporting service development which represented power and value. The researchers found that co-production had an impact on participants’ self-esteem and efficacy and gave them an opportunity to explore new professional identities. Inclusion in mental health professionals’ education influenced positive change in professionals’ attitudes and understanding (Wood and Wahl, 2006; Moxham et al., 2011; O’Donnell and Gormley, 2013). Experience- led inclusion in KUF has been shown by Davies et al. (2014) to enhance NHS mental health trust professionals understanding of personality disorders and increase positive emotions towards working with those with the diagnosis. However, other research on reducing professionals’ mental health stigmatisation through education has also suggested the more ‘expert’ a professional becomes, the more they perceive differences between themselves and experts by experience (Sadow, Ryder and Webster, 2002; Happell et al., 2014).

The benefits of including experience-led individuals in service development highlights how they can expand the understanding of mental health conditions and distress (Together/NSUN, 2014). Alternative approaches to mental health from experience-led perspectives can improve services and the delivery of future care (Tait and Lester, 2005). Borrill (2000) states that if professionals learn from experts by experience, they make their own practice more productive and person-centred by focusing on strengths and positives rather than the negatives associated with mental health problems. However, some services and professionals remain resistant. Most organisations that do include experience-led expertise, it’s use is still limited to consultancy rather than equal partnership within that service (Borrill, 2000).

The inclusion of lived experience through the creation of peer support roles has, according to Perkins, Rinaldi and Hardisty (2010) and Gillard and Holley (2014), developed as a valued feature of service design and delivery in mental health services through the creation of peer support roles in the UK. Peer support gives people the opportunity to explicitly refer to their own experiences of mental ill-health when supporting others within services albeit from a recovery-oriented approach (Gillard, Edwards and Gibson, 2013; Gillard and Holley, 2014; Oates, Drey and Jones, 2017). As well as providing understanding and empathy to those seeking help in building connections through the sharing of past experiences, peer support roles give back a sense of self-credibility and empowerment. Connor and Wilson (2006) found that peer support was considered hugely important to survival and recovery in both community and hospital settings particularly when support and care is very heavily dominated by the medical model. Barr, Townsend and Greyner's (2020) findings indicated that peer workers provided hope, connection and validation through reciprocal relationships between 'consumer' and peer worker which removed power differentials normally experienced with mental health professionals. Disclosure of peer workers thoughts and experiences built a greater connection and level of trust when compared to mental health professionals. The inclusion of peer workers into the mental health workforce offers an opportunity to address the knowledge base of professionals (Gillard et al., 2013). The growth of peer support and inclusion of experts by experience, acknowledges the importance of people who have experienced mental ill-health as partners within frontline services due to the distinct knowledge and experience they possess (Kirkegaard and Andersen, 2018).

Conclusion

Goffman's (1963) conceptualisation of stigma illustrated how mental ill-health is one category that carries stigma because it varies from the social and cultural norms that exist in society. Further, this review shows BPD is one of the most stigmatised of all psychiatric diagnosis. The phenomena of stigmatisation of the BPD diagnosis has become entrenched within organisational systems, hierarchies and structures, which influences beliefs and attitudes towards those with the diagnosis resulting in social and service exclusion. How people cope with the symptomology and the diagnosis can mean contravening social and cultural norms that results in people being labelled as non-compliant, challenging and even dangerous. The stigmatisation of people with a diagnosis of BPD has, thus, become an issue of social justice as people with the diagnosis become the object of oppression, exclusion and marginalisation resulting in lost life opportunities, access to treatment and being placed in a lower social status.

The literature here identifies that the majority of research on perspectives of the BPD diagnosis has been taken from the experiences and viewpoints of professionals rather than those with the diagnosis. This gives a biased view of people with the diagnosis and continues stigmatising beliefs about them. People with a BPD diagnosis and their experiences of frontline services are vastly under-represented in research. The literature from lived experience identifies that people with the diagnosis experience a loss of identity in which, the diagnosis becomes their dominant identifier when accessing frontline professionals regardless of their individual characteristics or presenting behaviours. Lived experience perspectives challenges the stigmatisation and discrimination of people in the mental health system by way of service user/survivor/Mad Pride movements and the growth of experience led inclusion in education and services. This has included reclaiming their identities, challenging the discriminatory and oppressive narratives used by professionals and aiding change in service delivery, evidence-based practice and mental health policy.

The literature review has highlighted two areas of concern. Firstly, despite the large amount of literature on the symptomology and diagnosis of BPD, there is still a lack of knowledge and understanding of it throughout frontline services, including mental health services. Secondly, the overrepresentation of professional experiences and viewpoints in the literature, including the diagnostic assessment manual, maintains these stigmatising and discriminatory narratives evidenced by literature in which people with the diagnosis of BPD are referred to as bad, manipulative, attention seeking, challenging, time wasting, draining services and unfixable (Breeze and Repper, 1998; Commons Treloar and Lewis, 2008; Ross and Goldner, 2009; Latlova et al., 2015; Tyrer, Reed and Crawford, 2015; Koning, McNaught and Tuffin, 2017).

Gaps in existing knowledge included not being able to evidence how to create any reduction in stigmatising perceptions, beliefs and working practice of professionals towards the BPD diagnosis and outdated government policies to combat stigma and discrimination of this diagnostic group such as *Personality Disorder: No Longer a Diagnosis of exclusion* (2003) which has had little impact on the persistent stigma that exists in frontline services. Government policy to be updated to address how people with a personality disorder diagnosis have been unfairly treated and excluded because of the diagnosis they have been given. This update should also address the current problems in mental and healthcare systems in providing adequate, timely access to treatment and care.

Future research should focus on evidence-based evaluation of whether stigmatisation of this diagnostic group is addressed through experience-led perspectives being included in the education of professionals and frontline services.

The focus on stigmatisation and the bias towards professional perspectives shown in this literature review, establishes the need for this (and more) research taken from the experiences of people with the BPD diagnosis to provide a critical contrast to the negative perceptions of the diagnosis. The next chapter presents the methodology and methods used to conduct this research, which in turn can be used to provide greater inclusion and understanding of those with BPD and other manifestations of mental health functioning.

Chapter 3. Methodology

Introduction

This chapter will discuss the importance and use of experience grounded data in a social justice constructivist philosophical position that adopts a Grounded Theory Methodology (GTM) framework for conducting research in the field of mental health. It will argue that social justice is an important position from which to conduct primary research with members of society who are marginalised and discriminated against based on a mental health diagnosis. The use of this philosophical position enables those who have had their voice quietened to be heard and their stories to be told. Next, this chapter will discuss the differing adaptions of this methodology between Glaser and Strauss (1967) and Charmaz (2005) and why using Grounded Theory Methodology in a constructivist form was suited to this study and why Charmaz's methodological approach was preferred.

The second half of the chapter will discuss the importance of conducting ethical research with vulnerable populations in society by maintaining awareness, facilitating safe procedures to prevent harm and limit potential risks whilst collecting data. Participant recruitment criteria, sampling techniques, data collection methods and analysis will be examined. Lastly it will describe the limitations that arose whilst in the data collection phase of this study and potential areas of research for future investigation.

Philosophical perspective

For social researchers, studies on the social world are devoid of any meaning until they are placed within an ontological, epistemological and methodological framework. The philosophical position of a researcher shapes how the area under study is developed, how the answers are sought, interpreted and studied from contrasting positions in the world to gain an understanding of a phenomena. These frameworks allow for an explanation of how the social world is perceived and interpreted by others and breaks down the complexities of that world by the revealing what is important, legitimate and reasonable (Guba, 1990; Patton, 1990; Mertens, 2005). Sarantakos (2008) suggests that a researcher's philosophical position informs the methodological approach chosen through what to conceptualise and how to design and conduct research. In adopting a philosophical position, theoretical interpretations can be made providing explanations as to why social relations, situations and phenomena exist (Krieger, 2001; May, 2002; Williams and May, 2006). The study of mental health requires a different method to that of natural science, but one that should be no less philosophical in its approach (Hughes and Sharrock, 1997). The research process culminates in a series of steps and judgements involving the application of techniques from the chosen methodology that fits within the philosophical framework representing the positionality as a researcher of the social world.

Social Justice Theory

Social justice theory promotes fair and equitable treatment of those who are marginalised, oppressed people who find their place in society is unequal compared to non-marginalised/oppressed groups (Bazemore and Schiff, 2001). This can be true of those with Equality Act (2010) 'protected characteristics', such as disability, gender, race or religion or any other form of inequality based on social divisions or group, however not every social division is protected (Equality and Human Rights Commission, 2019). Social justice theories believe that society can be improved through interventions and that education is a tool for reducing inequalities in society by addressing the unique needs of individuals and being inclusive of diverse interests and perspectives (Rawls, 2001; Sen, 2009; Freeman, 2010).

There are two main approaches in the understanding of social justice, the first which focuses on the re-distribution of wealth and reduction of class and economic inequalities which parallel the existence of social exclusion and marginalisation, with the main emphasis on the eradication of poverty (Watts and Hodgson, 2019). The second approach is a more holistic approach and promotes more wholesale anti-discriminatory practice (Watts and Hodgson, 2019). The importance of social justice lies in understanding that it is more than just individual fairness but rather understanding how social institutions, principles, practices and processes systematically combine to deliver unfair outcomes (Thompson, 2016). Strier (2007) suggests that social injustice is the systemic subordination of specific social groups, by the institutionalised use of authority and power. This is particularly apparent within mental health and the BPD diagnosis, where the predominant research focus has been perspectives of service providers, policy makers and academics with less focus on those living with a mental health condition. Sulzer (2015) evidenced this in their review of literature which found that academic discussions of the BPD diagnosis dating back to 1970 were all based on the experiences and perspectives of professionals. Knowledge, whether academic or societal, is typically constructed and maintained by those that hold the most privilege and power in society, rarely leaving those with less privilege and power in a position to defend themselves or self-represent against inequalities or challenge policies and practices that impact upon them (Freeman, 2010).

Power and empowerment are connected in social justice research; who has it, how it is exercised and from where it manifests. The social justice theoretical framework accepts that knowledge is not neutral but reflects power relationships within society and its purpose is to propose an agenda that can influence change within organisations, and challenge beliefs held about marginalised or oppressed groups. Social justice research thus enables all individuals affected by health and social inequities to be active participants towards a social change whether at local, national or international policy. Social justice theory promotes inclusion and equality in research participation so oppressed individuals are actors within the social world, sources of valuable knowledge and active participants in their own liberation (Friere, 1970; Griffiths, 1998; Cresswell, 2013). Without the promotion of such social inclusion, individuals with mental health conditions will remain marginalised at the edge of society (Rankin, 2005).

Social Justice Ontology

Ontology is defined as an assumption that is made about the nature of reality and what exists in the social world (Richards, 2003). It is the study of being, and questions what the nature of reality is (Guba, 1989; Ataro, 2020). Ormston et al. (2014) defines ontology as to whether a social reality exists independent from human interpretations and conceptions, and if there is a shared social reality or only multiple context-specific ones.

The philosophical underpinnings of social justice highlight injustices and inequalities faced by marginalised groups and shines a spotlight on oppressive practices within our society. Social justice ontology critiques how marginalised groups are often made invisible in research, which limits their opportunity to have their voices heard and increases inequalities and social exclusion, and instead considers the voices of marginalised individuals as central (Royal College of Nursing, 2004; WHO, 2008; Rudwick et al., 2014). Morrow and Weisser (2012) suggest applying social justice ontology to mental ill health because experiences of mental ill health and distress always take place in a social, cultural, and historical contexts of discrimination structured by medical, legal and psychological practices and policies. Psychiatric practice historically pathologized some groups of people resulting in psychiatric diagnoses being disproportionately applied to certain groups (Caplan and Cosgrove, 2004; Metzl, 2009). The researcher's social justice ontological position identifies that individuals with a diagnosis of BPD experience social and structural inequities. Research into the effects of social inequities on mental health have identified that it causes or exacerbates distress (Kirmayer, Brass and Tait, 2001). The medicalisation of mental (ill-)health dominates how society understands distress, determines socially accepted behaviour and places groups of people in a lower status with fewer life opportunities (Johnstone, 2014; Thoits, 2020). Furthermore, diagnostic labels of mental illness, which trigger existing stigmatised beliefs are thought to constitute a form of inequity of access to resources or achieving optimal health (Morrow and Weisser, 2012). People identified as mentally ill, and those with a diagnosis of BPD in particular, experience marginalisation and their voices, as people with lived experience of distress, are quietened (Day et al., 2018). Taking a social justice ontology position in mental health research means placing the voices of those with a diagnosis of BPD centrally to present, and challenge, injustices.

Social Constructivism

Social constructivists believe that as individuals, we seek to find an understanding of the world in which we live. Social constructivism is borne out of the ideas from works such as Berger and Luckmann's (1967) *The Social Construction of Reality* and Lincoln and Guba's (1985) *Naturalistic Inquiry*. Berger and Luckmann (1967) argued that human beings create and sustain social phenomena through three fundamental social practices: externalization, objectivation and internalization. People externalize their world/experiences by creating or telling of a story (belief/ feelings) which then enter into the social realm where others retell that story and it becomes factual existence of truth (objectivation). Finally, when others are told these beliefs, and they already exist in society, they are internalized as part of that new persons' understanding of the world. Lincoln and Guba (1985) proposed creating an alternative paradigm of naturalistic inquiry in which a world view produces a methodology to arrive at a set of beliefs, and as each paradigm emerges, comes to a understanding, ultimate truth and construct realities of the world.

Cresswell and Cresswell (2018) suggest that subjective meanings are not just imprinted on individuals but are negotiated socially and historically negotiated via interactions with others and the cultural norms that operate within their lives. As human beings we live between the past and the present, but we are aware of and can focus on the future. Social constructivists, therefore, can be defined as believing that human life exists as it does due to societal and interpersonal influences. Research from a constructivist viewpoint is generally focused upon social and societal influences on communal and individual lives focused on specific circumstances that surround an event or occurrence. For instance, taking a critical view in relation to how one group of people, those with a BPD diagnosis, are treated based on a mental health diagnostic label and how this changes their identity. This approach enables the researcher to understand how people negotiate and manipulate social structures and how reality, expectations and outcomes within defined contexts are constructed between frontline professionals and those with a BPD diagnosis.

Constructivist Epistemology

Epistemology means the assumptions made about the nature of knowledge and how it is interpreted (Crotty, 1998; Richards, 2003). Constructivists' research begins with experience and asks how people construct it in their world (Charmaz, 2014). Reality is constructed through human interactions where knowledge is gathered to create meaning (Gergen, 1999). Berger and Luckman (1966) suggest that reality can be different for everyone based on people's unique understandings of the world and their experience of it. Thus, constructivist researchers seek to understand the experiences and subjective truths of their research participants. This is externalised into the creation or telling of narratives about a phenomenon which enters the social realm of beliefs and is internalised to create an understanding of the world we live in. Constructivist researchers' epistemological position acknowledges the social nature of human experiences and encourages individuals to share their stories to understand particular situations or phenomena. The sharing of stories produces rich data from which solutions to the problems of a particular group of people, in this case those with a diagnosis of BPD can be formed.

Research context

Traditional mental health research approaches have consistently emphasised the perspectives of professionals or organisations that engage with individuals with mental health conditions, based upon their 'expert' knowledge of disorders, diagnostics, symptomologies and support (Chadwick et al, 2012). As highlighted in Chapters 2 and 3, psychiatry pathologizes people's thoughts, feelings and behaviour and suggests that individuals with a diagnosis of BPD are untreatable and a waste of resources, questioning what role they have in and what use they are to society (Dickinson, Wright and Harrison, 2009; Latlova et al., 2015; Tyrer, Reed and Crawford, 2015). Individuals with a BPD diagnosis have been treated as in(-)valid outsiders resulting in prejudice and stigmatisation particularly when they do not conform with the professionals' ideas of how services can engage and support them (Koekkoek et al., 2006). Coercive practices within psychiatry exacerbate discrimination and stigmatisation of mental health conditions and have made many individuals fearful of seeking help and support from mental health services resulting in self-exclusion (Sugiura et al., 2020).

Some professionals hold statutory powers and influence other agencies and individuals who themselves are in positions of professional power. Professionals can hold assumptions that individuals lack the ability to be autonomous with regards to their care or treatment leading to a dependent power dynamic relationship (WHO, 2008; Rogers and Pilgrim, 2014; United Nations, 2017). Issues of power are present within all human relationships whether overtly exhibited through verbal or physical actions or subtly within (domination over) conversation. The power dynamic in mental health is characterised by frontline professionals having and displaying power over 'the patient' and other professionals (Twemlow and Harvey, 2010; Brosnan, 2012). This is a clear transgression of distributive justice in terms of a socially just allocation of goods that places importance on the health and wellbeing of its citizens.

The effects of social inequities on mental health can worsen symptoms or their interpretation, cause distress, isolation, and self-social exclusion as a member of society (Public Health England, 2018; Mental Health Foundation, 2020). The diagnostic label of BPD can undermine an individual's interactions throughout the care system in England, negatively perceiving their thoughts, actions, and opinions as invalid and questionable (Klein et al., 2021). The credibility of these individuals as human beings is, thus, severely affected, and no diagnostic group in mental health is subjected to as much prejudice and stigmatisation as those with a BPD diagnosis (Klein et al., 2021). This inherently leads to an exclusion from services whether by inadequate provision or from fear of stigmatisation (Ross and Goldner, 2009; Latlova et al., 2013; Sulzer et al., 2016).

Many individuals with mental health conditions are socially and medically conditioned to be compliant and believe they are powerless at times of vulnerability and often experience domination and subjection to 'power over' in relationships with professionals (Brosnan, 2012). The dynamic of power and control favours professionals and organisations rather than individuals with mental ill-health. This is in part due to the 'medical model' discourses (Chapter 3) that remain dominant in mental health systems where professionals exert power over those in their care through control, organisational positioning or control of access to resources. Professionals exert power and authority over others with reference to science and their bodies of 'objective' knowledge (Johnstone, 2014). There is an imbalance of power between those who access services and those who provide them, which results in failures by services to account for and understand the relationship between a person's reality of living and their mental health (Bacha, Hanley and Winter, 2019). Therefore, these individuals unwillingly become members of an oppressed group. As a social justice constructivist researcher, it is important that this research address the lack of power and control and the stigmatisation that manifests daily for people with a BPD diagnosis (Constantino and Nelson, 1995; Lord and Dufort, 1996; Williams and Lindley, 1996; Tew, 1999; Nelson, Loed and Ochoka, 2001; Gore, 2003; Thornicroft, 2006; Hui and Stickley, 2007; Callard et al., 2012; Watts, 2018).

Mental health has been the focus of significant government policy changes, most recently the Department of Health and Social Care (2021) White Paper on reforming the Mental Health Act (1983), as well as attention on social media and campaigns from mental health organisations. Their collective purpose is to stop the marginalisation of mental ill-health and the voices of individuals with lived experience and to challenge the prejudice, oppression and discrimination experienced. Similarly, within the last few years, some mental health research has taken a newer approach to research in this field by championing experience-led perspectives and promoting autonomy in the research process (Syrett, 2011). This project, has therefore explicitly gathered the views and experiences of people with a diagnosis of BPD who have accessed and participated with frontline services in England to discover whether the BPD label is still stigmatised and subject to prejudicial attitudes or whether this has changed following the recent increase in mental (ill-)health awareness in England in the last few years.

Grounded Theory Methodology

There are academic debates on whether qualitative research methodologies are and can be scientifically validated, compared to positivistic scientific quantitative methods, due to the focus on subjective human experiences (Stanfield, 2011). This question originally arose during the Age of Enlightenment battle for the superiority of science in understanding and predicting human behaviours (Stanfield, 2011). Research within the social sciences has long drawn upon scientific traditions for conceptualising and categorising knowledge, human experience and truths. Empirical social science research involving the collection of data from individuals about their social reality, historically draws upon the tradition and practices of disciplines such as anthropology, psychology and sociology (Somekh and Lewin, 2005). While research paradigms provide frameworks such as interpretivism to create new theoretical and practical ideas about research methodology, their development divides researchers in the social sciences (Somekh, 2005, p. 2.). Critics, such as Carr (1994), have argued that social science research cannot develop solutions to social problems as our minds only enable us to make contextual decisions that vary with different motivations for the development of producing solutions (Choy, 2014).

Grounded Theory Methodology (GTM) was initially developed Barney Glaser, Anselm Strauss and Jeanne Quint in the 1960s at a time when qualitative methods were gaining traction as an alternative to positivist natural science logic which, legitimised the reduction of human experience to quantifiable variables. GTM challenged using these prevalent positivistic views of knowledge in qualitative research whilst maintaining systematic enquiry (Glaser and Strauss, 1967; Bigus, 1994). In contrast, Glaser and Strauss, and all subsequent grounded theorists, believe that theory should be grounded in the field, in particular in social processes, and in the interactions and actions of people and so fitted with the empirical turn of the 1990s in which Corbin and Strauss defended their methodological theory. Inductive approaches to research have since become more accepted within the field of social sciences despite research remaining strongly directed towards deductive approaches to research (Jebb, Parrigon and Woo, 2016). Charmaz (2006, p.188) defines induction as ‘a type of reasoning that begins with study of a range of individual cases and extrapolates from them to form a conceptual category’. It is a cluster of techniques which aid the identification of patterns, categories and concepts within data. Inductive analysis is primarily a process of theory generation, rather than scientifically testing or justifying theory. Glaser and Strauss (1967) argued that researchers should not propose an initial hypothesis but rather allow for the emergence of one through constant simultaneous gathering and analysis of data. Classic grounded theory even advocates against the exploratory investigation of literature as Glaser and Strauss (1967) argue that having knowledge of existing theories can negatively affect a researcher’s ability to maintain theoretical sensitivity. Its analytic approaches enable systematic discovery of themes that are constantly developing and unravelling the mechanisms of relationships and experiences (Tan, 2010; Guest, McQueen and Namey, 2012; Bergdahl and Bertero, 2014).

Glaser and Strauss (1967) proposed the development of codes and categories from within data rather than developing hypothesis from which to code data to pre-determined set of categories. Their (1967) methodology supports social researchers to follow a clear, sequential and systematic guide for qualitative analysis and fieldwork focusing on data, fit and coding (Bryant and Charmaz, 2007). Although Charmaz (2006) does not fully agree with Glaser and Strauss’ model, she also identifies GTM as a method of concept and theory construction grounded within empirical data. GTM therefore created a way for social researchers to attain a new grounded theoretical awareness, which, at the time, was in contrast to the orthodox approaches of deriving hypotheses from the existing grand theories and testing them against data to verify the theories themselves.

Glaser and Strauss (1967) described categories as indicators, conceptual elements of a theory that emerge from engaging with the data and which can achieve a higher level of abstraction through constant comparison of data. Categories play a key role in GTM in that they can be both sensitising, analytic and allow for the conceptualisation of key analytic features of a phenomenon. Phenomena can be classified and relationships between different elements of a theory can be (re)constructed (Dey, 1999). Glaser and Strauss (1967) suggest that in the discovery of theory, conceptual data categories can be generated and the emergent category can be used to illustrate a concept. A concept is then a theoretical abstraction highlighting circumstances or situations surrounding the subject being studied. Theoretical abstraction centres on a practical understanding of concrete real-world issues (pragmatism) based upon individual cases or events (idiographic research) and the creation of theories via sensitising concepts. These concepts are derived from participants' perspectives using their language, expressions and symbols. They are relayed between agential actors and their intersubjectivity (the shared understanding that enables us to relate to one situation or another) is central for humanity as well as qualitative research as primary instead of secondary significance; exploration is a central function and social action is the main focus (Dey, 1995).

According to Cresswell (2013) and Lempert (2007), memoing is an essential part of GTM. Memos are both a methodological practice and an exploration of social world processes that conceptualise the data in its narrative form by highlighting social reality in the interpretation of participants' social worlds. Charmaz (1983) believes this is where researchers are at their most present within a study, where they find their own voice and where ideas are formulated, expand upon and reconfigured to finally extract them for publication.

Pratt (2012) suggests that the philosophical, logical basis of GTM is flawed as inductive methods do not give certainty that the data collected provides valid conclusions (Bryman and Burgess, 1994). Considering Pratt's argument on the fallibility of the inductive nature of grounded theory, abduction also plays a key role in that 'abductive inference entails considering all possible theoretical explanations for the data, forming hypotheses for each possible explanation, checking them empirically by examining data, and pursuing the most possible explanation' (Charmaz, 2006. p. 188). What Charmaz is suggesting is that the researcher must be open to all theoretical considerations of the data in the pursuit of generating a best-fit theoretical explanation of a phenomenon.

There have been differing debates on the inductive nature of GTM since the 1960s. Another critique involves validation in inductive approaches, including GTM. Reichertz (2010) suggests that the relationship between the data and emergent conclusions or theories is problematic. However, constructivist approaches distinguish between the 'true' (universal or lasting) and the ‘real’ (as it really is). Instead of claiming ‘truth’, it instead is realistic as it addresses human realities and their existence in real worlds (Lomborg and Kirkevold, 2003).

Charmaz (2007) argues that the analytic power of GTM provides qualitative social justice inquiry researchers five key strengths: defining relevant processes; demonstrating their contexts; specifying conditions in which they occur; conceptualising their phases; explicating contributory factors for their stability or change and outlining their consequences. Charmaz (2007) emphasises the diversity of social worlds, realities, views, actions and complexities of the environment we live in. It embraces an interpretivist qualitative approach in research, guiding theory development based on people’s views, experiences and relationships as well as highlighting the hierarchies of power, communication and opportunity. Knowledge of persons within the social world can be gained through an interpretative procedure grounded in the recreations of their experiences to grasp meaning of their reality. There have been minimal grounded theory methodological studies in social justice that demonstrate the construction of theory, however the guideline of grounded theory has influenced the development and sharpened analytical processes (Bryant and Charmaz, 2007).

Inductivism

It is important as researchers that we recognise how our own backgrounds shape our interpretations, where we position ourselves in our research and to acknowledge how our interpretations flow from our own cultural, historical and personal experiences (Cresswell, 2003). As humans we engage with and make sense of the world based upon social and historical perspectives; we are born into a world of meaning that is bestowed upon us by our culture (Cresswell, 2003). Constructivist researchers’ focus is on the specific contexts of people’s lives. Any goal of social justice theory underpinned by qualitative research requires more than just a knowledge base, it must integrate a unique way of ‘being’ a researcher. Social justice researchers want those who are the focus of study to speak for themselves and to provide their own experiences and perspectives if they have the capacity to do so. Researchers strive to understand the lives that others have in the world and an individual’s narrative on how their lived experience serves to bridge the gaps between research, policy and professional practice.

> If we wish to understand the deepest and most universal of human experiences, if our work be faithful to the lived experiences of people, to have a union between poetics and science, to use our privilege and skills to empower the people we study then we should value the narrative (Richardson, 1990, cited in Hammersley and Atkinson, 2007, p. 199).

As a social constructivist, research does not begin with a developed hypothesis instead theory is inductively generated - a theory or patterns of meaning develop from participant data. Grounded Theory Methodology allows for the generation of theory from human discourse and the experiences of an individual's reality. In seeking empirical answers through the emergence of theoretical questions from a social justice constructivist perspective, we must obtain an understanding of the context of our research subject to achieve a clear and logical understanding of the findings (Charmaz, 2005). Without development, our findings can culminate in dull and tedious descriptiveness lacking debate and critique failing to provide a fair representation and assessment of the empirical world and the study of social justice issues (Charmaz, 2005).

Constructivist Grounded Theory Methodology (CGTM)

CGTM provides a platform for social justice theory construction as well as the study of social action, social structure and infrastructure. Its extensive use has led to significant advances within various fields (Bryant and Charmaz, 2007; Denzin, 2007) as it is the most widely used research methodology across a range of disciplines including the social sciences, education, psychology and mental health research. In the latter, its use has focused on the inclusion of perspectives from vulnerable and marginalised individuals to inform and enhance professional practice highlighting areas of concern in support, treatment and care of those with a mental health diagnosis (Connor and Wilson, 2006; Smith, Flowers and Larkin, 2012; Williams and Vogt, 2014; Kuek, Raeburn and Wand, 2020).

Adopting a GTM approach recognises multiple perspectives and variations in empirical experience. Researchers strive to represent the phenomena under investigation as naturalistically as possible, representing the complex and diverse real-worlds of those being studied and ensuring that experiences are presented as individually unique to the person and not just as a group with a common group. Bryant and Charmaz (2007) state that GTM produces generalisations, and not universal statements; the social scientist becomes an interpreter of the data and not the ultimate authority defining it. As researchers therefore we rely on research participants' experiences and views of the subject being studied. Subjective meanings of experiences are developed, and these meanings are diverse which aids researchers to investigate the complexity of views instead of narrowing meanings into minimalistic ideas or categories.

Influenced by Foucault's (1972) questioning of power relationships, Clarke (2005), sought to reclaim GTM from its positivist underpinnings. It is necessary to mention Clarke (2005) and Foucault (1972) as previous research on the BPD diagnosis has shown how dominant discourses interact with and influence the narratives used to describe this diagnostic group. Clarke (2005) sought to create a more open-ended practice that stresses constructivist elements emphasising positionalities, partialities and heterogeneities. Clarke's framework of discursive GTM was, he believed, the closest to interactionist thinkers in attempting to see the world from all perspectives, including those who have less power in society. Foucault's concept of 'discursive practices' described ways of being in the world produced 'discursive formations' or dominant discourses that fuse together social injunctions about practices. Foucault (1972) describes these dominant discourses as being reinforced by existing institutional systems like those that operate in health and social care, law, education and so forth and which often operate in conjunction with each other.

Clarke's situational analysis goes further to analyse the salient discourses within the situation of inquiry (Dreyfus and Rainbow, 1983; Clarke, 2009). Clarke's framework suggests that social situations should form the main analysis in GTM and three sociological modes can be utilised to analyse them: situational, social world/arenas and positional cartographic maps. Charmaz's (2007) approach, however, is more empirical and less focused on discourse, it leans towards a constructivist interpretation of subjects' meanings. The current research positions itself within Charmaz's GTM approach to understand the experiences of participants whilst also adopting Clarke's constructivist concept of salient discourses to explore working practices/belief systems held about those with a diagnosis of BPD.

GTM and Social Justice Research

Methods for social justice inquiry can address inequities, inequality and barriers individuals experience but can also provide critical views on the social structures and processes that shape individual and collective life. Social justice researchers tend to adopt a macro structure focus, but it is important to remember that social in/justice can occur on the micro level which in turn influences larger social entities (Charmaz, 2011; Harris, 2015). Charmaz (2008) believes that grounded theory provides a lens as to what is happening within the empirical world by the development and study of data and analysis from conceptualising rather than confining it within a theoretical framework. This in turn provides a way to increase innovative analytic power and the re-examination of established concepts. Research based on human experiences can be suggested as complex, and as a researcher with a personal interest in the subject under investigation one must be aware of the temptation to impose our own beliefs or theoretical ideas via the application of theory. The application of the GTM framework moves beyond description to generate 'a unified theoretical explanation' (Corbin and Strauss, 2007. p. 107).

Credible GTM social justice research is based on strong empirical foundations. Social justice researchers have a responsibility to address all social justice concerns through the aspects of research design and implementation using methods that can aid the advance of social justice and management of bias and power differentials (Chapman and Schwartz, 2012). The grounding of theory in the data collected is a vital component in supporting claims and bringing credibility to the evidence. Denzin and Lincoln (1994) have argued that qualitative researchers can no longer capture lived experience via research due to a representational crisis within the field of research as such experience is created within the social text that the researcher writes (Seale, 1999). However, Denzin and Lincoln (2005, pp. 26-27) question how qualitative research can create change in the world if the social world is only and always portrayed as text, they called for the traditional criteria for interpreting and evaluating qualitative research (validity, reliability and generalisability) to be reconsidered. Denzin (1998) also proposed that the modernist assumptions about objectively studying the empirical world through qualitative methods are not sustainable, because the theory generated by researchers obstructs the focus of observing the theories people use in their everyday lives. Social justice researchers endeavour to ensure that the experiences and views of people, their social environments and theories remain the focus.

Denzin (1994) suggests that in making qualitative research scientifically respectable, researchers can unintentionally impose interpretations on the social world that do not correspond with how the world is constructed and lived in by interacting individuals. Whilst Strauss and Corbin (1990a) argue that GTM provides a methodological lens for comprehending and observing the reality of the world, it does allow the direction of the research and data analysis to be guided by the researcher, not the participant. Individuals play an active role in shaping the world and interrelationships, whether by meaning, conditions or actions, which shapes our experiences of being in the world and is continually evolving creating a continual re-interpretation of phenomena (Strauss and Corbin, 1990a; Howell, 2013).

Social justice researchers need to remain aware of acknowledging an individual's truth and reality, should reject objectivity, should remain alert to variation and difference, and should be sensitive to oppression, power, privilege and equity (Clarke, 2005; Bryant and Charmaz, 2007; Clarke and Friese, 2007). Corbin and Strauss's (2007) and Strauss and Corbin's (1990b, 1998) modernised GTM's components (central phenomena, strategies, contexts conditions and consequences) can pose challenges to researchers as they advocated for a specific systemic approach to data analysis. For example, Harding et al. (2010) highlight these challenges in their research on service-user perceptions of developing NICE mental health guidelines. After using semi-structured interviews to collect their data, in the analysis phase they found that applying Corbin and Strauss's GTM in data analysis exceeded the time limits to complete their study and they were unable to fully analyse their data resulting in just a preliminary presentation of their results.

Social justice GTM research on mental health can provide a useful toolkit for researchers to extract rich data. The empirical scrutiny and analytic precision creates nuanced analysis of social and economic conditions and how they perform in specific situations (Charmaz, 2005; Speed and Luker, 2006; Dixon, 2007). Researchers who pursue social justice can advance the recognition of temporal, structural and situational contexts in qualitative grounded theory research and are aware of the silent workings of power and structure (Maines, 2001; Rivera, 2008).

As socially just interpretative researchers it is imperative that we prioritise that our research does not further marginalise our participants but upholds a level of respect. We must also acknowledge that power dynamics and imbalances be addressed so there is always an equal relationship and that participants' stories, experiences and individual differences can be captured (Feagin, 1999; Cresswell, 2013). Grounded theory can allow for the data to inform policies and practices that we as social justice researchers seek to change as well as contributing to the existing knowledge of our subject area. As researchers we ensure a level of ethical responsibility to our participants ensuring that the methods of inquiry allow for a full representation of their experiences (Chapman and Schwartz, 2012).

This Project

Smith (2008) suggests that mental health research needs more diversity in design, including non-random sampling strategies and qualitative methods of investigation. As PhD researchers, we are bound by a limited time frame in which to complete our studies and defend our thesis. Strauss and Corbin's (1990b, 1998) and Corbin and Strauss's (2007) GTM approach is less suited for this current study compared to the more adaptable social constructivist perspective of Charmaz (2006) and Clarke (2009). Charmaz's approach is an iterative process which allows researchers more manoeuvrability in theory generation through the ability to use differing variables in data collection and analysis as well as looking at/re-visiting pre-existing knowledge through literature review to establish what is already known within the subject area and key relevant frameworks. Time frame limitations in using Charmaz' approach is less structured and restricted, researchers can work on multiple parts of their research at the same time and build an interpretative picture from existing literature and data towards building a theory of the area being studied.

Charmaz' approach to grounded theory is suited to social justice research in developing an understanding of the unique needs of the population. This recognises that individuals' personal experiences of the phenomenon being investigated (here, having a mental health diagnosis of BPD) can provide lived, real, first-hand knowledge and inductive theory development collaborating with people with a mental health diagnosis can inform practice and policy (Lewis, 2015). Here, the GTM framework was appropriate because using an interpretivist approach, it encompasses the views and experiences of those that are the focus of the research to understand the relationships between people diagnosed with BPD and professionals working in frontline services.

Under GTM, researchers can utilise both qualitative and quantitative methods of data generation and collection. Interviews are a commonly used qualitative research method, however, focus groups, observations, field notes and secondary documentation can also be used (Tie, Birks and Francis, 2019). This variation provides the researcher freedom to adapt methods of data collection as needed because, due to the symptomology of BPD, individuals do not necessarily feel comfortable in social situations or unknown environments thus flexibility allows for a greater chance to collect data.

In social justice research, the GTM approach emphasises reflexivity which, as Primeau (2003) suggests, is the responsibility of the researcher to examine their influence in all aspects of qualitative inquiry. Reflexivity can enhance the quality of research by developing understandings of how a researcher's interests and position affects the stages of the research process. It can also assist in grounding categories by documenting their formation through the analytic process. The ability to reflect on research and understand how our own views and values shape our interpretation of data adds credibility to the research and should be an explicit part of the method of inquiry (Bryant and Charmaz, 2007; Jootun, McGhee and Marland, 2009; Cresswell and Cresswell, 2018).

Ethical research with vulnerable populations

The participatory involvement of human participants in research requires serious consideration from the researcher to limit potential impacts. Elliott (2005) suggests that there is the potential for the exploitation of individuals. Ethical principles and codes such as the Helsinki Declaration (1964), Belmont Report (1974), and the Nuremberg Code of Conducting Ethical Research (1947) were all born out of World War 2 atrocities of unethical human experimentation and act as a regulatory measure of the researcher-researched relationship to protect both individual participants but also members of societal groups under investigation (Weindling, 2001; Markman and Markman, 2007; Farrimond, 2013; Gray, 2014). Ethical research principles are generally agreed to be autonomy, protection of the vulnerable (respect), justice (treat people justly and fairly), beneficence (do good), nonmaleficence (do no harm) and fidelity (honesty and trustworthiness) (Kitchener and Kitchener, 2009; Shamoo and Resnik, 2009). The Nuremberg Code (1947) additionally ensures that attempts to improve knowledge are not at the expense of those participating. To limit this potential, researchers are strictly governed by their institutions to follow ethical guidelines and principles, and this becomes particularly necessary when dealing with vulnerable populations. This research received Ethical Approval from the University's Research Ethics Committee.

Ethical practice is not just about following these principles or guidelines, but also thinking, acting and doing what is ethically right if a problem arises. It is imperative that as researchers we follow moral principles when working with human participants and do not treat them as just a means of obtaining data (Farrimond, 2013). The last two decades have seen an increase in social justice research, approaches which do not follow one philosophical theory but share a common focus towards the advancement of social justice, using participatory and transformative methods. Social justice approaches do however align themselves towards ethical imperatives to challenge dominant groups and give a voice to the powerless, emancipate and encourage social change at a micro or macro level (Mertens, 2009; Brydon-Miller, 2010; Farrimond, 2013). Social justice in a sense is attempting to change or challenge discrimination and oppression through research in the hope of a more equal and just society (Mertens, 2009; Mertens, Holmes and Harris, 2009). The researcher's awareness of ethical issues within social research is of vital importance as knowledge has power (Foucault, 1972). Therefore, when in the process of gathering data from participants, who belong to a population classed as vulnerable due to having a mental health diagnosis, the researcher must be guided by and maintain strict principles of respect.

Policy makers, research ethics committees and researchers grapple with balancing moral protection of research participants with a psychiatric diagnosis with their inclusion in research by placing a framework of measures on their participation (Bracken-Roche, Bell and Racine, 2016). It could be that some of the perceived issues are founded in stereotypical assumptions around capacity to consent with a mental health diagnosis automatically casting doubt on the level of capacity held by individuals in this group to be autonomous in research participation. These stereotypical attitudes overprotect people with a mental health diagnosis by suggesting that their diagnosis makes them vulnerable. However, these views may, in fact, add to the stigmatisation, oppression and dis-empowerment of mental health research participants. Vulnerability in research can take many different forms which are unique to individuals, including poverty, health and level of education which can result in exploitation. Previous research on psychiatric conditions such as psychosis, mood and anxiety disorders which focused on the capacity to consent to research, has found that participants have capacity to make informed decisions which highlights that the generalisation of psychiatric disorders as vulnerability is unjust (Alexander, 2010).

The principle of respect within mental health research is highly valued by researchers in that participants should be and remain autonomous, meaning that they are able to make independent decisions on whether they wish to be involved in research and are free to decide to withdraw if they so wish. Individuals' autonomy can be ensured through the provision of information on the purpose of the study, procedures, risks and benefits and the understanding that participation is voluntary so the participant can make an informed decision. Maintaining autonomy can also be achieved by responding to queries or concerns participants may have without obstructions. In the current study one participant requested to be notified of which excerpts from the interview transcript were to be included in the thesis. The reasoning for this request was not questioned; the researcher had a duty to maintain the autonomy of the participant and ensure this request was completed.

The respect principle also ensures that participants are given anonymity, privacy and confidentiality within research by protecting participants identity. This principle is woven throughout the research process from recruitment, data collection and analysis by ensuring that research is conducted in the best interests of the population being studied and gives opportunity for representation of marginalised voices (Lyons et al., 2013). Anonymity is now the default ethical practice for researchers, removing or obscuring identifiable features in transcription including using pseudonyms or numbers as identification. However, it is depersonalising to assign individuals a number, and some participants can be unhappy with the name assigned to them, because once published their words are not relatable. Grinyer

(2002) recommends that allowing participants to take autonomy over the name they wish to be identified by as giving a sense of ownership. Naming is an important component in autonomy and addressing hierarchical balance for participants who experience stigmatisation and oppression. Therefore, here, participants chose how they wished to be identified within the study.

Research with vulnerable groups necessitates extra ethical consideration and such research is usually deemed a higher risk. Participants for the current study are considered vulnerable because they have a diagnosed psychiatric disorder which as demonstrated above means potentially traditionally marginalised or stigmatised both professionally, personally and societally. For vulnerable populations, psychological (Farrimond, 2013) and emotional harm is one of the most common risks in social science research. This encompasses many different aspects, for example: exacerbating mental health issues; flashbacks of traumatic memories; increased distress, upset, annoyance or other negative psychological responses. To conduct ethical research, given the sensitive nature of the topic under investigation, it was important to identify and address any potential risk of harm to the researcher and participants. Research methods such as interviews can be upsetting experiences for participants if they provoke a sense of intrusion or embarrassment, however this is not limited to discussing sensitive topics. To address this, interviews were conducted informally, with participants encouraged to share experiences they were comfortable disclosing.

Researchers can disclose their own experiences to participants as a way of creating a safer environment and building trust between participant and researcher. Self-disclosure during interviews can create a less intimidating surrounding and enhance the reciprocal nature of an interview. However, self-disclosure can lead to vulnerability and scrutiny of the researcher depending on what they have disclosed and can also ‘blur boundaries’ between the researcher and participant (Reinharz, 1992; Dickson-Swift, James and Kippen 2008; Elmir et al., 2010). In interviews for this project, the researcher disclosed that they had personal experience of BPD through their relationships on the participant information sheet, as a way of indicating that the research was not just academic but also of personal interest. During several interviews, participants’ experiences were discussed that the researcher identified with and had witnessed similar themselves and the researcher shared this with participants.

This self-disclosure created a safer space to share experiences, built trust between the participants and researcher, and validated what participants had experienced. Booth and Booth (1994) and Seidman (2000) suggest that sharing and receiving information form trusting connections, is vital to help participants share their experiences and enhancing access to participants' lives. To minimise potential risks to the researcher whilst conducting interviews, a list detailing the date, time and locations of interviews was given to the project's supervisory team. As a further precautionary measure, the researcher contacted the supervisory team and friends/colleagues prior to and following each interview to inform them of their wellbeing. Interviews were limited to two per week, based primarily on the location of the participants and considering the amount of travel time required, and the researcher ensured an appropriate number of rest days were taken each week to limit any undue stress or impact on the researchers disabilities.

Due to the nature of the topic and the researcher's own previous experiences, it was important to remain aware of potential psychological impacts, particularly the potential impact of traumatic memories associated with witnessing coping strategies at times of distress and recollections of discriminatory practice by care providers in response to non-suicidal self-injury, substance abuse, eating disorders, emotional dis-regulation, anti-social behaviour and suicide ideation. To address this, the researcher attended psychotherapy once a month to discuss emotional and stress related issues that arose whilst conducting the interviews and data analysis.

Participant safety parameters

Whilst the research methods employed here, gave individuals the opportunity to be active participants, rather than passive subjects of research processes, it was important to set parameters to minimise any risk of emotional distress or impact on coping mechanisms to manage any distress that may be caused by the re-telling of negative experiences. Therefore, a research participant minimum age limit was set at 18 years of age as a requirement. Further inclusion criteria were that participants have in place a personal/therapeutic support network and a requirement to not have experienced an episode of emotional distress leading to crisis for at least a period of one month prior to the interview.

Informed consent requires that participants are given sufficient, accessible information about the research for them to make an informed decision on whether to participate or not (Crow et al., 2006; Gray, 2014). Sudman (1998) recommends that the amount of information provided should reflect the amount of possible harm of being involved in the study and Crow et al. (2006) suggest that obtaining informed consent yields positive outcomes: it can improve participation rates by creating greater confidence in the research and encouraging participants to be franker and more open in their responses. The researcher developed the participant information letter and consent form having explored examples from previous research within social sciences and mental health. The participant information letter (Appendix 4) was required to be read before participation and an informed consent form (Appendix 5) detailing potential risks of participating was signed prior to participation. Informed consent forms are a critical component in all types of research with human subjects. They must inform the participant about the research, provide the objectives, potential risks and benefits of participation, rights and responsibilities of participants and researchers and presented in a language that can be fully understood by non-academics (Tugwell, Knottnerus and Idzerda, 2012). Ogloff and Otto (1991) evaluated the reading levels of forms used in academic disciplines found that in most cases they are at a higher than appropriate reading level for the intended population. Therefore, when researchers are developing information letters and consent forms, they must establish whether participants can understand the information contained and if they do not understand then they cannot give valid consent. It was imperative that the Participant Information Letter and Consent Form could be easily understood and accessible, jargon free and omit academic language. Finally, to ensure that the consent form was informative, well- structured and easy to interpret and understand the researcher gave a draft copy to friends, colleagues and family members to obtain readability feedback. In the end, there were no issues experienced by participants in understanding the information and requirements outlined in these documents

Zink, Wertlieb and Kimbereley (2005) advise that informed consent form is not limited to participants' signatures on Participant Information Letters but should also be designed into the research process to meet researchers' responsibilities to protect the rights and autonomy of participants. Due to the sensitive nature of the topic and potential psychological/emotional risk factors, as a further safety protocol, participants had autonomy in deciding where they would like to be interviewed to ensure that the sharing of distressing experiences could be done within a familiar space and/or with support networks nearby. In the event that participants visibly displayed or communicated emotional distress during the interview process, it was immediately halted so that the participant could decide whether to continue with or abandon the interview. Drury, Francis and Chapman (2007) advise that researchers should always be aware of and ready to make ethical decisions on when to halt or change the direction of an interview in light of a participant becoming emotionally upset. Within the Participant Information Letter, measures were also taken as a precaution against delayed emotional processing responses by provision of contact details of support groups/organisations for help.

Purposive and snowball sampling

Sampling approaches in research are said to be one of the most distinctive differences between qualitative and quantitative research. Qualitative research generally employs purposive, accidental, snowball and theoretical sampling (Coyne, 1997) and sampling procedures generally correspond with the philosophical stance of the type of research being conducted. According to Daly and Lumley (2002) sampling in a qualitative study that uses interview methods is like the collection of a slice of life to analyse and dissect. Given GTMs central focus on the development of theory by constant comparative analysis of the data via theoretical sampling, it involves a process of data collection, coding and analysis which determines where next to collect data to develop incipient theories (Patton, 1990; Coyne, 1997; Draucker et al., 2007; Bagnasco, Ghirotto and Sasso, 2014). Debates between researchers such as Patton (1990) and Coyne (1997) suggest that purposive and theoretical sampling have similarities and will constantly intertwine in data collection without the researcher's knowledge. Patton (1990) suggests that all variations of qualitative sampling can be bracketed under purposeful sampling as qualitative enquiry focuses on small in-depth samples are selected purposefully. Coyne (1997) agrees with Patton in that during the initial phases of collecting data, theoretical sampling includes purposeful components. Purposive sampling can be useful in selecting particular people because they provide topic relevant information that cannot be gleaned from other sampling designs. This allows the researcher a degree of judgement about who will give the best representation of the phenomena under investigation. Gray (2014) suggests one disadvantage to purposive sampling is that the researcher may accidentally omit vital characteristics in the sample selection and may be subconsciously biased in the selection process. Whether intentional or not, purposive sampling is a potential source of bias within research, that can lead to distortion in results and false conclusions, particularly where biased data collection is generalised to an entire population (Šimundić, 2013).

For this research project, purposive sampling was suitable to obtain participants to provide the information relevant to the research questions. Whilst conducting interviews snowball sampling also occurred. Snowball sampling is particularly useful in situations where a study concerns sensitive issues as participants often know other individuals who share the same characteristics, such as a mental health diagnosis, and can therefore provide the researcher with other potential participants. Snowball sampling removes the need for the researcher to purposively locate members of specific populations by penetrating social networks. This method of sampling is often used to obtain access to populations that experience marginalisation and stigmatisation (Noy, 2007; Heckathorn, 2011; Williams and Vogt, 2014).

For purposive sampling, an internet search was conducted using key words (such as BPD, borderline personality disorder, mental health support groups, user led mental health groups, personality disorder support) to identify organisations, user led support groups or private (non-statutory funded) that support people with a BPD diagnosis. Twenty-two organisations across England were identified ranging from statutory organisations to charities and peer support led groups (Appendix 2). Upon identification, an introductory email (Appendix 3) was sent to each of the organisations which provided a brief biography of the researcher, the reasons for the research topic and participant recruitment protocols and safety parameters for participation.

Lee and Renzetti (1990) suggest that our thinking about the sensitivity of a research topic, should encompass whether the research poses substantial threat that is problematic for researcher and the researched. What can be innocuous to one individual can be perceived as risky and threatening by another, therefore only individuals who want to be involved in the research are qualified to make the decision on sensitivity. Researchers can experience difficulty in recruiting participants via organisations due to gatekeepers who, as with Research

Ethics decision-makers as detailed above, believe participating in mental health studies can be detrimental to the people they support (Liamputtong, 2007). Alexander (2010) conducted a phenomenological investigation into the lived experience of people with malignant wounds and had just this difficulty in recruiting participants due to gatekeepers but found that those who took part found the process empowering, therapeutic and cathartic. In the current study, from the twenty-two organisations contacted, only four provided an initial response to the introductory email highlighting the difficulty with gatekeepers in the recruitment of participants. One response was an automatic email reply and one response stated that because the research was not commissioned or being delivered by the organisation themselves, they would not be able to promote it on their social media platforms or to their members. The other two responses received were extremely positive and agreed to promote the research on their social media platforms which resulted in six people making contact wishing to take part in the research. A second email was sent fourteen days later to the eighteen organisations that had not responded which yielded no response. After this purposive sampling, a snowball sample was used where information about the research was shared amongst friends and family of those that wished to or had already participated in the semi-structured interview. In total twelve participants were recruited for the study.

Semi-structured narrative interviews

Interviewing provides a way to understand human behaviour and encounter first-hand the knowledge which is under investigation (Morris, 2017). Semi-structured interviews stay on topic with minimal questions whilst allowing flexibility for the participant to narrate their story in their own unique way (Rubin and Rubin, 2012). Participants can elaborate and illustrate initial responses with the interview allowing time for in depth conversation whilst interview questions can draw on existing literature to focus the interview (Arksey and Knight, 1999; Gray, 2014). Semi-structured interviewing addresses reliability issues by making certain that questions directly focus on the research aims and the researcher builds trust with participants to give them the confidence to express themselves and their experiences. Actively listening to participants language helps identify and link their lived experience with the research questions. A total of eleven semi-structured narrative interviews were conducted, and one participant completed the interview questions via email. One participant was male, eleven were female with an age range of 27-80 years. Participants were located across England including the East Midlands, South-West, West, South-East and Yorkshire and Humber.

Where social injustices exist, semi-structured narrative interviewing can highlight their presence through understanding everyday social interactions through participant responses to questions about experiences within particular settings. Interviews are therefore one of the most common data collection methods (Gelling, 2015) in research that seeks to create a listening environment in which meaning is constructed through a verbal exchange of viewpoints. The Charmaz (2005, 2006) constructivist approach advocates embracing the diverse worlds, multiple realities, and complexities of participants. Charmaz' (2005, 2006) approach places emphasis on the views, feelings, values, beliefs, assumptions and ideologies of individuals rather than on specific research methods. Charmaz (2005, 2006) contends that complex jargon, and dogmatic approaches detract from GTM and represent attempts to gain power. Charmaz' approach does not minimise the researcher's role in the process but instead highlights their personal values, experiences, priorities and decision making. Similarly, Kelly, Burtons and Regan (1994) and Streubert and Carpenter (2011), similar to Charmaz hold that the choosing of a particular research method should not be because of its relationship to following certain methodological theories but whether it fits with the question being asked in the research.

The power dynamics of research interviews and the resultant production of knowledge must be reflected on and addressed (Kvale and Brinkmann, 2009). Power is intrinsic in relationships and conversations and can be difficult to eradicate from research interviews. In research interviews, the researcher initiates the conversation, defines the interview situation, determines the topic, poses the questions, decides on which responses to follow up on, terminates the conversation when necessary and has monopoly when it comes to the interpretation of participants' statements. According to Elliott (2005), Graham (1984) and Stanley and Wise (1993) researchers who willingly give space for participants to give accounts of their lives and experiences actively rebalance power differentials in research, provide opportunity for individuals to have an active role in the research process (Williams and Vogt, 2014) and also obtain rich information about individuals' lives and experiences.

Semi-structured narrative interviewing, as used in this study, attempts to understand the dynamics and themes of participants' lived reality from their perspective through the interaction between two people to co-construct knowledge of that reality. This social constructivist approach requires sensitivity to interpretative aspects by which meanings are accomplished in the interaction between interviewer and interviewee (Harris, 2003). Kvale (2007) and McDougall (2000) suggest that the participants and interviewer act in relation to and influence each other, producing knowledge constituted by the interaction itself. Researchers bring our own experiences, knowledge, values and personal histories to the subject under investigation to the research process, that adds richness to the interview process. Whilst conducting interviews for this project, some of the researcher's personal experiences and knowledge of BPD were shared with participants to assure them of the researcher's sincere intentions which resulted in a greater level of trust and deeper conversation between interviewer and interviewee leading to a deeper understanding of participants' experiences and their impact.

It is essential for the researcher to consider the social and cultural contexts in which data is collected before conducting interviews. This is particularly important when interviewing participants with a mental health condition.

Narratives

Narratives are one of the most natural forms for individuals to organise and express meaning. Narratives are simply a story with a beginning, a middle, and an end and provide an approach for recounting past experiences in a verbal sequence of events that have actually taken place (Labov and Waletzky, 1967). Narrative interviewing originated with the Chicago School of Sociology in the 1920s and is primarily concerned with the long humanistic tradition within the social sciences in the relationship between the individual and social experiences (Plummer, 2001; Owens, 2007) and particularly the meaning of behaviour and experiences from the perspective of participants. Bauer and Gaskell (2005) take the view that narrative interviews, as a method of autobiographical data collection, are the most highly developed of interview techniques because they are more naturalistic and provide rich data which brings the researcher closer to the real-life situations and experiences.

Narrative interviewing allows the interviewer to directly ask for stories of experiences relevant to the subject under investigation (Kvale, 2007). This form of interview can take various forms: a short narrative story of a specific timeframe or episode of events significant to the individual; a 'life history' as seen through the narrators' own perspective or an 'oral history' in which the subject moves beyond individual history into the history of their community (Bornat, 2000; Rosenthal, 2004). Participants can explain events in their life in the hope that the researcher will learn something about the topic under investigation be of benefit to others or contributing to existing knowledge or professional practice about this aspect of human experience (Clandinin, 2007).

Narratives are both chronological and retrospective, meaning that the narrator assumes responsibility to order and prioritise events, placing them within particular contexts to identify connections and explanations between events (Soderberg, 2006). Attention must be paid to the narrative quality of research material which means that the data cannot be fully understood without acknowledging who it has been produced for, that is the reader/researcher (Elliott, 2005). Charmaz (2005) recommends exercising caution in which narrative frame is applied and how this is done when using interviews as a data collection method. The narrative frame is the pre-judgements, boundaries and logic of temporality that can be over or under used. Knowledge can be assumed and given a status of power particularly when the words of others are taken out of the lived context, printed and placed within the public domain where they can be interpreted and given alternate meanings (Barbour and Schostak, 2005).

Qualitative researchers, such as Charmaz (2011) and Morris (2017) have developed understanding of the significance of narratives in relation to chronic ill-health, mental ill-health, diagnostic labels and the impact on one's sense of identity and social functioning. Morris' (2017) research on lived experience of care interventions for individuals with mental ill-health experiences conducted a series of narrative interviews which generated a sizeable amount of extra rich data on the difficulties around recovery and well-being. Morris (2017) used inductive analysis to generate themes from the data to make comparisons to related lived experience research. Without comparing findings to existing knowledge on the subject, both researcher and reader will experience difficulty in ascertaining whether the findings are new and what contributions they make to knowledge (Kvale and Brinkmann, 2009).

Researchers who conduct narrative interviews acknowledge that they are driven by ethical, personal and, at times, political standpoints to improve the social and individual circumstances of those who are stigmatised or socially excluded in society. The ability to tell a story of a previously silenced individual can advocate for changes in policy and academic thinking as well as empowering individuals (Chamberlain, 2013). Streubert and Carpenter (2011) and Birch and Miller (2000) suggest that participants of qualitative interviews, especially in mental health research, can experience qualitative interviews as therapeutic as it provides opportunity to voice an experience, have that experience validated and, for some, feel empowered. However, ethically, as in this study, risk mitigation must be applied when interviewing participants from vulnerable populations as the opportunity to share life experiences can expose and bring to the surface feelings of distress.

Data saturation

Originating from GTM and considered as an essential methodological element, saturation is described as the discontinuation of data collection (and analysis) when data becomes repetitive and does not provide new information. It must be considered in all research, and the researcher must have awareness of the right time to stop collecting data by debating whether any new knowledge can be gained from new participants. However, the inability to identify when saturation has been reached will impact on the quality of the research being conducted (Fusch and Ness, 2015; Saunders et al., 2018). In this research, saturation point was identified upon completion of the twelfth interview. Participants' experiences although individually unique, shared similarities, context and content relating to services or identical skilled professionals. The researcher, thus, questioned whether continuation would provide any new information or cause detriment to the quality of data already collected, and upon guidance from the supervisory team it was determined that saturation had been reached.

Transcription

Transcription is the translation of a verbal interview into a written account. It is not a simple task; the difficulty lies in interpreting the semantic properties of the voice such as tone, pace and emphasis which can fundamentally alter the meaning of the words (Gillham, 2005). Most research methods literature argues that the researcher should transcribe the data they have collected. However, due to the researcher's disability, the ability to transcribe interview recordings was not possible. The researcher felt this did not inhibit their ability to conduct good data analysis, the researcher was able to fully immerse themselves in the data, the interview recordings were listened to on numerous occasions, the notes made during the interviews reviewed and the transcriptions repeatedly analysed.

Analysis

GTM approaches the building of theory in a different way to other research analysis in that theory is developed and emerges direct from the interview data via analytical induction. Inductive analysis entails a number of defined stages starting with a research question following which data is gathered and examined to see whether it corresponds with the research question. Bryman and Bell (2007) propose that inductive analysis is a thorough analytical method in that if one data set is inconsistent then further data must be collected. One of the main strengths of inductive analysis is in the researcher allowing the data to be true, in that the researcher remains free of preconceived ideas/expectations of the data and is working exclusively from the experiences of the participants which is the main drive of the analysis and can often provide unexpected insights and understanding of people's experiences (Fielding and Lee, 1998; Chamberlain, 2013; Azungah, 2018). Bergdahl (2015) highlights a negative aspect of inductive analysis in that the experiences under analysis can have the potential to become repetitive and lost in translation when connections to previous research or theoretical perspectives cannot be found. This can be problematic in that the theoretical terminology used can lose meaning and not reflect or explain how things work. Strauss and Corbin's (1990a, 1998) analytic approach is to systematically develop theory to explain actions, interactions or processes of a topic. In most cases the researcher will conduct a sizeable number of interviews in the field to collect data until categories are saturated and all avenues to add information are exhausted. For this research, the process of analysis began during data collection, notes were made by the researcher during interviews of similarities, keywords and experiences as well as interview recordings being replayed before transcripts were available to analyse. This enabled the researcher to identify early the starting framework of the coding process.

In GTM, constant comparative methods of data analysis are applied and the data coding process to identify major categories begins. Strauss and Corbin (1990b, 1998) and Vollestedt and Rezat (2019) categorise these as casual conditions that result in development or appearance of a phenomena (factors that caused the central phenomena); strategies (actions taken in response to the central phenomena); interviewing conditions (situational factors that influence strategies) and consequences (the outcomes from using strategies). From these categories a visual model known as the axial coding is developed. Selective (theoretical) coding was then used to develop a model that describes the interrelationship of categories.

As noted above, there is an established process for classifying and identifying a central theoretical element that can be emergent from the core categories identified through analysis from the axial coding process. These occurring elements can appear through natural relationships of commonality between the concepts, similar occurrences or ideology, although this yields a lack of interpretation. The forming of categories begins from the first analysis of a transcript and increases when moving from one transcript to another (Gillham, 2005). Categories should be descriptive and indicate the quality of the statements allocated to them to enable analysis to make distinctions with the data in order that differences can be seen clearly.

Data analysis proceeded as soon as the first interview had been completed to draw out initial categories and sub-categories for analysis. Several keywords were identified within the text and then grouped into categories and sub-categories. Theoretical sensitivity and continuous analytical comparative procedures of grounded theory when applied to interviews, can progress beyond the data that is collected into a more conceptual level (Miller and Dingwall, 1997).

NVIVO 12

GTM heavily influenced the design of NVIVO as a tool to assist in identifying patterns in and the recontextualization of the data to move from analysis to theory development (Bazely and Jackson, 2013). Grounded theorists generally conduct a preliminary analysis before incorporating any research literature to maintain the grounding of analysis and theory. The inclusion of existing theory is not excluded but is delayed to form a part of later theory development with the aid of NVIVO. The organisation of interview transcription text into nodes and sub-nodes in NVIVO helps organise large amounts of data, link passages and connect theoretical concepts. A node represents a passage of text considered to be important (Gibbs, 2002). Dey (1993) proposes that the nodes should be a reflective mirror of the data as a way of aiding the analytical process.

NVIVO training was undertaken to enable the researcher to make full use of the software in analysing and coding the data. Interaction with the data through NVIVO helped the researcher to re-engage and ‘see’ the experiences of the participants. ‘Seeing’ is the sensing of a previously observed pattern in the data pattern (Boyatzis, 1998).

Coding

Coding is the main analytical process in GTM and requires asking analytical questions of the data and categorising concepts to develop an understanding of the social world (Charmaz, 2006; Maher et al., 2018). According to Charmaz (2006, p.45) coding “generates the bones of analysis” and shapes the frame from which analysis is built. She suggests that language informs what and how researchers code, as language carries meaning and forms the empirical realities and understanding of human experiences, as well as reflecting values and views. Coding is the naming of segments of text that simultaneously categorise, summarise and account for each piece of data. It is the initial step of moving data beyond narrative to analytic interpretation. It is achieved by extracting data into abstract concepts, systematically creating relationships to other abstract concepts and then theoretical concepts. Coding requires careful attention to enable researchers to develop a deeper understanding of participants’ experiences, actions and stories allowing comprehension of different peoples’ viewpoints and situations from the lines of interview transcriptions (Gibbs, 2002; Charmaz, 2006). This was found to be particularly relevant as it enabled the researcher to fully immerse themselves in the transcriptions to gain a thorough understanding of participants narratives, emotions and empowerment from taking part in the research.

Open coding

Strauss and Corbin (1990a) advise that open coding should begin with the researcher reading the texts line by line to identify and code ideas. The text should be constantly questioned to identify and understand the who, when, where, what and why in the narratives. This is designed to raise awareness of any theoretical issues and discourses behind the text and develop sensitivity to the deeper theoretical layers in them. GTMs constant comparison and theoretical sampling techniques are useful in the early stages of analysis although it can be difficult to know what to code. To address this, each transcript was initially read line by line with areas of text highlighted and side notes made as a way of immersing the researcher in the text, providing a visual aid and making comparisons between the transcripts. During the initial phase of coding, a total of twenty- four nodes (concepts) were identified with thirty-seven sub-nodes (concepts) and seventeen sub-sub-nodes (concepts) as indicted below (Table 1).

In Table 1, the arrows give direction as to which main concept contains the sub concepts. The first phase of coding identified codes relevant to the study question and seven concepts (PMDD, media representation of mental health, negative voice, causation theory, age at diagnosis and pre-diagnosis symptoms) which did not bring any value to being included in the current study were reserved for future study. A second sweep of the data to identify any new phenomena was completed but yielded no new concepts.

Node	Sub-node	Sub Sub-node
Advice for professionals		
Age at diagnosis		
Awareness of BPD label stigma	Dustbin diagnosis	
Co-morbid diagnosis		
Culture	Health professionals	General practitioner
→	Non-health professional	
→	Professional hierarchy	
→	Social acceptance of mental health	
Diagnostic assessment	Pre-diagnosis symptoms	
Education of professionals	Challenging perceptions	
→	Lack of awareness	
Experience led training		
Gender		
Impact of diagnosis	Family/friend/services support after diagnosis	
→	Information given on diagnosis	
→	Self-education of BPD	
Inappropriate professional behaviour		
Loss of identity		
Media representation of Mental health		
Negative attitudes of BPD		
Peer support		
Personal insight of services		
PMDD		
Power of language	Client	
→	Patient	
→	Service user	
Re-classifying BPD	Causation theory	Family
Seeking a service in crisis		
Self-empowerment		
Service provision	Activism for inclusion	
→	Engagement by services	
→	Exclusion	
→	Impact on coping mechanisms	
→	Impact on crisis distress level	
→	Therapy provision	
Stigma experience	Negative	A&E
→	→	CPN
→	→	Crisis team
→	→	Friends and family
→	→	GP
→	→	Mental health services
→	→	Other
→	→	Paramedic
→	→	Police
→	→	Psychiatrist
→	→	Therapist
→	Positive	A&E
→	→	GP
→	→	Non NHS
→	→	Paramedics
Validation by professionals		

Table 3 NVIVO open coding nodes (concepts)

Axial coding

Charmaz (2006) suggests axial coding allows for the exploration of connections between concepts to bring to light any phenomena that may exist. She also states that the reliability of axial coding potentially limits what and how researchers learn from the worlds that are their focus of study and can subsequently restrict the codes that researchers construct. Corbin and Strauss (1990) cautiously noted that although axial coding provides a framework for researchers, that can either limit or extend analysis dependent on the subject matter and the researchers willingness to remain open. During this phase, the researcher studied the concepts generated to identify emerging phenomena through connecting open codes based on similarities. A total of five categories were identified as indicated in Figure 1.

Axial codes

Theme –**BPD Stigmatisation awareness and experience**

Stigma experience negative (A&E, CPN, Crisis team, Friends and family, GP, Mental health services, Other, Paramedic, Police, Psychiatrist, Therapist) – Positive experience (A&E, GP, Non-NHS, Paramedic) – Awareness of BPD label stigma (dustbin diagnosis) – Loss of identity – Negative attitudes of BPD.

Theme – **The Power of language**

Identification (client, service user, patient)

Theme – **Service provision**

Engagement by services – service exclusion – impact on coping mechanisms – impact on crisis distress level – therapy provision – activism for inclusion

Theme – **Professional power**

Culture (health professionals – non-health professionals, professional hierarchy, social acceptance of mental health) – Inappropriate professional behaviour.

Theme – **Reclaiming power and identity**

Experience led training – peer support – self-empowerment – activism for inclusion – re-classifying BPD – Education of professionals (challenging perceptions, lack of awareness) – advice for professionals – validation by professionals.

Figure 2 Axial coding categories

Selective coding

After developing axial codes, central themes or phenomena began to emerge. These emergent central themes give a way to narratively bring together the major conceptual elements of the study, a theoretical umbrella that unites concepts and enables the researcher to position their argument of the thesis (Charmaz, 2006). This is the final process of coding within GTM (Strauss and Corbin, 1990a). Selective coding is important to GTM as it increases a study's explanatory power; in the absence of selective codes, axial codes become mere descriptive themes rather than explanatory categories. Selective codes are integrative and assist in telling a sound analytical story, add precision and make the analysis coherent and comprehensible (Charmaz, 2006). Glaser (2001) suggests that some researchers make errors in believing that core categories generate selective codes and suggest that they do not, instead they arise from researcher analysis of the core categories. After careful study of the developed axial codes, an emergent developmental theoretical framework was identified, the Dominant Identity Status Cycle (DISC) which provided the theoretical umbrella for the research.

Limitations

The first limitation to note is that the participants who volunteered were almost exclusively female. This was not surprising as BPD is predominantly diagnosed in females with a female to male gender ratio of 3:1 or 75% (Cartwright, 2008; DSM-5, 2013). Men are diagnosed with the condition however, it is thought they are often clinically misdiagnosed with narcissistic, schizotypal, anti-social personality disorder (ASPD) or substance use disorder which results in an inaccurate picture of the true extent of diagnostic rates for men. Consequently, little is known about men with BPD, but it is estimated that within the general population around 20% of men diagnosed with BPD can also present with co-morbid ASPD (Grant et al., 2008; Goodman et al., 2013; Robitaille et al., 2017). Studies on clinical populations, such as forensic settings, have found a high prevalence of men with the diagnosis (Black et al., 2007; Wetterborg et al., 2015). The gender divide in a BPD diagnosis has led to speculation as to whether the higher rate observed for women reflect sociocultural or biological differences between the genders (Skodol and Bender, 2003). More male participants would have provided a greater opportunity to compare differences of affect, cause and experiences of having a diagnosis of BPD between the genders. A small number of research studies (Sansone and Sansone, 2011a; Robitaille et al., 2017) have been carried out on the male perspective of BPD, as might be expected within western culture where it is known men are generally less inclined to share or openly discuss emotional aspects of their lives.

The second limitation is the lack of participants from Black, Asian and Minority Ethnic (BAME) groups. ETHNOS (2013), a research and consultancy agency, conducted a survey in England to determine the discrimination faced by people from BAME communities who used secondary mental health services. From a sample of 740 individuals from African, Caribbean, Indian and Pakistani/Bangladeshi groups, the research identified that BAME people experienced high levels of stigmatisation and discrimination: firstly, from their friends, family, and communities because of their mental illness and secondly, from mental health staff because of their mental illness due to race, social and cultural reasons (Rehman and Owen, 2013). Not only would more BAME participants have provided divergent perspectives of issues around a BPD diagnosis but also how mental ill-health can be viewed as taboo and something to fear within cultural and religious groups and the impact upon this group from stigmatising attitudes within their communities. For example, the South Asian community in England still largely considers mental illness a taboo with stigmatising attitudes influenced by the older generations to protect family status and public appearance (Rehman and Owen, 2013). Loss of status or appearance because of a family member with mental illness affects the entire cohort of family relations and can result in exclusion from the community, and damage marital prospects for younger generations. As a result of the taboo, there is fear about revealing mental health difficulties, and pressure to socially conform (Time to Change, 2010). The stigmatisation and discrimination faced by BAME people could mean they engage less with support services and so did not hear about the research recruitment and, separately, the stigmatisation and discrimination could have been a potential deterrent to participating in the research.

Finally, Covid-19 created unforeseen difficulties during data collection. At the time the first lockdown was implemented by the UK Government, the researcher was mid-way through data collection and at this point, participant recruitment rapidly ceased. The remaining interviews had to go online using platforms such as Skype or Zoom which was challenging because of the huge increase of demand on the internet from those who had to continue working from home which resulted in limited internet operating speeds. Interviews were difficult due to connectivity issues at times which disrupted the flow of narratives. Lockdown was also difficult to adapt to for the researcher who lived alone and found this time increasingly isolating, impacting their physical and mental wellbeing and difficult for potential participants.

The next chapter will present a reflexive account of the researcher’s personal experience in relation to stigmatisation of the BPD diagnosis and how this attributed to conducting this research.

Chapter 4. Personal reflexivity

Researchers are active representatives in acquiring knowledge of events, narratives, and experiences of the research context. Researchers do not just choose a topic to study, but as Hamdan (2009) states they also have distinct agendas in seeking answers to topics that have some sort of personal connection or interest. Reflection allows for researchers to identify and explore their position taken in conducting a study (Bukamal, 2022) and can be useful for managing emotions, boundaries and other complexities when undertaking research that has a personal connection. But reflection can also be uncomfortable in picking apart reasons, experiences and actions during the research process (Plummer, 2001; Ponic, Reid and Frisby, 2010). Reflexivity, however, has received criticism from some academics such as Finlay (2002) suggesting the practice of it is narcissistic and self-indulgent placing the voice of the researcher above the voices of participants.

The question I reflect upon here is how my personal experiences shaped my journey as a researcher during this study. Sharing my experiences and emotions, and opening myself up to the reader's potential judgments of you it is difficult and emotionally uncomfortable work. This is by no means a judgement of my previous partner, but when you witness the person you love(d) in distress or having hurt themselves, it is painful to recollect. However, I am aware that my discomfort and pain provided the catalyst for me to undertake this study to address the stigmatisation associated with the BPD diagnosis. Despite this being an uncomfortable reflective process, my personal experiences have provided me with an opportunity to challenge and question beliefs and assumptions of the diagnosis that have been shaped by ways of thinking in frontline services or dominant cultures (Wilson, 2020). I will outline a short summary of why I wanted to address this subject for research and my experience during this PhD.

Looking back on my experience of doing this study there have been challenging events which, at times, affected my ability to conduct this research. The first was the Covid-19 pandemic, which, as I live by myself with my two dogs, was a particularly isolating and lonely time. During this period, I lost four members of my family to various illnesses and, due to the Covid restrictions, I could not be there to support my family or pay my final respects, instead having to watch their final send-offs livestreamed by the church or crematorium. More recently, as

I was preparing to submit my thesis for examination in the Summer of 2022, my beloved mum passed away the day before her birthday after a short and unexpected illness. She was my secure attachment, my rock, best friend, she gave me guidance and was always there when I needed a hug or wise word. This loss was mentally, emotionally and motivationally challenging. However, I remained resilient and persevered, not for myself but for the participants and my mum who was my biggest and proudest cheerleader. In light of the losses I have had, reflection on my emotions which make me feel vulnerable and in my experiences associated with this topic, it was necessary for me to protect my mental well-being and set an emotional boundary.

The study of borderline personality disorder and personality disorders in general has been my area of interest and research for over nine years and so was the obvious topic to develop for my PhD. My interest began in 2005 when I started what would end up being a thirteen-year relationship with someone who had a diagnosis of BPD. Then I had little knowledge of the existence of personality disorders and their meaning, I expanded my knowledge and learned about how I could best support my partner. Everything I read however, whether from academic research or books such as *Stop Walking On Eggshells* (Mason & Kreger, 1998), was extremely negative, stigmatising and discouraging for anyone from interacting or being in a relationship with someone with the diagnosis. The language used to describe BPD as a condition and those with the diagnosis was inflammatory, describing them as emotionally erratic, dangerously impulsive, manipulative and self-destructive. However much I found the descriptions offensive, I reflected on how being described in such a way may impact those recently diagnosed and learning about the condition.

During the relationship, I also became aware of how the diagnosis not only influenced professionals' and services' behaviour towards my partner but also towards me as 'stigma by association' (discussed in Chapters 6 and 8) and this became the particular focus of my PhD. As a further insight into why this study is focused on stigmatisation experiences by frontline services of the BPD diagnosis it is important for me to share my personal experiences. There are many personal experiences I could choose for reflection here, but for ethical reasons, protection of my boundaries and a desire to protect my ex-partners identity and wellbeing, I have been mindful in my choices and have selected three experiences which are the least emotionally triggering to share. These relate to diagnostic overshadowing, stigma by association and stigmatisation by professionals in A&E. These experiences highlight the importance of having lived experience people in frontline services and delivering educational training to improve knowledge and understanding. To fully explain the experiences, I will provide some background context. As I have personal connection with the research topic, I felt it important to discuss how that connection relates to my researcher status with participants but also as lived experience which guided me during my data collection.

Insider-outsider status

Insider-outsider status refers to whether or not the researcher shares a group identity with their participants (Bukamal, 2022). Merton (1972) classes an insider as a person who has a substantial amount of knowledge of a community and its members or pre-existing connection to the group they are studying due to their lived experiences (Gair, 2012). The insider/outsider status is operational when gathering research data when the researcher highlights that they have a shared understanding of experiences. However, familiarity with or knowledge of a community and its members does not give automatic acceptance to an individual once they are collecting research data. Insider status warrants caution due to the potential to create a sense of familiarity that can be too close to the research and at risk of filtering personal emotions and beliefs into their research (Chavez, 2008). Although shared status can have benefits, it also has the potential to impede the research process and close connection to the topic can influence the analysis of data leading to an undue emphasis on shared factors. I was aware that my personal experiences could cloud my analysis but the methodology used gave me the necessary, systematic tools to view the data as data and explore only what was there and not what I may have wanted there to be based on my experiences.

My personal experiences situated me as an insider in the research process which I was able to use to help participants feel safe and supported to talk about their, sometimes painful and emotionally difficult, experiences. My standpoint was that if I wanted people to be open with me, then I needed to be open with them about my own lived experience to provide a source of connection and create an atmosphere of an informal conversation rather than a formal interview. Being an insider meant showing empathy and consideration in my questioning and discerning participants' emotions when describing an event because I could often relate to an element of what they had gone through and the impact it had on their emotional wellbeing and sense of self. My lived experience placed me in a unique position as a researcher and as a person participants could trust to write their reality with consideration. I also made a conscious decision to ensure that the language used in the thesis had no direct use of stigmatising narratives towards people with the diagnosis.

As a researcher, I hold power over the interpretations I make with Bryman (2016) suggesting that likes and dislikes, past experiences, interests, and expectations are all acknowledged to play a central role in the research process. Power can manifest in different ways depending on the researcher. Therefore, Shai (2020) suggests that researchers question themselves at the beginning of their work, and throughout, to examine their position of power. My past experiences and interest in the subject of BPD stigmatisation were motivational in ensuring that the participant/researcher relationship was not a power imbalance but one of as near equal standing as I could create and as this subject was one with which I had a personal connection, I wanted to provide a platform to try and ensure that the voices of the participants, their experiences, thoughts and meanings were at the forefront of this study. This was very important to me as it is common, and has been since I started my journey of discovery of BPD, that research into the diagnosis is dominated by medical/psychiatric professional narratives which can be negative and maintain stigmatisation of the diagnosis. This was motivated by witnessing how people with a mental health diagnosis frequently have their voices silenced or their experiences, thoughts and meanings questioned and judged. An example of this is my witnessing of diagnostic overshadowing, which during interviews was also shared by some participants' experiences and is outlined below. Conducting research undoubtably gives elements of power to the researcher which can influence the relationship between the researcher and the participants, how the study is conducted, what data is included and representation of the participants' 'voices'. However, critical reflection helped mitigate, to some extent, power differences between the researcher and researched (Naples and Sachs, 2000), as well as deepening interpretation and analysis.

As a researcher I might be affected by, and affect, participants, so it was important during the fieldwork stage that I was mindful of my emotions after interviews and had support if needed.

It was also important that participants had a support network as well, in case anything they shared was emotionally triggering. Considering my position as a researcher I was also aware of the power element between the researcher and the researched.

Diagnostic overshadowing

I accompanied my partner to GP and hospital appointments to act as an advocate as each time she presented to health services with a genuine physical concern, it was her mental health diagnosis that would inevitably become seen as the cause of her physical concern in a process of diagnostic overshadowing. I tried to ensure that diagnostic overshadowing did not happen, and that her mental health diagnosis remained detached from her presenting physical health concerns. However, her mental health diagnosis was always the lead condition on referral letters from the GP to Consultants and she was aware of this as she received copies of referral letters to our home address.

One example of this was during a referral to a Gynaecology Consultant after prolonged severe pain, heightened suicidal ideation and fluctuations in mood and ‘maladaptive’ management of those fluctuations. The GP inferred it was symptomology of her BPD diagnosis, but after much persistence and name dropping of the doctor she would like to see, the GP referred her to see a leading consultant based in London. On the first consultation he took her medical history and current symptomology and suggested a series of tests. It transpired that she had a condition called Pre-menstrual Dysphoric Disorder (PMDD) which is a very severe form of premenstrual symptoms (PMS) and each symptom associated with PMDD was what she was experiencing monthly. The mental and physical symptoms of PMDD are:

> **Mental health symptoms -** Irritability or anger, sadness, despair or thoughts of suicide, tension or anxiety, panic attacks, mood swings and crying often, lack of interest in life, trouble thinking or focusing, tiredness or low energy, food cravings or binge eating, trouble sleeping, feeling out of control.
> **Physical symptoms -** Cramps, bloating, breast tenderness, headaches, joint or muscle pain.

Awareness and knowledge of PMDD at that time was still limited in General Practice. Unfortunately, the only plausible option, due to the severity of symptomology, was to have a full hysterectomy and Hormone Replacement Therapy. Undergoing this major operation is difficult enough, but removing the opportunity to give birth was, for her, emotionally devastating and there was no emotional support offered despite repeated requests. So, I inevitably, became the main emotional support which was challenging and at times I did feel like an ‘emotional punchbag’. This was not her fault and I did not blame her, I was the only person with whom she felt secure and safe in offloading her emotions. However, I do think that we were both let down through the lack of therapeutic provision. Lack of access to therapeutic support and the negative impact of that was a point raised by the majority of my research participants.

PMDD is something I think about in relation to whether there is a case of misdiagnosis between the PMDD and BPD diagnosis. The mental health symptomology of PMDD is very similar to that of BPD and most females’ symptomology of BPD begins around the time of puberty when hormones are in a state of flux, and hormones are the master of one’s mental and physical homeostasis. However, I am not suggesting that this could be the case for every women diagnosed with BPD, and obviously for men could they have a hormone imbalance also, but I do wonder about it. The next experience focuses on how close association to someone with a mental health diagnosis can cause others to question that associate’s character and mental health.

Stigma by association experience

As I would always accompany my partner to medical appointments as my partners’ advocate, I was made to feel that I was challenging the power and knowledge of the medical establishment. As a result, I noticed that when I needed to see the GP for myself, their attitude and treatment started to change. When suffering from shortness of breath and heart palpitations for some months, I visited my GP, who was also my partner’s GP, on five separate occasions presenting with the same symptoms before they decided to refer me to a cardiologist. The cardiology appointment resulted in my being diagnosed with Ventricular Bigeminy and lifetime treatment using beta blockers. The GP requested a follow up appointment to discuss the outcome and the first thing she said was “Well you weren’t lying, were you?”. I was taken aback and felt insulted, responding in a harsh tone “Why would I lie?”. The GP could not answer my question and quickly moved the conversation along. After a few days of reflecting on what had happened, it became clear that I was now being treated the same way as my partner and associated with mental ill-health primarily because I would actively support and advocate on her behalf. However, that experience returned to me and led to questioning myself whether I had unknowingly done or said something for the GP to treat me in that way. I also became angry and frustrated; I had only had a small taste of what my partner had experienced and kept on experiencing because of the BPD diagnosis. One participant in this research shared her experience of stigma by association whilst advocating for her neighbour. The sharing of her experiences unexpectedly provided me with some comfort and validated my own experience.

The last experience I want to share is difficult and describes a visit to Accident and Emergency department. It is an experience that has always filled me with sadness, because of how distressed my partner was at that time, and my disappointment in the lack of care and empathy from the health service.

A&E stigmatisation

The experience occurred at a time when my partner was going through a very difficult time with PTSD symptoms including being in a constant state of hyperarousal, in part not helped by a lack of GP and mental health service support. My partners' coping strategy for the emotional rollercoaster she experienced was self-harm in a variety of ways. One evening I was woken by my partner who asked me to take her to A&E as she had a large open wound in an intimate and sensitive place that required medical intervention.

We arrived at A&E and explained to the front desk staff why we were there and took our seats waiting to be seen. After a few hours, a nurse called us into one of the cubicles and did an assessment, which meant disclosing her mental health diagnosis, and determined that the wound required stitches. I found the nurse's attitude cold, unempathetic and uncaring although whether this was because it was a self-harm incident or due to her diagnosis was difficult to determine. The nurse finished the assessment stating that one of the doctors needed to see her. We waited for another two hours until a doctor appeared to assess and close the wound. His attitude was authoritarian, and my partner said it made her feel like she was wasting everyone's valuable time and resources. He asked her why she had done it, and she explained her reasons which led to the usual response of, "Let's get the mental health team to see you before you leave”. She did not decline and said she felt some relief that she would get the chance to get some support. Meanwhile, the doctor got the necessary equipment to close the wound whilst I exited the cubicle to wait until the stitching was done. After a short while, the cubicle curtain was drawn back and my partner was white as a sheet and I could see she had been crying. I asked what was wrong, to which she replied “Nothing, it’s just a bit sore, can we go home now?”. I persuaded her to wait a bit longer for the mental health team but after an hour we were both tired, and she was in pain, so we left.

The next day I found out that the doctor had not used any anaesthetic before closing the wound. I was so angry and wanted to put in a formal complaint, but she asked me not too as she thought this would only cause her more trouble if she needed to go there again or if it was on her records. I later found out this incident was not the first time she had had this happen to her. This kind of experience, reflected by some of the participants in the study, and the lack of ethical treatment of self-harm wounds became such a serious situation that national healthcare standards were developed to ensure that this practice stopped. This is discussed in more depth in Chapter 6.

Final thoughts

I have always been an advocate for ensuring that people who are marginalised and treated unfairly should not be denied opportunity, treatment, or access to what can make their quality of life better. Mental health is I think one of those grey areas which will always have an element of social injustice despite positive actions to increase awareness and make it the ‘norm’ to discuss amongst our peers. My ontology and epistemology naturally went together based on my own personal beliefs. People who are singled out because of a diagnosis which is deemed one of the troubled conditions, should be heard, validated, and their experiences recognised to set in motion a change within services. As a social constructivist researcher my experiences allowed me to understand the participants’ experiences, the emotional impact and how that had shaped their reality and understanding of the world. I wanted to explore whether their experiences of frontline services had any similarities to what my partner had gone through, how they interpreted what they had experienced and how that made them feel. I could relate to everything they said and shared which ignited in me the overwhelming sense of injustice, inequality and lack of basic human rights that this diagnostic label imparts to the holder of it. I was able to share, in my understanding of their feelings, a genuine empathy when they remembered and discussed their experiences. Additionally, it enabled me to acknowledge their individual experiences, and encourage them to share certain parts of their life in the hope that they could make some difference.

Sharing these experiences highlights a commonality of stigmatising attitudes and behaviours towards people with the BPD diagnosis. The experiences I offer here, although unique to me as an individual, are reflected in the accounts by participants of how they have experienced frontline services and professionals. Despite maintaining systematic and rigorous analysis, the findings in this study were what I expected, however, I had been hopeful that there may be indications of positive changes happening. I hope, as do the participants, that this research can make a small difference, or at least leave readers with questions as to why this diagnosis continues to be so stigmatised.

The continuing development of my DISC theoretical framework represents a useful tool for services which can be implemented to change the narrative around mental health and behaviour and attitudes to mental ill health. The stigmatisation of mental health will continue to be an area of research for myself and other researchers in the pursuance of highlighting social injustice concerns, championing human rights no matter the diagnosis and guaranteeing access to needed help and support. Lastly, without meeting my ex-partner I would not have had the opportunity to pursue this area of research which has been important to me, so for that I am grateful to her and to the participants for their time, honesty and belief in this study.

The next chapter introduces a critique of the medical model of mental health and how it medicalises natural human responses to trauma including emotional distress and resulting behaviours. The medical model dominates professionals’ responses to mental health through the use of medical language jargon (‘symptoms’, ‘illness’, ‘treatment’), practice (diagnosis, hospitalisation, administration of drugs), and social factors (exclusion, stigmatisation, discrimination, identity). The medical model of mental health is the foundation of the new theoretical framework, the Dominant Identity Status Cycle (DISC), to theorise why people with a diagnosis of BPD experience stigmatisation, social exclusion and discrimination.

Chapter 5. Critique of the Medical Model

Psychiatric disorders are socially constructed through the medical model of psychiatry (McCann, 2016). The medical model of mental (ill)health medicalises a person's emotional and mental states and potentially their distress. It ensures that psychiatric 'expertise' is the dominant ideology and allows psychiatry to maintain power, status and control over people with mental health conditions (Thoits, 2020). This control of 'unpredictable' and 'disordered' people enables society to ignore oppressive treatment towards them by excluding them from society (Thoits, 2020) by suppressing people's behaviour. It also fuels the continuation of social inequalities and injustices for individuals with mental health diagnoses which result in exclusion, disempowerment, oppression and stigmatisation (Johnstone, 2014).

Until its medicalisation, psychiatry was dominated by the Freudian psychoanalytic approach of uncovering subconscious thoughts. This focused largely on childhood experiences, dream analysis and identifying suppressed trauma (Horwitz, 2002). Psychiatric practice did not originally place much importance on diagnostic categories as reflected in DSM-I and the views of prominent psychiatrists like Adolf Meyer (Grob, 1991) and Karl Menninger (Mayes and Horwitz, 2005). DSM-I conceived of mental health systems as reflections of underlying dynamic conditions and reactions to difficult life problems. The understanding of symptoms as symbolic manifestations of life events became meaningful only through the exploration of the personal history of each individual. Psychiatrist Karl Menninger argued that separating individual mental disorders into discrete diagnostic categories with unique symptoms was a mistake (Mayes and Horwitz, 2005). Instead, Menninger viewed all mental disorders as 'reducible to one basic psychosocial process: the failure of the suffering person to adapt to their environment' (Menninger, 1963, p. 325). He urged his colleagues to understand and explain what was behind the symptom rather than treating them. Thus, the institution of psychiatry was initially resistant to the medicalisation of mental health through formalised diagnoses and historically, many psychiatrists refused to prescribe medication (Mayes and Horwitz, 2005). While the medical model is considered by many to be a sound framework for understanding and treating mental disease, the interpretation between 'well' and 'sick' will never be clear and will continue to medicalise human responses to the difficult challenges in life and has no relevance for behavioural or psychological problems traditionally thought of as the domain of psychiatry (Engel, 1977).

Smith (2014) suggests that reliance on the medical model started with medical schools teaching the idea that the mentally ill have something wrong with them which can be cured, which was then repeatedly reinforced by doctors and patients and finally consolidated by the new classification system in the DSM-III (1980) which shifted psychiatry perspectives to believe the cause of psychiatric problems was brain chemistry and gene transmission and medication was the cure or containing force (Horwitz, 2002). As psychiatry could not stand out from other medical disciplines in relation to effective treatments, it instead became successful in the development and classification of mental health problems as illnesses (Smith, 2014). This process eventually culminated in diagnostic manuals such as the DSM (APS, 1994) and *International Classification of Diseases* (ICD) (WHO, 1992) with each updated version of both manuals adding newly classified illnesses (Kutchinns and Kirk, 1999). The DSM-III standardisation of diagnoses was one tool in achieving the shift from 'madness' being caused by a person's failure to adapt to their environment and interpretation-based psychoanalysis to standardized medical model diagnoses using specialised classifications (Kirk and Kutchens, 1992; Horwitz, 2002). Rössler (2013) argues that the mental classification system increases the number of mental illness disorders, but also lowers the threshold for psychiatric diagnosis or, due to restrictive diagnostic criteria, miss those who are truly suffering and in need of support.

Psychiatry abandoned its roots as an intellectual paradigm and adopted a whole new system where classification became the speciality of the discipline and psychiatry transformed from a discipline concerned with insanity and madness to one concerned with creating normality (Herman, 1992a; Hale, 1995; Horwitz, 2002). Since psychiatry affiliated with the medical model, it has become extremely profitable with the dispensing of pharmaceutical treatments for medicalised life experiences and distress (Perez and Esposito, 2009). The use of drugs in treating mental ill-health are designed to modify behaviours, suppress difficult emotions and enhance productive behaviour that is beneficial to the economy and society (Perez and Esposito, 2009). Pharmaceutical and, in the US medical insurance companies, benefited from the medicalisation of mental health. Eighty percent of psychotropic medication prescribed to treat mental disorders in the US is prescribed by primary care physicians who receive limited mental health training (Mark, Levit and Buck, 2009) resulting in more overdoses and deaths from prescribed medication than from the misuse of street drugs (Cunningham, 2009).

The medicalised discipline of psychiatry has been critiqued by sociologists of mental health who have mapped its significant impacts on people with mental illness (Peters, 1996, p.218). The medical model pathologizes thoughts and behaviours that deviate from what is defined as functional, productive, or desirable. It, therefore, devalues the diversity of human experience and perception and is concerned with analysis, mechanical and chemical constraint, physicality (physical causes) and eradication, rather than understanding, empathy, support and a holistic approach to the body and self (Albee, 1975; Beresford and Wallcroft, 1997, p.71).

Critics such as Esposito and Perez (2014) argue that efforts to expand psychiatric diagnoses and classifications have led to the increased medicalisation of human life and behaviour resulting in potentially harmful interventions. Mental disorder classification is far from a pure science, and some suggest it is being moulded by political and profit driven directives aligned with the corporatisation of medicine and pharmaceuticals (Watters, 2010; Jasso-Aguilar and Waitzkin, 2012; Esposito and Perez, 2014; Whitely and Raven, 2015). However, resistance to medication-based psychiatry had waned by the 1980s with the release of new anti-depressant medication, serotonin-specific re-uptake inhibitors (SSRIs) such as Fluoxetine (marketed as Prozac) (Horwitz, 2002). Conditions, such as hyperactivity, which would have been viewed as a character flaw, were transformed into a diagnosis of disease and sickness (Conrad, 1975; Conrad and Schneider, 1992). The growing medicalisation in psychiatry and it’s ‘expertise’ in treating conditions of the mind, has affirmed its position as the legitimate authority of mental health, with psychiatry’s influence on the political, social and socio-economic arenas alongside the endless classifications of so-called mental disorders, making it the only profession capable of effectively treating these problems (Esposito and Perez, 2014).

However, psychiatry also raises fundamental questions about legitimacy and whether forms of human suffering are best understood as disease processes. The medical model focuses on the biology of mental illness rather than the person and this determines how healthcare is delivered (Bleecher, 2009). Therefore, psychiatry is not focused on the person and their individual needs but rather on the diagnosis and control of symptoms. Psychiatric researchers have failed to demonstrate a biological substrate or laboratory marker for identifying mental disorders (Rössler, 2013) and thus there are struggles to defend or justify it as an authority of mental illness within the medical model framework as it cannot demonstrate itself as a medical speciality that treats medical diseases (Breggin, 1993; Boyle and Johnstone, 2014; Johnstone, 2018). Despite, or perhaps because of this, diagnostic practice has become what Kovel (1980) describes as the holy grail of psychiatry and the key to its legitimisation. Specific and specialist diagnosis has become an important function within psychiatry as it helps to support the assumption that it is a legitimate branch of medicine (Cromby, Harper and Reavey, 2013).

Psychiatry's pursuit to be taken seriously as part of the medical fraternity, and it's nosological (branch of medical science that classifies disease) turn, has resulted in a less than favourable past. One of the most repugnant episodes was compulsory mass sterilization in over thirty USA states of the mentally ill as they were deemed to be a degenerate part of humanity breeding at alarming rates. This, as Kaelber (2012) and Stern (2005) suggested, created an alliance between psychiatry and the Eugenics movement. In England, the Eugenics movement for mass sterilisation of the mentally ill had support but was never enacted (Luty, 2018). However, psychiatry appears to have developed and moved away from its past, but people are still being forced into situations and treatments that create physical and mental harm (Lakeman and Cutcliffe, 2016).

Pilgrim and Rogers (1994) argue that psychiatry is still reliant on preventative detention and a range of hospital-centred biological treatments including the use of psychotropic medicine to control people's behaviour. A person can be detained if they are experiencing a mental health crisis or deemed to be a risk to themselves or others and it is considered to be within their best interests. They can also be medicated to control behaviour.

While the medical model is considered by many as a sound framework to understand and treat mental disease, it has no relevance for behavioural or psychological problems traditionally thought of as the domain of psychiatry (Engel, 1977). Szasz (1997) suggests that the use of the medical model for mental illness is misleading because if it is defined and accepted as the same as a physical illness, there is no rationale for adopting a non-medical approach. If a mental illness does not always show biological disease in the brain, then it does not warrant a medical approach to it. Szasz (1974) and Klerman (1977) argued that mental illness was a socially constructed myth invented by modern society to explain the unwanted, weak, and vulnerable in our society and to deal with real occurrences of pain, distress, anguish, and disability with the use of drugs as a ‘chemical straitjacket’ (Szasz (1974). Sociologists such as Scheff (1966) and social psychologists like Rosenhan (1973) and Goffman (1968) criticised the medical model as a rationalisation of society’s attempt to deal with unwanted and abnormal behaviour. They proposed that the process of diagnostically labelling someone as mentally ill was one of the most powerful ways of controlling unwanted behaviour. They argued that the medical model served to reaffirm the responsibilities and roles expected of individuals role in society, and validated reasons for their isolation from the rest of society and contributed to the removal of autonomy, rights, and dignity.

Since the 1980s there has been a significant entrenchment in viewing behavioural and emotional difficulties as a psychiatric concern and the use of drugs to control symptomology. Potentially this may have been driven by pharmaceutical seeking to profit from increased demand, and the development of new drugs. Francis (2013) argues that drug companies are unique in marketing both the cause and solutions for anticipated life problems convincing the medical authorities and individuals that mental disorder is caused by chemical imbalances and easily rectified with expensive drugs. This is evidenced by rates at which the use of current diagnostic classifications have grown; behavioural disorders have tripled in the last twenty years and depressive disorders have doubled (Francis, 2013).

Children and young people, too, are increasingly pathologized for their natural struggles to find their identity, their way in life and the barrage of hormonal changes of adolescence and there has been a steady incline in the prevalence of diagnosed mental disorders amongst them in the UK. Childhood disorder diagnoses have increased forty-fold, Autistic Spectrum Disorders diagnoses, twenty-fold (Batstra, Hadders-Algra and Nieweg, 2012; Frances, 2013) and emotional disorders such as depression or anxiety have become the most prevalent diagnosed disorder in 5–19-year-olds accounting for one in twelve (8.1%) diagnoses in this population group in 2017 (NHS Digital, 2018).

Categorisation of people by professionals as ‘mentally ill’ can (further) reduce an individual’s psychological wellbeing (Kravetz, Faust and David, 2000). Accepting of a psychiatric label can reduce a person's self-esteem and lower their social status. Professional normalisation encourages acceptance of a mental health diagnosis and can lead to accepting the possibility of an inferior status and stigmatised social status (Kravetz, Faust and David, 2000).

Power and dominance of the medical model

Historically the notion of power implies a measure of interpersonal control and influence with or without formal authority (Lupton, 1997). Power is the capacity to enforce the will of a person or group of people to alter the behaviour in others and bring about change (Turner, 2005). Power is a significant factor in the interplay between mental and physical health services, and those that access and participate with them (Felton and Stickley, 2004). The medical model forces individuals to accept the 'sick role' and to accept an imbalance of power that exists between people and professionals. The concept of the sick role, first introduced by Parsons (1951) and said by him to be one of the most important components of the medical model in maintaing power and dominance, exempts people from the normal social responsibilities and expects them to cooperate in the recovery process, as determined by medical professionals, from their illness. If they do not comply, sanctions are used against them, even though they are not believed to be responsible for their illness. A diagnosis of BPD places people into the sick role. Critics such as Szasz (1960) have questioned the justification of applying the sick role to cohorts of individuals who have no biological brain disease but whose difficulties arise from emotional distress and/or traumatic experiences.

Psychiatry has cleverly learnt to identify sick individuals, prescribe a treatment to cure or ease illness and predict an outcome of their illness; those labelled as 'mentally ill' are expected to be recipients of 'medical' expertise and treatment interventions whether they welcome it or not (Williams and Heslop, 2005). Those that challenge the hierarchy or promote their autonomy are classed as difficult to 'engage' with, putting the negative onus on those already positioned as more vulnerable and lower status in society.

The superior power of health professionals is exemplified through their use of clinical and labelling language which can be difficult to understand and derogatory, thereby limiting people's autonomy and their control over options for care and treatment (Lammers and Happell, 2003). Some examples of this use of language by professionals in health and social care discussed by participants included terms such as psychiatric jargon which is alien to people’s everyday vocabularies and ‘service user’ which implies that a person has a lower status/less power than ‘service-providing’ professionals.

Dominance of the medical model appears in the application of status labels to distinguish between mental or physical illness. People with physical illness are generally referred to as ‘patients’ which implies temporary ‘sickness’ and is cure orientated. People with mental ill health are generally referred to as ‘service users’ which does not have the same temporary and cure-oriented connotations. The ‘service user’ label serves to remove a person’s individuality and can have derogatory implications and detrimental effects for the person it is applied to (Link, 1987).

Medical power shapes the boundaries of what is appropriate, normal and healthy. It is, according to Lupton (1997), a disciplining power that guides people’s views on how they understand, experience, and regulate their minds and bodies. The medical model gives control to those who have and exercise their knowledge in their area of ‘expertise’ and positions advocates with lived experience of BPD as challenging and threatening (Felton and Stickley, 2004). Medical professionals are taught, via the medical model, that they know what is best for a ‘patient’ and patient involvement consists solely of compliance meaning that those who access and participate with services often have a limited influence in their own care. This creates a limitation in people questioning their care or treatment or suggesting alternatives (Felton and Stickley, 2004).

This power relationship is hard to challenge, not just because of the less powerful status of the ‘patient’, but because medical professionals are the gatekeepers to treatment and support. Whereas people with BPD often attribute distress to life experiences or personal, social or other factors, the medical model applies scientific medical explanations which is reflected in the care and treatment on offer (Faulkner and Layzell, 2000). Receiving mental or physical health support is diagnostically driven, and due to the high levels of stigmatisation of the BPD label, many with the diagnosis are left without the help they need, are excluded from services or refused mental and physical health treatment altogether (Faulkner and Layzell, 2000; Koekkoek, Meijel and Hutschemaekers, 2006; Ross and Goldner, 2009; Sulzer et al., 2016). As a result, services fail to meet the needs of those with a diagnosis of BPD or have developed exclusion criteria which makes access to service provision extremely difficult (Warrender et al., 2020). The failure of services to meet needs prompted the NICE (2009a) guidelines for the care of people with personality disorder diagnoses however, these guidelines were critiqued by Recovery in the bin's (2017) "Not so NiCE guidelines" (2017) which highlighted that despite official guidelines, most services do not cater for personality diagnoses leaving the needs of people with a personality disorder diagnosis regularly unmet (MIND, 2018).

To improve mental health services for those who experience exclusion, lived experience inclusion has provided the start of essential collaboration to identify and change decades of medical model domination. Despite real change being made across some health sectors, some inclusion work remains tokenistic and maintains the power and dominance of the medical model. Rutter et al. (2004) suggest that change made in service provision is generally moulded to serve the objectives of professionals rather than the people who access the services and Rush (2004) argues that professionals fear the undermining of their professional status and role and so limit how much influence people with lived experience get in co-production roles.

Critiques of the medical model have taken various forms. One, popular amongst professionals calls for the reform of medical practice to make clinicians more aware and sensitive to the psychosocial aspects of health and illness (Hogan, 2019). Proponents such as Gray (2009) suggest that medical intervention in areas like mental health are oppressive and stigmatising and should be focused on a social model of mental illness, as opposed to individualising treatment plans. As an alternative to the medical model, the social model is underpinned by an understanding of issues of oppression, exclusion and power and is based on the complex intricacies of health, well-being, and the value of lived experience (Duggan, 2002; Beresford, 2005). Rather than the medical model's focus on diagnosis, the social model of mental health focuses on a person's needs and considers, as well as biomedical interventions, the social and practical support required. This framework allows for immersion into another person's lived experience and their environmental, economic, and social world. It works on bringing together all the various support networks available for people to feel and be empowered (Duggan, 2002; Williams and Heslop, 2005).

The social model proposes that mental distress, such as hearing voices or self-harming behaviour, should be viewed as a survival strategy to oppressive situations (Duggan, 2002). Tew (2002, p. 147) aligns with the social model's interpretation of distress by stating that "mental distress may typically be understood as a response to problematic life experiences. In one sense it may represent a deployment of the best available coping strategies that a person may be able to access". In contrast the medical model places mental distress into categories of mental disorder and has a one size fits all approach to support and treatment instead of an individualised approach to understand potential life experiences accounting for a person's difficulties.

However, Hughes and Patterson (1997) believe that the social approach to mental illness has limited challenge to medical dominance as it has interwoven mental health within the medical discourse of understanding impairment. Albee (1975), influenced by the medical model exclusionists such as Szasz, believed that mental health problems or any form of disability, should be valued as a form of human diversity rather than an individual problem to be (medically) solved. He argued that the medical model inappropriately pathologizes people's problems of living and called for alternative approaches that focused on social reforms that would be more supportive of individual differences rather than medical interventions.

The dominance of the medical model in relation to mental health, and BPD in particular, places the emphasis on a narrow, one size fits all, framework of diagnostic treatment. Psychiatry's pursuit of inclusion as a serious branch of medicine has left it restricted by the strict parameters it places on itself and its' professionals in treating mental health as a disease in line with physical illness. The medical model's interpretation of life difficulties, traumatic events or experiences as an illness result in a diagnosis being given that indicates or labels the 'illness' of a person. Its only weapon to combat mental 'illness' is the control of patients through drugs, fear of exclusion, forced containment or withdrawal of services which are all harmful interventions against distressed people. The medical model and psychiatry's dominance over the understanding and treatment of mental health has influenced how professionals and society interpret, behave towards and treat those with a diagnosed mental health condition. The medical model's ability to maintain power and dominance over vulnerable members of society has meant future physical and mental health doctors and nurses are taught knowledge that is discriminatory, derogatory, and stigmatising towards people with a BPD diagnosis. The next chapter will present the main findings of the research.

Chapter 6. Findings

This chapter presents the main findings beginning with BPD stigmatisation in experiences of frontline services and professionals, followed by the power of language, service provision for people with a diagnosis of BPD, professional power and dominance and reclaiming power and identity.

“BPD, those letters, they carry a lot of stigma […] But actually, it’s just a diagnosis” (Sarah): BPD stigmatisation and experiences

Participants indicated that from their experiences they felt that BPD is one of the most stigmatised of all psychiatric diagnoses (Ferguson, 2016; National Alliance on Mental Illness, 2017; Day et al., 2018):

> Helen: I’d say it’s probably the most stigmatised mental illness to have, whether that’s lack of awareness of what it actually is…the name itself is disastrous, really, really, bad. I can’t think that that would particularly help anybody.

The measurement of stigma from the experiences of people with a diagnosis of BPD has received limited attention (Rogers and Dunne, 2011; Holm and Severinsson, 2011). In one of the few studies available, Horn, Johnstone and Brooke (2007) asked people with lived experience for their perspectives of a BPD diagnosis and personal accounts highlighted how professional stigmatisation left them feeling stereotyped, patronised, shamed, incompetent to make decisions, dehumanized and blamed for the way they are treated. Some psychiatric practitioners have questioned the continued use of applying the BPD diagnosis to individuals due to the associated stigmatisation towards this diagnostic group, as Ash shared “There is definitely stigma about the diagnosis, my psychiatrist said, or psychologist, I can never remember, said that, ‘borderline is an archaic term that should not be used anymore’. He said that it just shouldn’t be used, it’s out of date, its left over from the seventies, he said it’s not a term he’s comfortable with anymore”.

“It’s even stigma in the people who are supposed to be the people helping you” (Louise): Negative attitudes towards the BPD diagnosis

Despite an increased focus on the underlying causes of mental health conditions and mental health stigma, people continue to experience negative attitudes from some professionals that can have adverse effects on them and their support networks. Herman (1992a) argues that

that the BPD label is nothing more than a sophisticated insult which contributes to the continued stigmatisation and negative attitudes towards people with this diagnosis. One participant, Angela, experienced ‘stigma by association’ through caring and advocating for someone with a BPD diagnosis.

> Angela: I had endless meetings with them [Mental Health Trust], and they lied, and they patronized me, and they treated me like it was my fault for being involved. I’m saying, well if I’m not involved who is going to look after her?... the overwhelming burden on me, as I was the only person who actually seemed to do anything.

Negative attitudes can perpetuate marginalisation of people with a BPD diagnosis, but also influence the development of organisational policy and practice delivery for this diagnostic group (Kealy and Ogrodniczuk, 2010). Global studies examining mental and health professional’s attitudes towards those with a BPD diagnosis, identified that they are the least popular diagnostic group and the most avoided in terms of interaction or treatment (Fraser and Gallop, 1993; Cleary, Siegfried and Walter, 2002; Markham and Trower, 2003; Black et al. 2011). Rosa raised this point in the comparisons of more favoured mental health diagnoses.

> Rosa: I used to always hear like, bipolar is manageable and BPD isn’t manageable. I always hear that bipolar is like the, the best one to have, you know. Like, it’s easier because it’s, your mental health is scheduled, you know when you are going to be depressed so you can sort it out.

The belief systems of professionals in mental and health care services towards people with a BPD diagnosis hold that they are not ‘really in distress’ and as one participant, Sara said, ‘kick off’ towards those that are trying to help them (Deans and Meocevic, 2006; Feldman and Crandall, 2007; Munro and Baker, 2007; Commons Treloar, 2009; Westwood and Baker, 2010; Bates and Stickley, 2012; King, 2013; Gras et al., 2015; Sukhera et al., 2017; Chartonas et al., 2017), will continuously present with self-destructive behaviour and attempts on their lives. Corrine raised this perceived stigmatising connection between BPD and self-harming behaviour:

> Corrine: Stigma is extremely bad for BPD sufferers as the professional services see you as attention seeking person with behavioural problems. Self-harming as well creates even more stigma from these people. I have been made to feel ‘dirty’ for self-harming.

The behaviour is interpreted as looking for attention, manipulate situations to get their needs met and purposefully antagonise others (Black et al., 2011; Burke and Greyner, 2013; Sansone and Sansone, 2013; Wnuk et al. 2013). Helen spoke of her opinions on misconceptions of behaviour.

> Helen: You almost brace yourself and be particularly scared and that's not being manipulative, that's not, it's a very different way of looking at it, if somebody's got needs, they need those needs met. It's not attention seeking, it's help-seeking, a really subtle difference in language but a massive difference in interpretation in terms of what people do. People are in pain, people are distressed, people are traumatized, they perhaps will behave in ways that aren't desirable, aren't very nice.

James and Cowman (2008) identified that 80% of mental health nurses in Ireland viewed this diagnostic group as difficult to communicate with and treat. Louise described her experience of negative attitudes from mental health nurses:

> Louise: I've been hospitalized in [mental health hospital] several times as a result of crises and stuff. The last time I was admitted…I was supposed to be there for a week and then I ended up getting sectioned and was there for seven months. So, it was a really, really, tough admission…I was stigmatised for my diagnosis even on a mental health ward. Basically, I was having a crisis at some stage and the one, one of the nurses said to me really exasperated, basically shouted at me, and said, 'Look, Louise, there's people here that are a lot iller than you are',…I felt like I was just taking up space and wasn't important […] So, it's even stigma in the people who are supposed to be the people helping you, it's like you can't win. If the people who are supposed to be supporting you are kind of prejudiced against what your diagnosis is, then how are you are you ever going to get help?

Markham (2003) found that healthcare nurses were more negative and displayed less sympathy to and optimism about people with a BPD diagnosis compared to other mental health diagnoses. Louise also discussed her experiences of healthcare professionals and provided a comparison of how negative attitudes of the BPD diagnosis between mental and physical healthcare professionals had impacted her.

> Louise: I feel like overall, the number of people who I felt stigmatised from in mental health is lower than general healthcare. So, generally, general healthcare professionals, I think, have less understanding than mental healthcare professionals. But, when I do experience stigma from the mental health care professionals it almost feels worse, because, and more extreme, because they are the people who are supposed to understand.

The negative beliefs about/towards this diagnostic group fuel the active stigmatisation towards individuals from mental and health organisations and professionals in the care and support that individual's with the diagnosis receive. For some people not disclosing the diagnosis reduces the level of stigmatisation and increases help and support.

"I'm very, very wary of telling anyone, friends, even like most of my closest friends wouldn't even know that I've got it" (Sara): Not disclosing the diagnosis

Stigmatisation towards the BPD diagnosis can result in some individuals maintaining secrecy about their diagnosis when seeking help or treatment for issues unrelated to their diagnosis or avoid seeking help at all for fear of having to disclose (Angermeyer and Dietrich, 2006; Mannarini and Boffo, 2015; Mannarini and Rossi, 2019). Three of the participants described how they have or would consider withholding their diagnosis due to previous stigmatising experiences.

> Louise: I try and withhold giving my diagnosis unless people ask for it specifically because literally, as soon as I give it, the treatment changes completely […] the last time I presented at A&E, when they asked me my diagnosis I didn't tell them, I didn't say I had BPD, I said I had CPTSD [Complex post-traumatic stress disorder] instead, because I thought I'll see if it makes a difference and it did, it made a massive difference to how I was treated. They didn't just shove me in a corner and leave me forever, they made sure they came back and spoke to me and let me know what was going on, and they weren't, you know they didn't have that look of disdain about them all the time. And they made their, their care was more trauma informed than it would if I had said that I had BPD, which was interesting because that, in terms of traumatic history, both of them have you know, features of traumatic history generally or they do in me anyway, to them, so actually they should be treating me the same way for BPD as they do for CPTSD but they didn't. It really surprised me how much it changed. So, now if I present again I'm not going to say that I have BPD, I'm going to say that I have CPTSD.

> Helen: I wouldn't say to any of my family and quite a few of my friends that I have this or, on the other occasions when I have told people (about BPD) they always think I'm talking about bipolar. Sometimes, it sounds awful, sometimes it's easier just to leave them with that assumption. Because people either, don't know what a personality disorder is or are actually quite scared and its horrible to know somebody really, really, well, be really, really, close to them and then to divulge something which is just, you know, some words that are meant to describe your difficulties, but they don't describe your difficulties, they are actually really, really, disparaging against you as a person. Well, that's what all the connotations are, I know it's just a label and I know it can cover all sorts of things and I know that it could be interpreted very, very differently, but they don't.

Sara described her awareness of her parents' possible reaction if they knew of her diagnosis;

> Sara: I come from a family that were very, very emotionally repressed and the thought of having someone in their family who was labelled as this thing. I was very aware that they would see it as like, an embarrassment or something to be hidden away […] I think the kind of image of personality disorder that everyone has in their head, whether it's subconscious or unconscious is like, the crazy ex-girlfriend kind of thing, and I'm very, very wary of telling anyone, friends, even like most of my closest friends wouldn't even know that I've got it, have I told, I don't know if I've told [her boyfriend] or not. I think I have, yeah, having said that, I don't think he really knows what it means or will ever research it, he just knows that I am how I am… I don't see it as something that I would kind of wear as a badge and tell people. I have met people that are like that, I've worked with people that are like that and it's like, almost encouraging the sort of stigma, more than anything.

"I've got countless examples, I don't really know where to start" (Louise): Stigmatisation awareness and experiences

Fallon's (2003) research identified that people with a BPD diagnosis were aware of negative attitudes from professionals. Participants gave examples of their awareness and experiences of stigmatisation covering a broad range of professionals in physical, mental health and public protection services. Most participants described situations in which they felt discriminated against based on their diagnosis.

> Eloise: You do find like, you do find it all over the place, like this stigma attached to it, and it tends to be more, I find that it's more with mental health staff that stigma, rather than the general public. The general public, if you say borderline personality disorder, they've got no idea what you're talking about, they don't tend to have a lot of stigma, but you find that there's a bit more stigma maybe in like, police and ambulance staff and there's a bit more stigma in A&E staff and then a bit more in like acute hospital staff.

> Sara: I definitely, definitely noticed a change, even from the first, from the psychiatrist I saw in London who actually diagnosed me. I felt he was so cold and clinical and doctor-like that that really actually made me feel frustrated, and like I say I'm a very calm and rational person, I don't ever get angry but in that appointment with him I did get really quite frustrated, because I felt that, I would kind of tell him something and he would say it back to me but, he would twist it in certain ways or something like that. And I'd had enough by that point of people not listening and not getting any help, and I was so kind of, felt so abandoned by the NHS.

Helen experienced a change in some professionals' attitudes towards her before she knew that she had been given the diagnosis.

> Helen: Unbeknownst to me this had been on my records it's just, suddenly a few things clicked into place, if that makes any sense? All the things I'd read that people might experience once they've been given this diagnosis, it just suddenly, I just suddenly

> realized, when professionals had been very rude or very dismissive and tended to just ignore what I was saying, [there was a] massive fear of me ever becoming over-dependant on services, the neediness, things like that. I just started to piece together, oh this is how they've framed me; this is how, the lens they've been seeing me through, certain people, not everyone […] now that I know, well if I've been labelled this then that's why they expect x, y and z. Its confirmation bias isn't it? Once you've got something in your head, you will look for certain things. That's the only way I can describe it really.

For those with a BPD diagnosis, stigmatisation by professionals in physical health care can adversely affect seeking care at time of suicidality, self-harm, periods of crisis, depression and anxiety (Lawn and McMahon, 2015; Sulzer, 2015; Hong, 2016; Mack and Nesbitt, 2016; Shaikh et al., 2017). Rogers and Dunne's (2011) study on the experiences of people with a personality disorder diagnosis in an inpatient ward in England found that they received sub-standard care because of their diagnosis.

> David: You're [made to feel] part of a cohort of dysfunctional people that clog up their system, that make their jobs very difficult when there are people that are accessing emergency treatment through no fault of their own, that need real attention and that's what you're essentially being told as well is that there are people here that really need care […] you're in here taking up our time and we could be doing much better things with our time and I've heard that a few times as well, 'well you seem together, you seem normal, and you look fine'.

It has been established that for some people in a period of mental health crisis attending A&E departments are treated with a lack of dignity and care by staff (Anderson and Standen, 2007; Thornicroft, 2007; Ross and Goldner, 2009). Some participants shared experiences of healthcare support and treatment mapping people's journey through A&E, triage, nurses', doctors, treatment and discharge.

> Louise: There's generally a kind of cut-off point, where people initially are really friendly and helpful and reassuring and comforting when you go to A&E, and then as soon as you find out their diagnosis then it all changes…as soon as you go to be triaged it, that initially starts with, 'so, what's brought you here? How are you feeling', and blah, blah, blah, and I feel that there's sympathy and understanding until the point where they ask, 'what's your diagnosis?

> Sarah: It was a few years ago now but I presented at A&E and they, I think I'd overdosed and I think they were, basically, they were kind and understanding and were like we are going to do this and that and the other, but as soon as they found out, they passed me from triage into, kind of, the actual hospital and the nurses found out what my diagnosis was. Basically, they shoved me in like, one of the little cubicles,

> but, said, to each other, they said, ‘well no she can’t close the curtain, we need to keep an eye on her’, and you know, I could kind of hear them talking about the fact, about my diagnosis…
>
> Rosa: They told me the doctor will see you now, go sit in this room and the doctor will be there in a minute. The doctor didn’t turn up, and I understand what they were doing was moving me because the waiting room was too distressing for me […] But they moved me in a way, by lying to me, which was weird. And then what they did was, I fell asleep, because if you sit me still for long enough with nothing to do, I will fall asleep automatically. And the doctor came in, saw that I was asleep and just left me and then about 2 hours later came and woke me up and went, ‘do you feel better now love?’ and then made me leave. So, they’d sort of diagnosed me as just needing a nap and that was all they did.

People self-harm for a variety of reasons, to manage anxiety, depression or frustration, limit feelings of alienation, dissociation or loneliness or to reach out when distress cannot be verbally communicated (Nixon, Cloutier and Aggarwal, 2002; Klonsky, 2007b; Koning, McNaught and Tuffin, 2017). One topic that was raised was the refusal by medical staff to dress and close self-harm wounds or pain relief.

> Eloise: I’ve had a consultant in A&E refusing to suture a wound that went down to the muscle because I was just going to go and do it again.
>
> David: I remember overhearing two nurses talking behind the screen and they obviously looked at my history, which was kind of self-harming, and said ‘All his admissions seem to be self-harming’, it was the first time I’d heard the expression, ‘He’s a PD, he’s definitely a PD’ […] I was having my thumb reattached, I’d gone through a car window and they were looking at my medical notes where I had issues with addiction to opiates, so then they were essentially asking, ‘We’re not going to give you pain medication because we know you like that’.

Refusal to close self-harming wounds is a violation of the National Institute for Health and Clinical Excellence guidance on self-harm (NICE, 2004) which states that analgesia should be offered to people who have self-injured, throughout the process of suturing and other painful treatments. Veysey’s (2014) research on discriminatory experiences described one participant having a laceration closed without anaesthetic by a doctor who justified it due to the participant being dissociated and therefore not feeling pain at the time.

“You just can’t win, even if you present as a normal physical [ill-health] patient, if people find out, you know, it changes” (Louise): It's not mental health, it’s physical health

Stigmatisation of BPD silences people with the diagnosis and can lead to avoidance of healthcare services (Schulze and Angermeyer, 2003; Abbey et al., 2011; Stuart, Arboleda-Flórez and Santorius, 2012; Ungar, Knaak and Szeto, 2016). Sarah said she knew people who were not believed or taken seriously because of their BPD diagnosis;

> Sarah: They had been [to see a medical professional] for physical things and have basically been told, not in so many words, that they’re making it up and its part of the BPD.

Previous research suggests that ‘diagnostic overshadowing’ happens when a mental health diagnosis is accounted for as the main source of all other physical complaints or accounts for inadequate care and treatment of non-mental health concerns. This is said to contribute to greater risk of chronic, physical illness and increased mortality of people with mental health diagnoses (Druss et al., 2001; Thornicroft, Rose and Mehta, 2010; Atzema, Schull and Tu, 2011). General practitioners are the main instigators, who do not consider presented physical symptoms as necessarily an underlying physical problem (Anderson and Standen, 2007; Thornicroft, 2007; Ross and Goldner, 2009; Van Den Tillaart, Kurtz and Cash, 2009).

> Louise: Even when I present with a physical problem, if they then found out that I have a mental health problem, and then what the mental health problem is, everything suddenly is all down to my mental health problem, you know, there’s not, I do, I have a chronic physical condition as well and I had to go to the hospital to deal with that when I was at the [hospital for severe and complex personality disorders] actually, and as soon as they found out where I was from, like, you know, if I said I was an inpatient there, they’re suddenly, ‘oh right, so you’re, you know, there’s nothing really wrong with you you’re just here because you’ve got some kind of personality disorder’.

Some people with a BPD diagnosis experience direct stigmatisation from their GP. Reynolds’ (2017) Guardian newspaper article described this sort of stigma; one interviewee was told “I wasn’t ill, I was just a bad person; another two (GPs) didn’t know what BPD was…[and] asked me to explain it to them’. One GP was quoted as saying “GPs are the frontline of care in the UK but have a lack of knowledge of BPD despite seeing it regularly’.

“I felt dead. And that moment I knew I had no hope.” (Carol): Mental health services

Lewis and Appleby’s (1988) study determined that psychiatrists held negative views towards people diagnosed with personality disorders who were seen as less deserving of treatment and care and this was more influential on psychiatrist’ attitudes than class or gender. Chartonas et al. (2017) found more stigmatisation amongst psychiatry trainees towards those with BPD compared with other mental health diagnoses. Louise described how she finds the impact is harder when stigmatisation comes from mental health services.

> Louise: I feel like, overall, the number of people who felt stigmatised from in mental health is lower than general healthcare. So, generally, general healthcare professionals, I think, have less understanding than mental healthcare professionals. But, when I do experience stigma from the mental healthcare professionals it almost feels worse, because, and more extreme, because they are the people who are supposed to understand. So, it’s difficult to kind of judge, I don’t know objectively, which is worse.

Three participants discussed psychiatry interactions as being negative and/or stigmatising:

> Sarah: I had a psychiatrist who I saw, this was my last inpatient stay, which was 2016, I think. And he basically said that BPD wasn’t a mental health condition and he said that the reason I was having these symptoms was because I wasn’t eating properly and my weight was low and put me on mirtazapine and olanzapine, purely to make me gain weight. I refused olanzapine because it’s an antipsychotic, I’m not psychotic, don’t give me that […] And then he said, ‘And anyway if you’re going to kill yourself you’re going to do it anyway so just go off and do it’…he was a knob…he was very, very like that with all BPD patients.

> Helen: It was an appointment I wish I honestly hadn’t gone to because I felt much worse when I came out…he didn’t care, he wasn’t interested…very dismissive, not remotely bothered that I was crying, not remotely bothered that I went out of the room distressed.

Whilst in a mental health hospital, Carol

> Started to uncover things that had been successfully buried, covered over […] When I found myself eventually being able to start talking about things, I was called a liar [by psychiatrist] […] because as far as he was concerned it couldn’t possibly be true. He was the registrar, he was a clever psychiatrist, I was a, just the slightly hysterical nurse. Because I was unravelling and unpacking all of this stuff at the time, it started to come on its own. It was recurring dreams, frightful nightmares while I was in hospital…I was frightened…I knew I was uncovering something I didn’t want to re-experience […] The consultant psychiatrists said to me ‘there’s a show on in the West End at the moment called Billy Liar’ he said ‘I think you ought to go and see it, so that you can learn what a big mistake it is to go through life making these lies about people who care for you’.

> Everyone in the room laughed, everyone […] I know on one dreadful occasion, I went into a case conference and they've got my father, who was my abuser. They'd found him, tracked him down and got him there and I was invited by this room full of people, I was invited to question my father about the things I'd been talking about […] I felt as though I'd been killed… It was as if I'd just been quietly put to sleep.

Psychiatrists negative and stigmatising attitudes of the BPD diagnosis can and does influence other mental health professionals as explored in the next sections.

"I don't actually like working with people with your diagnosis" (Sarah's CPN): Psychiatric nurses

Markham (2003) found that mental health nurses are more negative and display less sympathy and optimism towards the BPD diagnosis compared to other diagnoses like schizophrenia or depression. Nurses viewed people with BPD as more dangerous prompting increased social rejection towards them (Markham, 2003).

Two participants described negative and stigmatising attitudes from community psychiatric nurses assigned to their care. Corrine described a community psychiatric nurse trained in personality disorders "very short with me and totally uncaring" whilst Sarah's CPN made her dislike of people with a BPD diagnosis known.

> Sarah: She was saying 'oh you're doing really well' and stuff like that, and I'd said to her that I'd been struggling with the eating disorder symptoms, because I'd got the BPD stuff under control a little bit. But because of that I was struggling with really strong urges to restrict what I was eating, and all this kind of stuff and I was worried that it was going to spiral out of control and stuff. And she just looked me up and down and went 'oh well you've got room to lose a bit of weight haven't you' and then basically told me that she was going to discharge me.

Unequal care and treatment or change in support can perpetuate periods of crisis and distress with people seeking the help of crisis resolution teams. However, crisis teams can also hold stigmatising beliefs of the BPD diagnosis influencing their care of people.

"The crisis team members have shown no concern for your welfare" (Corrine): Crisis resolution teams

Crisis resolution teams were introduced in England 2000 to prevent or minimise harm when in crisis. However, often people do not experience the best working practices or support

(Lloyd-Evans et al., 2018). Some individuals in distress, they have been advised to 'take a bath' or 'go for a walk' as self-soothing or distraction techniques or are simply made to feel that they are attention seeking (Mental Health Today, 2018; National Elf Service, 2018).

> Corrine: Except those times when I had been sectioned the crisis team members have shown no concern for your welfare. It was like them slapping your wrist, telling you to go home and get on with your life.

Angela described a similar experience from someone she had been supporting through talking on social media:

> Angela: She contacted me via social media, she said, 'I just want to talk about my experiences', I said, you know, great, whatever, sometimes an extra ear is brilliant for people. And she had a habit of throwing herself off quite low-level bridges, but hurting herself, you know. The crisis team knew this, she was in an absolute desperate state, she phoned the crisis team and they told her to go for a walk. So she said I did and threw myself off a bridge and I broke my back. So, the other thing I would say another thing massively under-looked at is the fact that they treat people with mental illnesses as though they are stupid. They're not stupid, they're ill…I have heard a lot of people who have been in crisis say that their conversations with the crisis team are enough to tip them over the edge to actually go and commit suicide.

Angela had several interactions with the crisis team whilst caring and advocating for her neighbour who had episodes of severe crisis, self-harm and multiple attempts to end her life when her care and support was changed or withdrawn by the mental health trust:

> Angela: They didn't care. I asked the crisis team one day, or the care coordinator one day, what would you do if you lived next door to her? And she said that other people would shut the door on her, I said no, I'm asking you as a human being, what would you do if you lived next door to her? And she just said that other people would shut the door on her…three and a half years, solidly, I had endless meetings with them, and they lied, and they patronized me, and they treated me like it was my fault for being involved. I'm saying, well if I'm not involved who is going to look after her?

In another incident the crisis team missed multiple opportunities for crisis intervention for her neighbour. Afraid of violence from the neighbour they involved the police as a calming measure which exacerbated the situation:

> Angela: The trouble with [crisis team] is they say there's a crisis team, but there's been thirty-two plus incidents they've failed to prevent a crisis from happening by ignoring it, and it would escalate and escalate and escalate and escalate and still they would ignore it. And then they couldn't ignore it, but rather than sending somebody into section her, they would send the police in, which you know, you're in a highly charged state, you've got eight police officers on your door and all their radios are going off

> and they're walking up and down…It's not their fault, but that's how they operate, and it escalates and exacerbates situations. There is not one incident that she was involved with that couldn't have been prevented with early intervention, not one.

"Fundamentally I had to talk the police officer down into a calm state" (Angela): The Police

Individuals who experience states of extreme mental distress can have an elevated rate of engagement with the police (Hallett et al., 2019). Mental health crises have become more common in society, the police have been forced to adopt healthcare roles on top of law enforcement. Despite increased attendance at mental health call outs, policer officers' awareness of mental health conditions is limited (Baker and Pillinger, 2020). For some individuals (including those with a diagnosis of BPD), interaction with the police is far from a sympathetic experience. Martin and Thomas (2015) found police officers expressed anger, frustration and powerlessness at the amount of resources and police time taken up by people diagnosed with a personality disorder. Negatives views related to the BPD diagnosis, included the ideas of people with the diagnosis behaving badly rather than being in distress. Some participants described their interactions with the police when they were in vulnerable states:

> Sara: The police showed up and I'd just taken this overdose, my friend was with me, and they just came and saw someone was with me and then left and were like, 'oh well, if you need any help go to A&E', and I was like, 'Well no I won't because I want to die, like, why would I go to A&E for help?' And they just left. […] it's not even that it's happened the once, it's happened again and again.

> Eloise: I've had all sorts, I remember having a situation where I was with the police in A&E and I was really quite upset and there was something quite traumatic happening around me at the time and the policeman just went, 'Stop it you silly little girl, there's really poorly people here' and stuff like that.

> Corrine: [During a period of crisis, I had] taken overdoses as well as severely cutting myself that has required myself attending A&E. On all occasions the police became involved. When I am in such a state I am usually confused and scared and on each of these times the police have handcuffed me despite some protest from my then CPN. I have been sectioned a few times and have had different experiences with the police in attendance.

The use of physical restraint can be terrifying, humiliating and trigger psychological trauma for those with past trauma. Physical restraint has increased in England and Wales; in 2018-19 there were 56,000 incidents with 13% of them against people with a mental health condition

(Home Office, 2019). When police officers become involved, it can be frightening for those already in deep distress and can make a situation more charged.

> Angela: There were instances that required a police officer to draw a taser [on her neighbour], she had a knife, so, and she was off the wall, I mean completely off the wall. I would say absolutely one hundred percent had I not been there he would have discharged it and she would have been killed because her BMI was thirteen or something.

The use of force is further increased by a person's ethnicity and more likely to be used against people from marginalised ethnic groups (McLeod et al., 2017; Rossler and Terrill, 2017; Baker and Pillinger, 2020).

To conclude, negative attitudes of the BPD diagnosis can perpetuate the marginalisation of people with the diagnosis and can influence professional's interactions and limit access to support. Physical, mental health and public protection services hold stigmatising beliefs and working practices towards this diagnostic group, people with the diagnosis are aware of the stigma resulting in fear and concern of accessing and participating with them. As a result, withholding the diagnosis is an option for some to get fair and equal treatment and support. The participants' experiences show that there is a lack of knowledge and understanding of the diagnosis despite people with BPD being considered high 'users' of services. Improvement of professional training on mental health would assist in reducing the level of stigmatisation would greatly benefit people with the diagnosis.

The Power of Language - Can the language we use make a difference in health and social care practice?

Heffernan (2006) explores this question arguing that in relation to health and social care practice, practitioners as well as social scientists need to understand the social construction of language, terminology, and how it develops and is used within professions to identify individuals that come into their services. Language and words can have a significant effect on the lives of people, can carry positive or negative meaning and can be used as way of subtly conveying power and dominance over others. Ash highlighted why it is important that professionals are aware of their choice of words, how it is conveyed and subtleties when working with a person with a BPD diagnosis.

> Ash: With borderline you're always having to pick because you overthink so much about everything. You're always having to look into things that you think you've missed, all the time, so using language that is clear and concise…that doesn't have emotional ties to it.

Language evolves over time and influences the way we think, feel, see and ultimately act. Boroditsky (2011) and Whorf (1956) suggest that language influences our thinking and that attentional biases (paying attention to a negative aspect of a person's character while ignoring positive attributes) arise from frequent and habit-forming use of words or terminologies (Boroditsky, Schmidt and Phillips, 2003). Language can make more prominent particular attributes or qualities in an individual (Wolfe and Holmes, 2011). In direct relation to mental ill health, negative words can be patronising, stigmatising, derogatory, categorising and excluding whereas positive ones can express equality, affirmation, worth, validation and respect (Richards, 2013). Ash explained how the use of words used by a paramedic responding to her call for help made her feel not worthy of being helped.

> Ash: 'oh you're nice and small doesn't look like you can do too much damage'… he [paramedic]thinks I'm an animal, he thinks I'm a failure as a person, I don't deserve to be given treatment, I don't deserve to go to hospital, I'm not bad enough….maybe being in the job you get desensitized to things, you see such crazy behaviour and stuff but you see a 19-year-old girl shivering with no coat on trying to kill herself and you're like, 'oh it's just another Tuesday' type of thing, but actually you need to remember that, you know, if that guy hadn't of turned up that could've been the day that my parents dealt with my suicide. So, they need to remember the gravity that their words can have.

Language can be influential based on the weight given to specific words and the social position of the speaker and definitions that are socially constructed. To address the derogatory language used in mental health, The Royal College of Psychiatrists developed the 'Core Values Report' (2017) to improve working practice in the delivery of mental health care and the constructive use of language across the health sector. The report outlined eight core values, one of which to develop constructive language rather than destructive language, through use of person-first and inclusive language. Recognising the person first before their diagnosis, illness or disability, they believed leads to a more accomplished process in delivering person-centred care (Richards, 2019).

“My preference would be a person with BPD” (Corrine): See the person not the diagnosis

Person-first language separates an individual’s identity from any diagnosis, disability or chronic condition; it maintains that individuals are people first and not a diagnosis or a label and emphasises strengths and qualities rather than limitations and illness (Granello and Gibbs, 2014). Previous research with people with a diagnosis of BPD has highlighted how people should be seen as an individual (Kverme et al., 2019). Person-first language can convey respect and is a starting point for addressing the discrimination and social exclusion that people with a BPD diagnosis can experience.

Labels for those that access and participate with services conjures up different identities, relationships and power dynamics. The use of labels to define individuals with a mental health diagnosis solely by their diagnosis results in increased stigmatisation within medical and social structures. Labels given to those with mental ill health hold a lot of power, as well as influencing professionals’ responses and working practices. Labels can result in exclusion, discrimination and marginalisation and stereotyping an individual stripping away their identity and individuality.

Participants were asked about the use of language and terminology within services, how they wished to be identified and referred to by professionals and services and their thoughts on the use of identifying labels such as service user.

“It really diminishes us as people and it’s really derogatory” (David): Service user

The term ‘service user’ is the most commonly used in frontline health and social care services for individuals with mental ill health (McLaughlin, 2009). The term is used as the main identifier of individuals who seek out help and support. It is a one size fits all label which according to Heffernan (2006) is meant to imply collaboration between the individual and the organisation. However, the term ignores all the other things a person does which makes them who they are a as a person. Hutchinson and Lovell’s (2012) participatory action research with statutory mental health services found that statutory services had minimal regard to the identities of people beyond the ‘service user’ label and unwittingly maintained negative impacts of mental illness. The term also does not identify which service(s) are being accessed. Thus, it can be argued it inaccurately homogenizes a vast group of people within society, what is also known as a marginalised identity and eradicates a humanistic approach to care and support (Meleis and Im, 2002; McLaughlin, 2009). The service user label has remained largely unquestioned by professionals, social scientists and academics in the UK, but one critic Pugh (1996), argues that the term could be described as more oppressive than liberating and categorises people through a common characteristic and obstructs their individuality whilst creating a power divide between them (service users) and us (non-service users). A further criticism of 'service user' raised by McLaughlin (2009) is it disregards those unable or refuse to access services over concern of being stigmatised.

In his interview, David expressed strong feelings about being identified as a service user and described how it held negative connotations:

> David: Yeah, because I hate the word a 'user', it has such negative connotation, like, you think I'm using you? Another, it sounds very manipulative again doesn't it? You're someone that's draining something from someone, taking something […] I don't think it has any place in society.

Corrine described how the term service user lacks recognition of a person: "I am not sure that I really like the title 'service user' as it does not necessarily acknowledge the individual, just the need". Ash also spoke of her dislike of being identified as a service user: "I didn't like service user, it's just the word user, being you know, when you're borderline you get accused a lot of being manipulative and being a user". Sara described similar feelings to Ash, stating that a 'service user' has a lower status than other people. "I can understand why there is a need for a collective term of people that use the services…but I can also see that it doesn't feel particularly positive, or nice to people at all".

Sara suggested that umbrella terms for those who access services isn't necessary and in her work she is mindful of using person first language.

> Maybe there isn't a need for a term for it, maybe it's just people who present at A&E…I guess from a point of view of like writing research papers and stuff, sometimes you do need a collective term that describes people, especially if you've got a short word count. But then, I'll always try and put, you know…the BPD population or stroke sufferers or something…put the person before the thing.

In contrast, Eloise described a preference for the term 'service user' saying "Yeah, I think service user's good because it encapsulates a lot of things like patient, client, like patient, a lot of people are like 'well I'm not if I'm in the community I'm not a patient'. So, that's why service user is useful". Rosa shared how "service user" means they are able to recognise and identify with others as well as share experiences and feel part of a community.

> Rosa: I was a service user. I definitely was and I was proud of it. And I was proud to be engaging with other service users, but I don't think that's because it's the best word I think it's because it's the best one out of the ones we had at the time. Yeah, because you've basically got that or patients. So, we're going to have service users. I don't know if I've found one that is my preferred one yet.

Despite professional critiques and participants opinions of the service user term and the negative connotations it implies, organisations continue to embrace 'service user' as an active and positive term.

Participants also felt that the word 'user' held a strong negative association of a person who is addicted to drugs, one who exploits another (Dunne, 2010) and the myriad of all other derogatory terms. Lucy, Sara and Ash said how they think of it as using drugs when they hear the term.

> Lucy: Well a user is like drugs…I wouldn't want to labelled with service user.
> Sara: Sounds like a drug term doesn't it?.
> Ash: When you hear the word user what do you think of? Drug using or its abuse.

Rosa describes her thoughts about the use of 'service user' when delivering the Knowledge and Understanding Framework (KUF) training and the negative perspective she has of the label as well as professionals lack of awareness of the terminology, "User is very, drug-like to me. Like, you're a user of heroin, like that kind of thing. And there is a lot of stigma attached to people who use drugs. Yeah there is something about it that's not two-way, it's not engaging, that kind of thing".

The negative associations of service user and drug abuse highlights that services and professionals can wrongly apply judgements to a person's character and limit access and resources to people that are seeking help and support.

“We’re not consumers, we don’t get to pick and choose really. You get what you’re given and sometimes you’re not given what you need” (Helen): Service user autonomy and choice?

There has been focus over the last twenty- five years to give people choices in the services they wish to receive. Approaches to care, such as the recovery model, advocate for greater involvement, increased personalisation and facilitating choice over treatments (DoH, 2001). Service user choice has been set out in best practice guidance, with service organisations guided to involve individuals at every level (Papworth and Walker, 2008) based on government policy that people have rights and preferences and rely on a system which supports their individual needs (Department of health and Social Care, 2021). However, in reality, this has not always happened. Whilst the term implies that individuals have some choice over the care and treatment they receive when the stark reality can be that there is little or no choice at all, but rather the service user must accept whatever is offered. Carol and Louise for example, highlighted that the term ‘service user’ does not describe their experiences of choice and autonomy in services and treatment.

> Carol: I discovered this term service user, and I didn’t know what it meant, it didn’t make any sense to me. It implied that you have some sort of choice over what you are going to use. I’ve never really like it or approved of it but I always thought of myself as a patient which isn’t, not the word I’m looking for, not subjective, its not pejorative its, it doesn’t mean that you’re just powerless and silent and you just take what’s given to you.

> Louise: It implies that we’ve chosen to use that service, when actually you don’t get to choose what service you use…so I think service user suggests that you have a choice in what you use, when most people don’t have a choice…I don’t like the fact that it sounds like we are using up resources. I don’t like it from that aspect.

Additionally, Eloise believes that service user can misrepresent a section of people who in fact never to get to work with or access services because of excluding criteria set by service providers.

> Eloise: Service user also doesn’t cover the fact that some people aren’t, don’t ever get to use services and that’s through no fault of their own.

The research participants shared their opinions on what they preferred to be called as an alternative to the ‘service user’ label, identifying that client and patient where the preferred terms.

“Calling them clients was just reminding us as staff, we are here for them, we are not here for anything else” (Ash): Client

A small number of participants identified with the use of being called a client as an alternative to ‘service user’. For them it represented a more empowered perspective on the interactions between a person and physical/mental healthcare providers. Although David would ideally rather be identified from a more person-centred approach, client was preferable, “I mean I prefer the word client…for me, I’d prefer to be addressed just as me but people have to make it official to say that this is how we refer to people that we provide services to, and yeah, I’d prefer to be known as a client”.

The use of client can also be an established reminder for professionals on their role within practice, as Ash described her experience of working within the health and social sector saying “When I was a support worker we called them clients and I thought that was better because we were working for them and that was the way it needed to be.” Although Ash had worked in mental health support services, when she was receiving support from mental health services being personally identified as a client felt “hoity toity, it made me feel like I was paying for Bupa or something when I wasn’t”.

However, being called a client can for some still imply a ‘user’ element as well as indicating that an individual has a choice over when they are accessing a service Louise said, “I don’t particularly like client either, because again that seems to put an element of choice in, like, I’ve chosen to be there”. So, although client presented as a better alternative it still had associations with the negative connotations of ‘using’ a service. For some of the participants another alternative in being identified as a patient within medical settings and periods of being unwell which required support felt more applicable.

“Because you are a patient, you’re there because you’ve got a problem, you’re there for some treatment” (Helen): Patient

Historically people who required medical support or treatment were invariably identified as a patient. The Patient Rights Act (2011) recognised that this terminology did not differentiate between physical or mental health problems and entitled individuals to the same rights regardless of need according to Christmas and Sweeney (2016). Carol described, from her past experience as a registered nurse, how there was an element of respect within professional practice towards those identified as patients.

> Carol: I must say I prefer the word patient, but I always have, and I suppose that's because I'm a nurse as well. And I trained in the sixties, so I go back a long way, when patients were actually accorded a lot of respect. Because they were the people that the service was there for.

Gradually, as society and health and social care practice moved forward, the use of patient, became synonymous with physical health medical settings. For some of the participants there is no difference between physical and mental ill health. Louise said for her being called 'patient' had an element of reducing shame in identification by others.

> Louise: Personally my preference is just to be called a patient, because I am a patient in a sense that, in the same sense that I would be if I presented at, you know, with a physical health problem…I don't think there's any difference in being a mental health patient from being a physical health patient…patient I think sort of signifies the fact that there is something, that it's an illness, that you have an illness and it's not something that needs to be kind of hidden away or sort of covered up in any way. Your ill, so you're a patient, so yeah, that's why I prefer that.

Ash raised the point on her preferred use of 'patient', that it signifies a temporary status of being unwell and has less negative connotation attached to it "Yeah, because you're not always going to be a patient and it gives, yeah, service user, you could be a service user forever, whereas patient sounds much more temporary. I think it was much more of a temporary and emotionless word".

For some participants, being identified as a patient has less stigmatising and negative connotations than being called a service user. The term 'patient' provides no direct indication as to whether their participation with services is due to mental or physical ill health and implies a temporary sick status with a focus on personal recovery. Participants opinions on the use of identifiable labels has questioned the continuing use of 'service user' to describe a collective of people, and for professionals to enable and encourage people to be identified by their personal preference.

This section sought to understand the social construction of language and how it is used by professionals to identify people that come into their services. Participants shared their views on the most common identity markers (service user, client, and patient) and their personal preference when participating with services. 'Service user' can be argued to create an unequal, hierarchical 'them and us' power dynamic between people and professionals. Some of the participants believed it removed a person's identity and individuality and instead placed direct focus on their diagnosis. Critically it disregarded those unable to or do not wish to access services through fear of stigmatisation. The term 'service user' implies people have an element of choice and autonomy in their care, treatment and access to resources. However, the majority of participants described how inaccurate this was and detailed how there was no element of choice involved. Further concerns about this label are it's strong association with drug addiction, and it's sense of the exploitation and manipulation of others for personal gain which amplifies the negative views of the BPD diagnosis. Despite negative views of the term, for a minority of the participants, it was the most preferred descriptor for a collective group of people that access services. Alternative terms, such as client, were thought to be more empowering, however this still implied choice through it's sense of consumerism. While 'Patient', which provided for a temporary status of being unwell, was felt to be emotionless and reduced the level of stigmatisation as it does not signify between a physical or mental health illness. Person first language was preferred to separate the diagnosis from their main identity.

"I have tried to stress the need for someone to work with who specialises purely with BPD but am hitting a brick wall" (Corrine): Service provision

Despite ever-increasing awareness of mental health in England, service development for those with personality disorders was and is limited. As a result, the needs of people are neglected as they are excluded from mainstream services and marginalised in service decisions thus limiting access to the necessary resources and treatment (Kealy and Ogrodniczuk, 2010). The impact on the lives of people who lack continuity or provision for care and support includes isolation, loneliness, less opportunities and experiencing social vulnerability (Jones, Ahmed and Catty, 2009; Nolan, Bradley and Brimblecombe, 2011).

Personality disorder services in England are organised in tiered systems defined by the level of intervention required for the individual. Service and treatment provision focuses on which diagnosis someone has rather than the complexities of their conditions or the trauma they have experienced which leads to unnecessary distress and unmet needs (Keir Harding in The Mental Elf, 2017). This system can be difficult to navigate and can result in people with co-morbid diagnoses being denied access to effective treatment (The Royal College of Psychiatrists, 2020). This is significant because people with BPD diagnoses have high levels of co-morbidity with PTSD, eating disorders and addiction. In the light of these co-morbidities, the ICD-11 (World Health Organisation, 2018a) introduced new levels of diagnostic identification (difficulty, mild, moderate and severe).

However, Morris, Smith and Alwin's (2014) research determined that mental health services are unable to meet the needs of people with BPD due to staff lacking the necessary skills and knowledge. Similarly, Dale et al. (2017) National Personality Disorder Service Study identified that despite specialist Personality Disorder services having multi-disciplinary teams, generic mental health services employed twice as many different staff groups, specialist Personality Disorder services had more exclusion criteria than general services and the availability of treatments was generally the same. Staff from specialist Personality Disorder services were more likely to be involved in continued education, training and research compared to generic mental health services. As Dale et al. (2017, p. 254) concluded, 'There is continued exclusion, variability of practice and inconsistencies in the availability of services'. The authors noted that despite the Personality Disorder Capabilities Framework (NIMH, 2003b) describing the knowledge and skills required to work with this client group, specialist service staff are still limited in their practice. The Royal College of Psychiatrists highlights this continuing issue that despite policy and practice recommendations the distance between knowledge and practice has grown and that specialist services and mainstream interventions remain tokenistic and limited (Royal College of Psychiatrists, 2020).

The Royal College of Psychiatrists initially recommend that all psychiatrists are suitably trained in the assessment and diagnosis of personality disorder with knowledge of treatment and therapeutic approaches, and appropriate use of medication. This recommendation indicates that those already in the profession are not suitably trained or have the level of knowledge required to work with and support people experiencing mental health conditions. They recommend that children and young adults with an emerging and diagnosable personality disorder be provided with interventions from services. The RCP also note that people should not be denied mainstream services because of their diagnosis and services should practice equality and inclusivity including a coherent pathway for those transitioning from CAMHS to adult services which have historically left young adults without suitable support upon reaching the transitionary adult age. Based on policy and guidelines this should already be paramount in organisational working and ethical practice and is highly concerning for the people who are yet to experience mainstream services. Services which meet the needs of, and are informed by, the individual provide not only therapeutic value but also opportunity to learn from patients, improve practice and enhance the quality assurance of their service (Klein, Rosenberg and Rosenberg, 2007; Elstad and Eide, 2009).

All participants were asked whether they received care or support from any service and whether they had been offered any form of treatment since their diagnosis, including in periods of crisis. Ninety percent of the participants shared that they had received no treatment or support from mental health services since diagnosis or when in periods of distress. Angela raised concerns about the lack of suitable treatment available from healthcare trusts for people with a BPD diagnosis:

> Angela: One of the keys things that you need to be asking is, why do they take people into their services, with borderline personality disorder or personality disorder, when they don’t do treatment for it?...we are talking about people’s lives so, they get paid for the person on their books, but they don’t give them any of the recommended treatment. And if you go through their [Healthcare Trust] board minutes […] they actually say in their board minutes, basically there’s no treatment and no drugs that treat personality disorders. Which is nonsense. I sent it to an expert in personality disorder, he just said that’s laughable.

However, psychotherapeutic treatments are considered the best option for those a with a BPD diagnosis. Types of therapy that are found to be supportive are Dialectical Behaviour Therapy (DBT), predominantly offered by the NHS/mental health services for women and those who self-harm or exhibit suicidal behaviour, Mentalisation-Based Therapy (MBT), Cognitive Behavioural Therapy (CBT) and Systems Training for Emotional Predicatibility and Problem Solving (STEPPS). These treatments are recommended to last a year or longer to be fully effective, but funding for a course of treatment through NHS/mental health services is generally 6 months (McMain et al., 2018).

At the time of interview (2020) 14 months after diagnosis, Sara had not been offered any support or treatment from mental health services and had to pay privately for treatment due to long waiting lists in her area.

> Sara: I'm on the waiting list…it really annoys me…14 months ago I was living in London, I got the diagnosis from that psychiatrist….I moved back up to Nottingham to move closer to my friends and stuff….I had a private therapist for about a year. So, when I first started realizing; okay this might be a thing now, probably about 3 or 4 years ago that was, I went to my mum and dad and said, look I need some money to help this, so I did get a private therapist. She was, she specialized in transactional analysis…she was really good. If like, I ever needed to call her, and we could make two appointments a week if needed. So, I had her for probably about a year and a half and that really, it really helped to get me to understand what was going on, and like, I understood the process, but I couldn't change it. She got me to that point and then she said to me, 'unfortunately, Sara, I think you need someone who can take you to that next level and have specific knowledge in BPD'.

Psychological therapy can provide a lifeline, however the majority of people are waiting months and even years to get the treatment and support they need (Mental Health Foundation, 2021). According to a House of Commons (2020) briefing paper, waiting times in England for NHS psychological therapy (IAPT) vary from 4 days to 61 days depending on location. However, these figures are misleading due to 'hidden waits' that people are facing (BBC, 2019). The first appointment target of between 4 to 61 days to be seen is generally met, but people are having to wait more than two years for the second appointment which kick-starts therapeutic treatment (Centre for Mental Health, 2017; Mental Health Foundation, 2021). The RCP suggests that the increase in mental health problems caused by the Covid-19 pandemic will result in even longer waiting lists (Campbell, 2020a). Lack of support by mental health services can amplify a person's coping methods, result in life threatening distress and suicidality leaving people with no alternative but to go to A&E when in periods of distress.

> Corrine: When things get bad and I have not had the backup from the mental health team I have resorted to overdosing on paracetamol. [When the crisis team does engage] they show…no concern for your welfare…no help or follow up as to how they intend me to do this…currently [I am] awaiting one to one therapy and up until recently the backup I have is regular visits to my GP. As this is not the best option, I have had to fight to have a mental health worker reappointed to be there for me when required. I have for about 5 months been allocated a mental health social worker who I can only access on a monthly basis through a telephone call unless I have a crisis.

The Healthcare and Quality Improvement Partnership HQIP (2018) undertook an investigation of the National Confidential Inquiry into suicide and homicide of people with mental illness and found that people with personality disorder who had died by suicide were not receiving care consistent with the NICE guidelines and people were not offered appropriate or timely crisis or psychological intervention by services. Long waits for therapeutic support have shown that there is an added impact on crisis services who do not meet the needs of people in periods of distress. Additionally, Llyod-Evans et al. (2018) found that some crisis teams had reservations about their ability to effectively provide constructive crisis support to people with personality disorders generally, and particularly those with a BPD diagnosis.

"Nobody sees you and nobody follows up" (Rosa): Engagement by services to those in need of help or in crisis

Crisis Resolution and Home Treatment teams are designed to improve delivery and accessibility of mental health services by providing a 'around the clock' service to those in crisis, giving practical guidance and support and individual interventions based on input from the person, family and carers to increase a persons' ability in avoiding a crisis situation in the future (Nelson and Ashman, 2016). The RCP (2020) recommend that crisis teams are staffed and available 24/7 for adults and younger people and that staff need to be adequately trained, regularly monitored and supervised in order to work with people with a personality disorder. For some people their only hope is to get support indirectly from mental health services by going to their local accident and emergency department.

> Rosa: I'll sit in A&E and wait for the mental health team to come see me, and they don't. Nobody sees you and nobody follows up. So, I've had ones where they've made me stay overnight for me to see someone in the morning, I've had ones where they've made me go home and told me to come in for an appointment in the morning and if I don't come in they don't chase it up and it's like, actually I could be dead right now. There is never follow up to these, there's never like, right you've come in with a crisis therefore you probably need a mental health team, there's never any of that going on.

Some people's first experience of interacting with mental health services is when they are in crisis and looking for support. However, being in crisis does not necessarily open the door to service provision (Newman et al., 2015) as first the person in crisis must be acknowledged as someone actually experiencing mental health crisis. This delays access to services and potential treatment options and deters some from seeking help in the future. Carol strongly expressed her opinion on seeking help from mental health services based on her previous experience whilst a patient at the Maudsley and Broadmoor.

> Carol: Never and I wouldn't [seek help from services] to this day and I'm in my seventies now…If I might put it like this; I would never trust the bastards again as long as I could see them. Never. And nothing has persuaded me…that they are any better at understanding women…no I wouldn't…over the years I've learned and understood that the best person to help me is me. And now I have a great deal more understanding and I believe in myself. I'm not going to some professional who's going to think of me as some seventy-year-old woman who doesn't really want help I don't think so, no, I know how my system and my thoughts and my feelings operate. I understand myself.

Mental health services' pathology orientated approach guides support, treatment or inpatient admissions which can result in those experiencing distress which sits outside of the clinical indications receiving less or no support (Lyons et al., 2009; Grant and Westhues, 2012; Rhodes and Giles, 2014). This highlights why services should re-orientate their approach to focus on how mental health crisis affects everyday life, rather than on specific symptomology.

Studies of peoples' needs during a mental health crisis highlight services should adopt a holistic approach as opposed to a narrow medical focus, services should focus on helping people feel safe and included, give practical support and access to talk to someone to voice how they are feeling (Winness, Borg and Kim, 2010; MIND, 2011; Voronka et al., 2014). To address the issues of mental health crisis service provision, the Mental Health Crisis Care Concordant, a national agreement, was set up in 2014 between twenty-two national bodies involved in health, social care, policing, local government and the third sector to ensure that people were fully supported during a period of crisis. It focused on four main areas (access to support before crisis point; urgent and emergency access to crisis care; quality of treatment and care in crisis and recovery and staying) (Department of Health, 2014). Despite the Crisis Care Concordant, to improve crisis care, services are failing to live up to national standards as Angela experienced.

> Angela: [the mental health team] literally just left her and this would go on for weeks and weeks and weeks, with the crisis spiralling, with ample opportunity for them to come in, to intervene, to work with her either avoid the crisis or to help to turn her around and they did absolutely nothing. I have got a letter where I literally begged them to help. I was so ill, Donna, I was so ill, and my mum was dying at the same time and I couldn't breathe, I couldn't sleep, I slept inside, I used to go to bed on my sofa fully dressed because I was just waiting for the next incident to happen. I asked myself so many times why am I doing this, and the only answer I could really give myself was

> to say that I believe she had a right to live, I believe she has a right to die as well, if that's her choice, but not because she could not get basic fundamental care from the people who are being paid to look after her.

The failure by mental health services to provide crisis support and long waiting lists for therapy has resulted in people exaggerating their mental health out of desperation.

> Sarah: The only way I could get support now is if I, if I exaggerated. […] I don't like doing that, and like, to be honest I perhaps have done it once or twice in the past when I've been really desperate, because I've been scared that if I don't I'm not going to get the help. And it's not that I want to die, I'm just scared that I could do something, that I could end up, I could do something to myself when I'm having those lapses in control. But I haven't done that for years and years and years, and it means that I don't have any support...It's awful, it really is. I can have times where I really, really, struggle and at that point, not having somebody to do it for you, but to have somebody who could, sort of be a support like, those practical things, for me that would help massively.

The Care Quality Commissions review of mental health services found that people are facing difficulty in accessing services due to severe gaps in provision. As a result, GPs are advising people to emphasise that their mental health is worse than it is as many are reaching crisis point before they can access mental health services (O'Donoghue, 2018). The review also noted that services were creating inappropriate high eligibility criteria to create exclusion from support.

"You can have very, very valid argued points about why you need such and people can still turn you down" (Helen): Exclusion by services

Research on mental health has identified that individuals with mental health conditions such as personality disorder are still among the most socially excluded from society and services (Huxley and Thornicroft, 2003; Pilgrim and Rogers, 2003). Williams and Keating (2005) argue that, along with diagnosis, gender, race, class and sexuality are all determinants of an individual's inclusion or exclusion from services. Services therefore can replicate some forms of societal discrimination through controlling and restricting treatment based on narrow clinical definitions. Attempts to rebalance inequality in service access not only means an increase in overall service provision but also addressing stigmatising cultures, protection of resources and diagnostic group exclusion criteria. For example, before David could access any support for his recent diagnosis and addiction after moving to Bristol, he came up against exclusion criteria.

> David: I had to navigate the mental health system here, plus I was told because you are, I was using benzodiazepine, it was tight, you've got to be free from benzodiazepine for three months and cannabis and alcohol before we give you another assessment. But I'd been assessed, this was a diagnosis, 'yeah but we can't do anything until you've had a period of abstaining from self-medicating'. So, I did that I've contacted the drug and alcohol team here, they were initially going to put me in a detox unit, but I just threw away all my medication and just went cold turkey, which was horrendous. Looking back on it I think why did I do that? But I knew I wanted to enter into some kind of therapy, I'd like me to change drastically and them saying this was my barrier to having any treatment or service as such. I'd abstained for three months and it took them another three months to see me…I see it for what it is now but, when you're not getting any treatment and you're not having information to help you understand what's going on for you on a neurological, psychological and biological level it's scary.

People's willingness to participate with services at times of real need may result in exclusion as Helen experienced:

> Helen: In 25 years of being under psychiatric help, I'm really, really struggling to think if I have ever been offered, you know I can turn things down, but I've not been given options and definitely, definitely at times there have been times that I have specifically asked for specialist help, with very specific needs and I've been turned down….based on all sorts of obscure criteria. I understand why it's there, it's there to ringfence funds for certain things and it's not a, you know, an endless money pot.

Access to services are based on suitability criteria, however the BPD diagnosis can be an exclusionary factor whereby professionals can be unwilling to participate with them.

"There's a lot of things you are counted out from" (Eloise): BPD diagnosis service exclusion

For people with a BPD diagnosis, it can be a 'postcode lottery' in accessing relevant services.

> Sarah: When I was discharged from [bigger city], I was discharged back to [smaller city]. [Bigger city] has the personality disorder support, but [smaller city] doesn't. Or at least at the time [bigger city] did, and [smaller city] didn't I don't know what the situation is there now. So, it meant that I was kind of hopeful that I was going to get some support but then found that there was nothing in place. So, that was frustrating, because I wanted the support as well. But then over time, I can't remember the timing of it, I found out there was people accessing dialectical behaviour therapy in [smaller city]. But, at the time it was for people whose postcode was from outside the city, so it had to be like a county postcode, just because, I think it must have been funding or something. I'm not sure. So, although they met, they had the sessions in [smaller city], if you lived in [smaller city], you couldn't get it.

Despite the influence of *Personality Disorder: No longer a diagnosis of exclusion* (NIMH, 2003a) on policy and practice, people with BPD can still experience a ‘revolving door’ and exclusion by services based on their diagnostic label (Horn, Johnstone and Brooke, 2007; Warrender et al., 2020). HQIP’s (2018) national survey of people diagnosed with a personality disorder (92% describing their diagnosis as borderline) found that the majority (82%) were current ‘users’ of services but that people expressed exclusion from mainstream services based on their diagnosis as they were discharged as having too complex or too serious needs for services to manage and they felt stigmatisation attached to the diagnosis left them marginalised and labelled as beyond help. Service professionals’ responses to this were that services are disjointed and lack a clear pathway in interacting with and supporting those with the diagnosis, referrals were often refused based on criteria not being met, needs being too complex, or co-morbidities such as substance misuse or anxiety. Professionals also described resistance from other professionals who wanted to divert people away from their service citing complex needs and those with the diagnosis being better placed elsewhere. Two of the participants discussed their experiences of exclusion based on their diagnosis.

> Eloise: It’s just, there’s a lot of things you are counted out from, ‘oh this is not appropriate because of your BPD’, like actually I have other diagnoses as well. So, they’ve quite often not been treated, even though the treatment line for that is quite clear, because of the BPD…I am relatively lucky that I am in an area where you can be under other services at the same time, like, I’ve got some friends who live in places where you can’t be under eating disorder services if you’ve got BPD and things like that, which is not the case here, but they are very cautious of that.
>
> Helen: Some eating disorder clinics actually won’t take people if they’ve got BPD on their record, or BPD traits.

Exclusion from and lack of accessibility to services can have a direct impact on people with co-morbid diagnoses and influence the use of individual coping mechanisms to manage distress.

“When things get tough” (Corrine): Impact on crisis and coping mechanisms

For people not being actively supported by specialist services, exclusive criteria for treatment or the removal of support that is working, results in exacerbating methods of managing emotional distress and periods of crisis including suicide (HQIP, 2018).

> Corrine: When things get tough, which can be daily, I resort to self-harming. I have not been able to have therapy yet that can teach me the necessary skills to identify when something is getting out of hand and how to overcome it or at least maintain some sort of control over my emotions…I don't want to self-harm but until I get the help I need this is my coping mechanism to get from one day to the next.
>
> Ash: I think I'd destroyed my bedroom, I'd hit my dad, I'd taken an overdose, I'd been in A&E literally once a month for about five years, I had had enough and they still wouldn't section me.

In Louise's case on a visit to her GP for some advice and support she was left emotionally distressed.

> Louise: So, basically her saying, 'I can't see you unless you are having a massive crisis', basically sent me into a massive crisis. But I didn't want her to deal with it, so I left feeling so much worse than I did when I went in…[it is] really difficult to find somebody that understands a: mental health in the first instance, and then b: personality disorders on top of that. I think, you know, it's the most un-understood, misunderstood, kind of diagnosis and, I don't know, people just, GPs just don't have the time or the inclination to spend any time with you. That's my experience of it anyway.

Angela described the impact on her neighbour when her care plan was removed:

> Angela: She went to a care planning meeting in December 2009 and she came to me afterwards, she was absolutely distraught and she basically said that 'Even though I wrote down everything that I wanted to say to them they still didn't listen'. She was beside herself. The one thing, and the only thing that worked well for her was that she was allowed to go into respite for a week, one week in six… they were going to wean her off it. And it was literally the key thing that worked for her. So, she was distraught, and she was very distraught because they just didn't listen to her opinion. So, she started to deteriorate from that point onwards […] there were ambulance callouts, I think six in the three years when she had respite, very few of them resulted in hospitalization, no calls from the police, no nothing. It was all very low key, so low key to the extent that even when she had an ambulance, I wasn't aware that that had happened. As soon as they changed her care plan it just escalated beyond anything I can even possibly begin to tell you. It was just absolutely shocking […] I saw her hanging herself twice […] I sat with her while she cut herself and she hit her head against the toilet and she knocked herself out.

The participants highlighted from their experiences, treatment accessibility, whether at the time of diagnosis or post diagnosis, is minimal or non-existent with the only option to finance private therapy. The option for therapeutic treatment is further compounded by long delays between initial assessments and the first therapy appointment due to increased demand.

Furthermore, limited provision, specialist personality disorder services, lack of engagement by professionals and exclusionary criteria negatively impact people at times of crisis, influencing their use of coping methods to manage emotional distress. There is no concise framework of how mental health services should provide treatment or work with those with a personality disorder diagnosis which puts people at risk, despite previous policy and practice guidance and recommendations. Mental health services neglect the needs of people with a BPD diagnosis which continues to fuel the marginalisation and stigmatisation of this diagnostic group.

Professional power

Research into mental health care cultures has found it steeped in the medical model discourses of treatment, control, compliance and professional expertise (Van Hoorn, 1992; Rogers, Pilgrim and Lacey, 1993; Stark et al., 2000). Connor and Wilson (2006) highlighted that professional hierarchy remains a facet of organisational existence with new members of staff pressured to conform to work in established ways and not challenge the equilibrium. Angela described a time her neighbour was attended by a paramedic:

> Angela: The paramedic came and said she [the neighbour] was bradycardic [slowed heart rate] she is seriously ill, she needs to be hospitalized, which means she needs to be sectioned. The girl [from the crisis team] phoned [her office] and they said "No, we've got other priorities". So, she actually sat there in front of me and said, "So you're questioning my professional judgement, are you?". So, it didn't happen that one.

The attending professional (the paramedic) was over-ruled by the Crisis Team, placing her neighbour at more risk. The Crisis Team Worker was told by her colleague on the phone to leave. Eventually, the attending paramedics organised for a local on-call psychiatrist to attend as Angela's neighbour's condition became critical:

> (Researcher) Do you think it was because that they don't want to accept any responsibility for people with Personality Disorder's?
> (Angela) I don't think it's even as basic as that. I don't know what they think is important, apart from preening themselves about how fantastic they are with sort of low-level depression and things like that, which I understand, yeah let's get people back to work if we can and things like that. But how are we going to save the people who are critically ill, that can live a life that is meaningful and well and not just say, 'oh you might just as well die'. You know, what a God like decision that they're making. Maybe it is too complex for them, but at the end of the day if they listened to their service users or they listened to someone like me, who went into it with them being

> very amicable and saying, and as the months went on the lie upon lie upon lie that they told me, and I realized they are so incompetent.

Differing perspectives on practice between staff can cause conflict, causing harm and risk to the people under their care and support. A wider understanding of diversity between professional groups is needed, with staff not being constrained by complex hierarchical structures that exist in services (Pollock et al., 2004).

Psychiatrists are generally identified as the professional who wields the most power over both people under their care and other professionals (Warne and Stark, 2004). Whilst delivering experience led-training to A&E staff, Eloise saw how professional hierarchy can influence colleagues.

> Eloise: There was a sister who I'd met before like, when I'd been in the hospital and she was quite aloof and not interested, and she was the same in the training, she was sort of sitting there, like went out for the loo part way through…and all the people, the nurses and support staff who worked with her followed suit, because she was a senior who wasn't interested…the [police] sergeant was really interested and really keen so everybody else followed suit…getting the people a little bit further up the ladder, if they are on board with it then everybody else will…

Carol added that in her experience of mental health services:

> Carol: As soon as I strayed away from being amenable and cooperative and just having depression, that was the end of my career as a successful patient really. Because I wasn't conforming with what they wanted me to be…So, anybody putting their head above the parapet, which in a way may be regarded by other people as being weakness, are really for it.

Professional dominance can influence how other professionals respond to and treat people with a mental health diagnosis. However, it can also create a culture of compliance where vulnerable and marginalised people accept professional authority. Professionals and services should shift the focus away from controlling individuals with a personality disorder diagnosis towards autonomy and social inclusion by promoting full involvement of individuals in their own care and treatment (Bates and Stickley, 2013).

“It's never questioned because they’re the professionals” (David): Professional dominance

The concept of power is multi-faceted with two main facets; ‘power over’ and ‘power to’ (Cavanaugh, 1984). ‘Power over’ is exercised by one person over another (less powerful) person and ‘power to’ describes the individual’s capacity to act effectively. Parsons’ (1951) ‘sick role’ theory, although primarily directed to physical ailments, is applicable in psychiatric diagnoses in that professionals must consider a person to be (or appear) unwell and compliant enough to allow for professional help.

Dahl (1957) suggests that psychiatric professional dominance over diagnosis is intentional use of ‘power over’ a person or group of people. Professionals become dominant, considered ‘expert’ and gatekeep resources. Some people thus adopt the ‘sick’ identity as (sometimes the only) means of obtaining help and accept, rather than challenge, the power imbalance (Breeze and Repper, 1998; Borg and Karlsson, 2009). Connor and Wilson (2006) found that people who required mental health service’ support and treatment were very aware of the ‘them’ and ‘us’ power dynamic with professionals, particularly psychiatrists, which made it difficult for individuals to be involved in planning their own care. David, for example, felt that he repeatedly had to mute his opinion for fear of losing support:

> David: It’s a very regulated form of abuse as well. It’s never questioned because they’re the professionals, they know best, they know everything there is to know about mental health, making people do what they want, making people compliant, making people agree to things that might not be in their best interests.

Connor and Wilson (2006) also found that, sometimes, professional control was (experienced as) abusively humiliating, bullying and bossy. Professionals in services create an unequal power dynamic with people to ensure they cooperate and not challenge their authority (Hem, Molewijk and Pedersen, 2014). Some elements of professional dominance’s ‘power over’ are explicitly controlling, such as people being detained in secure units. For example, after her breakdown had led her to being arrested for arson, Carol was told by the Police that they, and the court, would be happy for her to be on bail, but evidence from the psychiatrist at the Maudsley hospital meant she was sent to Broadmoor, a high security psychiatric hospital.

> Carol: He’d submitted a report that I didn’t recognise at all. That was read out in court, and the whole time I remember standing there feeling icy cold because I’d thought he’d actually got the wrong person. Perhaps he had confused me with someone else.

Sometimes this professional dominance is exercised for the personal benefit of some who work within the mental health sector. Sarah experienced this with a CPN who tried to take advantage of her vulnerability.

> Sarah: This one, she just had no sense of boundaries. Basically, she'd been doing all sorts of things. She'd been, she asked me to change my bank account to her bank account so she could get £100, so we could both get £100, because you know sometimes when you get somebody else to switch to your bank you get money, and I felt really pressured to do it, and I was going to do it because of that pressure, but then it turns out I've got a savings account with that bank so actually I couldn't because I was already with them. And then she was trying to get me to sign up with Top Cashback again so she could get money.

The situation was reported to the mental health team's manager as a safeguarding concern, whereby the CPN laid blame on Sarah's BPD diagnosis to save her professional reputation.

"'Are we covered if she dies?'" (Angela): Organisational culture & protecting professional reputations

Risk and culpability are central in health and social care organisational policy (Brown and Calnan, 2013) thus the care, interests and needs of people with mental ill-health diagnoses can be impacted by concerns over reputational risks. Rothstein (2006) demonstrated that the dynamics of managing perceived risk within organisations leads to protection of individual and organisational reputation, influenced by a modern focus of blame if things go wrong (Weber, 1978). Carol spoke of the cultural dynamics of institutional practice experienced during her time in Broadmoor in the 1970s. Inpatients would be held and treated until it was no longer apparent that there was a mental health issue, they were not a risk, and they could be productively re-integrated back into society.

> Carol: In those days you were admitted to the ward and you stayed there, for weeks and weeks or months and months, until you were completely well enough to go back, the phrase used was, be a useful member of society. Because as somebody suffering from an acute mental illness, you weren't of any use to society, that was the implication [...] What they do, they take away your drugs. Everybody, doesn't matter what your diagnosis is or what medication you've been given before you get to Broadmoor. It's all dismissed. Because they say, well we want to see how you are without all these meds, we can't make a diagnosis until we know what's going on and we can't do that if you're taking lots of medications which might obscure the diagnosis you see. So, everyone gets stripped of [their diagnosis] and then they start again.

This reinforces the hierarchy position of Broadmoor staff and psychiatry over other medical professionals.

Angela described that, whilst helping her neighbour, she found that services would actively protect each other by way of not taking responsibility for care and support. She found she was put in a position by them to carry the blame for the lack of support of her neighbour leaving the neighbour in a prolonged period of crisis and self-harming behaviour. In doing so, Angela felt that the main priority of the services was in protecting their own reputations and financial stability. Before interviewing Angela, she had sent me documents from the mental health trust and other organisations to evidence what she had experienced which are referred to in the following excerpts of conversation.

> (Researcher) From their report they tried to actively get you involved, didn't they? They actively engaged you to become involved.
> (Angela) Yes, absolutely they did.
> (Researcher) So it kind of eased the responsibility that they had towards her.
> (Angela) Absolutely that. It's a blame game, its everybody else's fault but theirs…And all the while you're talking about somebody who has a personality disorder, so the overwhelming burden on me, as I was the only person who actually seemed to do anything, was astounding…So, it's like Dickensian days, let's just pick up a bloody great big carpet and sweep it all under there.
> (Researcher) That's because you were the one that was trying to contain the situation and the more that you were doing the less that they'd have to do.
> (Angela) It was worse than that, Donna, what it is, is that they would have to answer questions about a member of staff being attacked and that would be serious shit, but me, they'd just lie about all the things I said and I would've been collateral damage. Yes, they were definitely leaving me to look after her, and I couldn't take a step back, I couldn't face going back, what can you do?

On one occasion the (Mental Health) Trust held a meeting concerning Angela's neighbour the week before her respite was taken away.

> Angela: I knew somebody who was in one of the meetings at the trust and she told me that they said in this meeting, 'Are we covered if she dies?'.

On another event her neighbour was placed in hospital for a number of weeks:

> Angela: I phoned up one day because he [a psychiatrist] has a pattern of behaviour that I think is basically to trigger people. So, she had been in hospital, she was doing really well, the day before she was due to come out, he gave her some bad news. So, I was thinking, why don't you, because you know you've got her for three weeks or whatever, why don't you tell her at the beginning of that? Then you could contain any upset from it. So, he did it the day before, she left hospital, she went walkabout, she

> phoned me in an absolute tizzy, she was so distraught and despairing. So, I rang up [the Mental Health] Trust and I just said, I can't speak to [Psychiatrist], I wouldn't speak to [psychiatrist] and I said would you pass a message on to [psychiatrist] for me, the woman said yes, I said, ask him, from me, if he could be any more stupid if he tried.

Underfunding of mental health services by the government, as well as their commitment to private provider's delivery of public services, has led to increased reliance on private companies to manage the shortfall. The provision of mental health inpatient care and treatment has become a commodity with private companies bidding for contracts. According to the NHS Support Federation (2019) contracts awarded to private, non-NHS companies were estimated to be valued at £611 million in 2017/18 and accounted for 65% of all contracts granted. Angela discovered that the Trust used private companies to deliver patient care.

> Angela: So, [Trust] use a portal for auctioning off their clients with profound difficulties, learning difficulties and mental health difficulties, and they are one of the only counties in Britain that actually do it. And out of a study of twenty-one different mental health organisations in Britain, they came third for auctioning off services of their clients, and every other council or health trust said 'We don't do it. We won't use it because we want to give our clients person centred care', you know and it's like a bloody cattle market [...] I think there's just a rotten culture […] if you take the country as a whole, and see how much, how much is affected by poor mental health services, obviously people not going into work in the economy, people in the prison services, particularly with the personality disorders, impact on the police, ambulance service, A&E, GP's, families, neighbours, and the impact on the carers, the immediate carers, is phenomenal. So, where is the logic in not providing proper treatment?

Three participants discussed the uncomfortable dynamic of working within mental health settings and not disclosing their own mental health diagnoses. Ash described a 'them and us' dynamic whilst employed as a support worker:

> Ash: Dealing with borderline patients, it's very odd, when you're borderline yourself and you can't tell them, very odd, and the patients go, "You just don't understand how I feel" and it's like, I know exactly how you feel…Once that information is out there, you can't take it back so no, they didn't know, that made me weaker to them.
>
> Eloise: I used to work in an acute hospital […] yeah there is a culture within a service, and people may come into a service with absolutely no opinion's about it [BPD] but if everyone else is saying, 'oh you know, this is a particular difficult service user set to work with', everybody is going to start believing that and presuming that, looking for evidence for that as well. I've definitely seen that…new members of staff start in units like that. They come in all bubbly, like with an idea, and they realize what the culture is like and they slowly like, turn into that, sort of…It's about culture change, not individual's I think. Whole culture change.

In Louise's experience of the working culture of services in terms of the diagnosis, she found them very dismissive and intentionally trying to limit any interaction as soon as possible.

> Louise: Everybody else in the system seems to be, 'well ignore her', or, 'just get rid of her as fast as you can', or you know, 'patch her up and get on with it', and it's so infuriating...I think there is a really strong culture of, we're un-helpable with BPD and we're just there to get in the way.

Negative belief systems operating in mental health settings around the BPD diagnosis result in unequal treatment and support and contribute to the continued stigmatisation of people.

"The lower classes have personality disorder and the middle classes have bipolar, and upper classes are just eccentric" (Rosa): Social acceptance of mental health

Societal non-acceptance of mental health is based on the structural beliefs that operate within society as well as in professional services. This can result in unequal and unfair access to treatment or the creation of service criteria that affects this population group. Society and frontline services steer away from associations with those who are deemed as having challenging characteristics based on their diagnosis. This creates a hierarchy of mental health conditions considered more accepted than others (Link and Phelan, 2001; Ahmedani, 2011; Bracke, Delaruelle and Verhaeghe, 2019).

Social acceptance of mental health helps normalise people's diverse responses to adverse situations and the challenges they experience. Helen, Carol and Rosa talked about why social acceptance is important:

> Helen: In an ideal world it would be nicer to be able to describe to people and explain for them to have some level of understanding, I think that's what would be really, really, helpful.
>
> Carol: This kind of growing awareness in society, could move towards persuading people to use their own strengths, that we all have, might be well hidden sometimes, but again, using society and the immediate community, having a space to work with other people, a friendship group, I don't know, call it what, a gardening group, a thinking group, to tackle issues like this don't go near psychiatry.
>
> Rosa: I think we are starting to acknowledge that a lot of mental health is caused by, a lot of mental health is worsened by things like awful jobs and that it's our fault that people are in awful jobs.

Societal attitudes towards mental health conditions can be influenced by media representations, which are generally negative and present people with mental health conditions as violent and dangerous regardless of diagnostic label (Thornton and Wahl, 1996; Teplin et al., 2005; Antanasova et al., 2019). These depictions of mental (ill) health promote stigmatising belief systems about behaviour and influence the seeking of help and support (Jorm, 2000). Rosa discussed how people in the media can influence acceptance and normalise mental health conditions in society.

> Rosa: Monty Don, I do quite like him, I like his gardening programs, but he is very upper class and he was always touted as very brave for talking about his mental health, but I feel like in the position where he was able to, compared to other people, because he's one of the poshest people on TV really. There's just that, I think it just goes with that, you must be more clever if you are upper class so, you must be better at looking after our mental health.

Rosa added on how the class system in the UK influences how someone's behaviour is interpreted as well as influencing their diagnosis.

> (Researcher) Do you think that people that show that kind of emotion [in relation to mental health crisis] we automatically judge and become fearful of?
> (Rosa) I think that people who show that emotion are [seen as] lower class, mentally ill, like they're those kind of things. Like they must be stereotyped as these things, they don't fit and yeah…And then it links with class…that the lower classes have personality disorder and the middle classes have bipolar, and upper classes are just eccentric. And just that, yeah, you're more likely to be treated like a person if you have a diagnosis of bipolar. And it just makes me feel like, BPD is related to working class oppression.

The participants have highlighted an awareness of the power dynamics that exist between professionals and those with a BPD diagnosis. Professionals in mental health settings exert power and control to maintain the hierarchical position between the 'expert' and the 'service user'. Dominant cultures that exist in frontline services can manipulate other professionals to adopt negative and stigmatising belief systems. To challenge this culture of control, people with a BPD diagnosis are resistant and fearful due to risk of losing treatment and support. To challenge dominant cultures that exist and people with mental ill-health to have increased autonomy, equal and fair treatment, experience led inclusion in services and social acceptance, can help to facilitate change and challenge the stigmatisation of the BPD diagnosis.

Reclaiming power and identity

Early activism and the ‘user movement’ grew in response to the use of electro convulsive therapy (ECT) and tranquilisers, the law to detain individuals without trial and in response to the anti-psychiatry movement and the work of people like Laing (1965) and Szasz (1973) who believed mental illness was a myth (Connor and Wilson, 2006). Szasz (1973) proposed that psychiatry coerced power over people, deprived them of freedom and autonomy and classification as citizens. The medical model in Szasz’s opinion was not fit for purpose to help people who had ‘problems with living’ and what Laing (2010) suggested as a normal response to a mad world (Szasz, 1973; Szasz, 2010; Baklien and Bongaardt, 2014).

Mental health activists describe madness not as an illness but as an alternative state of being and advocating for autonomy and inclusion in care, support and service development.

“Making it so that other people didn’t have the same journey that I had had, in not being so lost and failed in services” (Rosa): Activism for inclusion

Inclusion (regardless of race, gender, disability, sexuality, or mental health diagnosis and so forth) is concerned with ensuring the availability of equal access and opportunities and the eradication of intolerance and discrimination and is a human right. Some participants shared their frustrations and disappointments at the lack of equal access or resources and described how their interactions with mental health services had inspired them to make a change:

> Louise: I’ve launched a petition last year [2019] to basically get a specialist personality disorder service in [county], because obviously we don’t have one and we’re in the minority of the country that doesn’t have one, and basically the generic services don’t fit a lot of people with personality disorder, but anyway, in the process of doing that I now sit on a Personality Strategy, like, Working Group, with people from the Clinical [Commissioning] Group. And we’ve produced this strategy of what, what should happen to people with personality disorder traits or personality disorder diagnosis in the county and what help they can access and how it’s going to be set up, you know, there’s just this big document.

> Rosa: People with mental health problems get treated like they’re nothing but people with a personality disorder diagnosis get treated like, like they’re nothing but also like they’re super crazy so you shouldn’t listen to them…I started with all of my activism kind of stuff, basically. And not just looking at what I thought was affecting me, but also looking at making it so that other people didn’t have the same journey that I had had, in not being so lost and failed in services and that kind of thing.

Activism challenges power inequalities, protects the rights of people and promotes social justice through empowerment and participation of people that may be otherwise silenced (Newbigging and Ridley, 2018). Angela became an activist as she felt compelled to help her neighbour get care and support provision reinstated against institutional resistance and reputational self-protection.

> Angela: The correspondence I've got from them [the mental health trust], I quite literally could tell you could be written by a ten-year-old, it was pathetic, and it's all an arse covering exercise, you know if something goes wrong. This is then helped by the Coroner's Offices because the coroners just take their [the mental health trust's] word for everything that they say, and they ignore the families. I've taken up with the Coroner's Office too, and the other thing that they don't do is they don't actually specify the diagnosis of the person who has taken their own life on the death certificate. So, it doesn't necessarily go through to the Office of National Statistics.

In her quest to get support Angela contacted multiple organisations but received little help or interest.

> Angela: It didn't matter where I looked, nobody cared, so all of these organisations like Healthwatch and whoever, that you are supposed to be able to go to, and there's seventy, there are seventy NHS complaints organisations in Britain […] I just got to the stage, I was so tired, I talked to everybody I could possibly think, so I was talking to government, I was talking to people in universities who specialize in mental health services etcetera, etcetera, etcetera, Norman Lamb, everybody, the woman from Cure the NHS, Sarah Ryan whose son got killed in Oxford […] so, I was getting good feedback and good advice from them, but you go into the system and I got no help whatsoever.

In 2017-18 the Parliamentary and Health Service ombudsman highlighted five common failings by mental health trusts, failure to diagnose and/or treat the patient; inappropriate hospital discharge and aftercare plan; poor safety practices and risk assessment; not treating people with dignity and infringing on human rights and poor communication with the patient (Parliamentary and Health Service Ombudsman, 2018). The overall number of complaints indicates that people are taking an activist approach in the care and treatment received from service providers.

David had to advocate for himself to get support from mental health services after his diagnosis.

> David: It was all me, constant having to phone up, you know, what's happening with my referral? Where are we at? Have you allocated me a [support] worker yet? I thought, you know, had I been maybe lower functioning at the time, I think because I could articulate what was going on, contextualize what was going on, it was very much

> then feel like, ‘well you’ve got coping skills, so maybe we can hold you off a little bit longer’ and if you’re at the other end, you happen to be bat shit crazy, then we’ll medicate you heavily to make you compliant.

Other participants’ activism was more collective.

> Carol: I was very active again in the trade union movement. This was long after I’d come out of Broadmoor. That was how I dealt with it. By looking at it as one of many injustices perpetrated by mental health services […] But what’s so sad is that I knew other women that were going through the same system, who were as dismissed, they were dismissed with such contempt. This is just women being women, you know […] When I was more kind of active, because I was active in terms of being involved with pressure groups as well as working in the field. I was quite happy to be out and proud, you know, that was kind of how I thought about it. But now that I’m no longer involved, I don’t mention it [diagnosis]. I don’t raise it. If I see anybody it’s not an issue anymore. It’s really not.

> Rosa: I started volunteering with New Hope at St Mungo’s and doing the service user feedback and that’s about, it was them that was delivering the first KUF [Knowledge and Understanding Framework for Personality Disorders] course that I went to.

As Sarah described earlier, when she was discharged from services in [bigger City] and moved back to [smaller City] she was unable to access DBT despite the therapy taking place in [smaller City].

> Sarah: We kind of, fought a little for it, but I think it was sort of changing anyway. So, I’m not sure how much impact we had on that, but anyway I ended up being able to access DBT [dialectical behaviour therapy].

“I was with a bunch of people who understood what was going on for me and it felt really supportive” (Rosa): Peer support

Peer support is acknowledged as a formula for individuals to overcome limitations imposed by mental health labelling. The peer support movement traces its beginnings to the mental health consumer activist movement of the 1970s where individuals campaigned for human rights, mental health reform and autonomy. The growth of mental health peer support offers acceptance, friendship, build alliances and support through shared experiences (Mead, Hilton and Curtis, 2001; Solomon, 2004; Davidson et al., 2006; Tomes, 2006; Bracke, Christiaens and Verhaeghe, 2008; Nasland et al., 2014). Peer support operates outside of the confines of the psychiatric model offering a culture of ability and health rather than a culture of disability and illness, challenging the ingrained belief systems of mental ill health services. Peer support validates a person’s lived experience and helps them to regain their identity rather than being identified purely through their diagnosis (Miller and Striver, 1997; Curtis, 1999; Mead, Hilton and Curtis, 2001).

Some participants experienced peer support very positively:

> Lucy: I've got a friend that has BPD as well […] she's been quite a good help as well and she's the same age as me but she's known me since she was like 19, 20, so she's obviously had a bit more time to like, sink it in [...] she's not like a super over-sharer and I'm not really, so, it's kind of, its more just having that knowledge that there's someone there like, and I said to her a couple of times, like just random questions, like I'm, 'So what is this? Like that, what is that?', like that and she'll say, because she works in mental health as well so, she's quite supportive and if we're meant to meet up or whatever and I'm like, I'm just not having a day of it and she's like, neither am I, that's fine, let's not bother, and I'm like, yeah cool, like I don't feel like, she's one person and I actually don't mind, if I cancel on her because she'll understand.

In the interview with Rosa, she explained how peer support on one occasion provided a sense of safety and support during a trip that she found difficult.

> Rosa: There was something really triggering happening on one of those trips to the beach, but I was with a bunch of people who understood what was going on for me and it felt really supportive.

Helen discussed the underlying complexities for her of the first time she had experienced peer support within a therapeutic environment.

> Helen: I think that was probably the first time I met somebody with the diagnosis, I actually found her difficult to be around actually […] But I'm not saying that she was a bad person or anything like that, she had an awful lot going for her, she was just a bit spiky […] having peer support workers or whatever they would be called, in a team and, a team of professionals, would increase, the kind of, perception of what having that disorder is like and could kind of, infiltrate knowledge from inside to people, rather than there being that culture of, you know, BPD is manipulative and time wasting and attention seeking.

For another participant, Carol, employment to set up a 'women with a BPD diagnosis peer support group' proved a benefit and a burden.

> Carol: We were given this amount of money and it was pinpointed for this group of women […] I think there were about 15 of these women to start with, in the end 10 stuck around and we started a self-help support group. Which in some senses was a dream because we could say, what do we think our needs are? Well let's meet them, because we had the money and we had the degree of flexibility and trust within the group […] I loved them all, they were brilliant, as individuals, brave, courageous women.

The participants' experiences highlight the benefit and importance that peer support can provide. Peer roles in services can benefit the workplace and colleagues to change the negative perspectives towards the diagnosis and clients. Peer support contributes unique benefits in the acceptance, understanding and support for people who participate with services.

"It's kind of helping to reverse the stigma a bit" (Eloise): Experience- led training of professionals

The experience led movement allows for direct action to improve service provision, treatment opportunities and to challenge discrimination and stigmatisation. It provides a platform for marginalised groups to have their voices heard on issues that directly affect and concern them. The World Health Organisation promotes the inclusion of experience-led people in mental health services to ensure that services are tailored to meet the needs of people (European Commission, 2005). However, promotion of experience-led work has produced limited and variable results in participation, meaningful influence and development of services. This results in services seeking experience-led views, but relatively small numbers of experience- led people in leadership positions or co-production in service design and delivery (Perry, Barber and England, 2013). Organisations that promote experience-led inclusivity can impact the negative attitudes and practices of professionals and promote accessibility. Too often, professionals are only involved when an individual is experiencing a difficult period of mental ill health symptoms or when coping strategies are at their worst (Solomon, 2004; Postle and Beresford, 2007). Seeing a person when they are well to explain how the mental health condition affects them and what works best to avoid crisis, provides a more humanising version of the illness to professionals.

The inclusion of experience-led people within mental health services can and does improve the effectiveness of mental health delivery and enhance the ability of that service to meet the needs of those who participate with that service (Royal College of Psychiatrists, 2009). However, services that provide employment positions for experience-led inclusion have been criticised for diverting attention away from the structure of power, gender inequality in diagnosis and the need for organisational change (Barnes, 2002; Lewis, 2014). Connor and Wilson (2006) found that individuals interacting with mental health services as experience-led contributors felt professionals occasionally saw them as threatening the power dynamics of status and role within health care services and as agitators. Hannigan and Cutliffe (2002) argue that regardless of the growing trend of experience-led inclusion in mental health organisations, it remains tokenistic and has limited impact on policy and practice guidelines whilst being portrayed as inclusivity.

Some participants had used their experiences to become experience-led contributors in services.

> Eloise: Now I'm working and people are like, 'you're giving really useful input into the service, you're this that and the other', that's what I start to believe about myself…I think, one of the things that I do, do now is training for staff such as police and A&E staff and general medical staff. And I do that, we sort of talk about like, personality disorders, we talk about managing suicidality and self-harm and stuff like that […] I've found it really like, that it's kind of helping to reverse the stigma a bit, because in my job I'm seeing Eloise, sparkly hair, like that's who I am, whereas like I spent a lot of my life being Eloise with BPD, that was like people to tend to find out I've got mental health problems because they know my role is lived experience, but not necessarily straight away that I've got a personality disorder, and even then people, when they see me in this capacity and see me functioning they're like, 'actually, maybe it's not all as bad as its made out to be'.

> Rosa: So, I trained in delivering the personality disorder awareness [KUF] really quite soon after starting all of that stuff [activism]. So, that means I've now been delivering it, forever, so 2012 this must have been, so like, 8 years, so it's like been around for the whole, it's been really, really, consistent. Which is weird because not much stuff has been consistent in that time, like, not many people have been consistent or anything like that so, every time I come back to delivering that course it's like, it's like an old friend's course material now.

Challenging professional's perceptions through the delivery of training de-mystifies the negative beliefs surrounding the diagnosis and enables professionals to increase their understanding and knowledge (Cleary, Siegfriend and Walter, 2002; Markham and Trower, 2003; Servais and Saunders, 2007; Wright, Haigh and McKeown, 2007; Millar, Gillanders and Saleem, 2012).

In Rosa's experience of delivering the KUF training to frontline health professionals and now in the criminal justice sector she spoke of the ways in which she challenges the perceptions that are held about people with a personality disorder diagnosis and the reactions to her once she shares her diagnosis with the trainees.

> Rosa: So, now I'm doing the criminal justice sector so, you sort of, the way that I do it, is I sort of come out as a person with a personality disorder on like, day two of delivering it. Because if you do it too early on it has a different effect then if you do it later, and so I've had some people from the criminal justice course say like, oh but you're not like the other people with like, personality disorder that I know because they've all got criminal records and they're all dangerous criminals and you're not one of those. Just because my illness hasn't manifested in ways that has offending behaviour, doesn't mean I'm any different, I'm just not, in their realm of work, particularly […] I normally get warmness toward me, but there's a bit of, a bit like, babying that comes across, like, 'oh bless you for telling us that', and like, wanting to look after me more, wanting to make sure I'm like, okay and you know, 'that bit you just delivered was really emotional, are you going to be alright now?' and that kind of stuff. There's a bit of like, infantilizing about it.

In Sarah's interview I asked her whether as a person with the diagnosis, she had experienced any negativity when delivering her training to professionals.

> Sarah: We've had negative attitudes to start with. We've had people kind of like, almost like, with a kind of 'what have you to teach us?' kind of thing, 'we're the professionals'. But never had negative feedback at the end, it's always the attitudes have always improved […] I think for them to see us when we're not severely unwell as well, because they see people in acute psych wards who are at their worst. You're not seeing somebody at their best are you, when you're in that situation. Some of the staff are people that were staff when we've been in there, so I think for them then to see me in the situation where I'm standing at the front, I'm presenting, I'm doing this workshop, and they're like, 'oh'. Like they see the person, rather than just seeing the illness.

Eloise highlighted the implications of professionals' attitudes towards the diagnosis in relation to negative beliefs when seeking support and impact on self-worth. She described how she addresses this in the training she delivers by sharing her experiences.

> Eloise: One of the things I feel a lot, and I know a lot of other people do is guilt, like I feel a huge sense of guilt of being a burden, and not good enough sort of thing and it just, it just like, those kind of core beliefs that a lot of people have, like, reinforces them. And I think one of the things with personality disorder is people do have such an unstable sense of who they are that they take their cues from the environment a lot, so if they're constantly being told, 'you're worthless, you're not doing good enough, you're not trying hard enough', then that is what they feel […] I've found that a lot of people come into that training being like, you know, we're going to be talking about the revolving door cases like it's just really frustrating, we don't have time for them, like actually when they sit down and they have a day when they're learning about it, they're looking at cases, realizing what's happened in the past, they're

> listening to my experiences, and sometimes having known me as well when I was in that situation where I was that person coming round, and then seeing me now, it really, really changes people's ideas. So, I think like, that bit of extra knowledge can really help.

David recalled a conversation he facilitated in a group he runs around suicide and suicide ideation, showing that the extra knowledge gained by professionals can influence understanding and beliefs.

> David: You don't necessarily have to understand why someone is doing the behaviour, just that it comes from somewhere. Why would someone choose to do something so awful? You know, what is life like, that they would sooner engage in something like that. It was a topical conversation in a group that I facilitate in, that was suicide and suicidal ideation and again, the misunderstanding around it, a lot of people in the group had never experienced it saying you know, 'when people choose to want to end their lives like that', its actually, not all self-harming behaviour is with the intention of ending life. For me it was the only thing that made me feel alive, where everything else had felt so dead, it almost was actually like a reset and it scared the absolute living daylights, coming that close, coming right up to the point of, I'm not going to be able to come back from this.

Experience-led people educating professionals on personality disorders is important for those working in services and those accessing them. Helen believes more training should be BPD focused to challenge beliefs held about the BPD diagnosis.

> Helen: I think a lot of re-education needs to happen, I think there's been so much stigma and it's in so many textbooks and gone on for so long, seeing people with this diagnosis through that lens and therefore interpreting every action, every word in certain ways so, so badly. I think they need to start again and be taught from scratch and trauma informed and informed that people aren't out to manipulate you or make your job hard or be troublemakers or attention seeking or all these negative connotations. That actually, people, it's just another mental illness, it's not something people choose, it's the last thing people would choose because it can be highly, highly distressing. So, people just need to be a bit kinder and a bit more open minded and maybe realise that actually, all these past research papers and all these things that have said this person will be manipulative or this person will do that, actually, it could be wrong and that it is just somebody's interpretation. It could be right sometimes, but it might not be right all the time, you see what I mean? I just think it's really sad.

Previous research has indicated that professionals who regularly encounter a personality disorder diagnosis have limited or no specific training. For example, James and Cowman (2007) found only 3% of psychiatric nurses had been given any specific training on BPD outside of their undergraduate training. This was reflected in the negative treatment, attitudes, and stigmatisation that people experienced. Happell et al. (2014) proposed that people with mental health diagnoses sharing their experience should be part of the education of future health professionals and that experience-led academic positions can offer the most substantial collaboration in the education of professionals.

However, David believed that professionals' lack of education wasn't the reason that suitable resources were withheld from people in need of support. Instead, lack of education was an excuse, in the light of available resources:

> David: It's just humanity. I could never, you know, the thought of actually like, causing somebody emotional distress, compounding somebody else's emotional distress, that would absolutely tear me up, to think that I may have impacted somebody in a negative way like that. I think it's probably one of the gifts that does come through having the disorder is the somatic empathy, because we feel that pain in other people and we respond really well to that, that kind of trauma and pain. But you'd always think if that was the kind of profession that you were going into, those, when you're going to be coming into contact with people, you know that there's going to be the eventuality, meeting people that are really, really distressed and they do things that may seem completely irrational, completely alien to you but it happens and think this is the environment you've chosen to come and work in because surely you have, you know you wanted to come to help people, not to say some people are more deserving of help than others are, you know, there's a sliding scale for you, you know, they should just get a grip and just be normal you know.

Eloise described the importance of professionals educating themselves:

> Eloise: I find that when you go more towards like, psychology staff, people like that who've looked even further, learned further about what happens deeper and like the impacts of trauma and things like that, they tend to have come back round into having a positive and more compassionate view of people with personality disorders and actually what they are trying to face. I kind of felt that sometimes like, you haven't necessarily been equipped with enough knowledge to see the whole picture, so people are only seeing part of the picture, they are seeing people you know, playing out quite big, they are seeing people reacting to circumstances that you know, isn't in proportion with what's happening, but then not seeing the further on picture of what's happened to this person in the past that's making them be like this. I think that it is kind of like the lack of education, that just having a little bit of education is kind of dangerous […] I say this to people when they're getting frustrated treating people with BPD, when they feel like there is nothing they can do, and I always say that you can't, you can't make someone change, they have to be ready to change, and sometimes it's just about like, you know, walking beside them, giving them a little nudge until they can do that themselves. And that, I think it's exactly the same with staff not wanting to know as well. You can't make them be compassionate, you can't make them want to know, but something might happen someday that changes that in them.

The inclusion of people with lived experience in frontline services and educational training provides a unique and relevant opportunity to improve professionals' knowledge and understanding of the BPD diagnosis. It can challenge and alter the negative beliefs, attitudes and stigmatisation of mental health and influence professional practice and experience for others who participate with services.

Advice for professionals

Participants were asked what advice they would like to impart to professionals based on the experiences they have had throughout their lives including with frontline services and professionals. The responses were varied:

Don't assume everyone with the diagnosis is the same

> Eloise: It's very hard to give advice because some people, even with the same diagnosis as borderline, respond to different things.
>
> Rosa: Understand that everybody is an individual and even though they've got this diagnosis […] but everybody is an individual and everybody needs that individualistic care. In the same sense that a physical problem needs an individualistic care plan, you know people presenting with BPD need that just as much as the people presenting with anything do. And, I guess I would urge them not to be looking for examples of people being manipulative or being attention seeking or being any of those kind prejudiced sort of stereotypes that's going on, because if you start looking for people being attention seeking, you are going to find it, and if you start looking for people being manipulative, you are going to find it […] So, I think basically my advice would be treat the person as a blank slate and don't put, don't put predetermined ideas about what BPD is in front of this person, just treat them as a person like you would any other patient. I think that would be my overriding advice to them.
>
> Sarah: Just get to know the person. Find out what's going on and if you've got somebody who is quieter or smilier, don't assume that they're fine and ask how people are rather than ignoring it because they're smiling, I suppose. I think it's just not assuming that everyone is the same.
>
> Corrine: I think the professionals need to understand that even though someone is diagnosed with BPD we are different from each other and have differing behaviours, thoughts and emotions. They need to look at us as individual and not just a generic BPD sufferer. The main thing for me is making them understand that often we don't always know the reason why we are having a bad time nor the emotions at that point in time.

Being mindful of language used towards a person with a BPD diagnosis

> Carol: Having some kind of mental illness doesn't mean we're losers or failures and that's inherent in the language 'Oh you're a bi-polar', no I'm not. 'You're a BPD', no don't define us with those words […] I don't go a bundle on diagnosis anyway because I don't find they help. It's a tool in mental health, in the field of mental health and mental illness, none of it makes sense and all of them when you look at them, it doesn't matter whether its bi-polar disorder, or BPD or schizophrenia. They don't make sense and they don't answer people's fears and anxieties about themselves.

> Corrine: First and foremost, not to say stupid things. For example, I rang the crisis team one evening after cutting myself. The response I got was why don't you get a takeaway as that will make you feel better. We don't need pathetic comments like that.

See the person first and do not make assumptions based on diagnosis

> David: See me, first and foremost, as Dave, as myself, David and not a personality disorder an individual. And I think, someone just asking me, you know, what do you want right now? What would you like to happen? Not doing things to me, let's have some dialogue, some back and forth, work collaboratively, allow me to be involved in making decisions about what I want to happen. That's very much I think, you are, you're waiting for people to do things to you all the time…

> Helen: Person front and foremost, that goes for all things doesn't it and we're all different, and like I said even people with the same diagnosis can manifest very, very differently. So, I think people need to be far more careful about their prejudice and preconceptions and just meet the person where they are, just, you know, perhaps don't rely so much on past notes, because again, if people can just dish out a diagnosis without the person even being there or aware of it, I wouldn't say that's very valid.

Listen and try to understand

> Eloise: They just need to be aware that the person, if they are calling A&E, or calling emergency services, they are at their last, they are at their last wits, you know, and I, the glib attitude of, 'oh we're just popping into A&E' and I know that hospitals have their regulars and things like that who, and there are people that do abuse services etcetera, etcetera, etcetera, but I think that's so much rarer than its made out. I just think they really, maybe being in the job you get desensitized to things.

> Rosa: Hear what's happening, hear what's coming out of that person, instead of that response that comes from statutory services and A&E and stuff like that.

Understand the association with and effects of trauma

> Eloise: I try and encourage people to, instead of asking the question, you know, what have you done, ask what's happened to you instead, because there's usually, even if

> it’s not actually trauma, there’s something in peoples background that’s, that they deal with the problems the way they do.
>
> Louise: The people with BPD are often some of the most traumatized people that are ever going to be in the mental health system, and need the, kind, tailored care to stop that trauma being reignited constantly, and yet, we’re not given it.

Do not be fearful of asking people questions about their lives or feelings

> Rosa: My St Mungo’s boss who, I don’t know, he was there a long time with me starting to work in mental health and eventually a paid role in mental health, would always say to me like, what’s going on for them? The way he lived his life was like, what’s going on for them? Whereas a lot of me at the time was like, threatened by men that had sent me an email shouting at me and he was sort of, more on the, ‘why are they shouting at you’, ‘what’s going on?’, that kind of thing. Which is a curious stance, and it’s like, I don’t know, I feel like, especially in Britain we’re more likely to shut someone down if they are shouting at us, rather than being like, you’re clearly trying to tell me something and I need to listen to that. That’s what I would, that’s what I want services to do and that’s what KUF is trying to do in a longer way, is these are a person’s past experiences, this is what’s happened right now, this is why they are shouting in your face. It doesn’t mean that you should never talk to them again, it means that you need to, maybe, try and help the situation calm down a bit, maybe do some containment, that kind of thing.
>
> Carol: Start talking to people about the lives they’ve had, what their feelings are, honestly and how they feel about themselves. Everything other than trying to work towards the BPD.

The advice that the participants shared is for professionals to validate people with a/the BPD diagnosis, recognise their personal experiences and struggles and place value on their humanity, rather than focusing on their diagnosis.

Validation by professionals

Validation should be a central tenet of actions by professionals’ who encounter people with mental health diagnoses. Lack of validation can result in periods of distress which have a severe impact that puts people at risk of harm; being validated at times of severe crisis can reduce the risk of self-harm (Bateman and Krawitz, 2013). The participants discussed the effects of professionals validating or invalidating their concerns or life experiences. David described the impact of not having his feelings validated:

> David: I didn’t understand my emotions, they’d always been invalidated so I thought they were always inherently shameful to have. So, you hide them and then they

> manifest to a point you can't keep them down anymore, so you have massive outward projections, or you go into other coping mechanisms which are scary and dangerous.
>
> Sarah: Validate, validate, validate, validate, validate, validate, validate…and validate. Yes. Listen to the person and even if you do not think that what they are saying is rational, try and understand where they are coming from, and validate the feelings even if the logic isn't spot on […] Do you want to talk about it, yeah, and kind of getting through that validating the feelings. And then maybe saying, "Ok right, so I know it's really, really scary for you and I acknowledge that, blah, blah blah, but let's look at it as it is" […] Or like if somebody is absolutely convinced that they are a terrible person and they need to punish themselves, again validate that they are feeling that way, don't just be like, 'well you're not so stop it'. You know, validate the feeling but don't obviously validate the fact that they are a terrible person. So, I think for me that is a huge thing and like not saying, 'oh well everybody feels like that […] So, I think validation is massive. And validating that you have done the right thing by talking as well.
>
> Angela: [My neighbour] would come home upset and she'd be cross because somebody had said something, I'd just say to her, really nice to see you cross.' She said, 'what do you mean?' I said, well don't assume this is your illness, this is you as a human being responding in a human way, and actually what you just told me would really piss me off too. It's just helping her to actually recognise that her behaviour is normal in those circumstances […] So, if you look at person centred care and you really listen to what the person needs and wants, which you do all the time with people generally, I don't hear what they say to me, I read between the lines and approach them accordingly, I could tell you a million percent all this girl needed was the respite reinstated as a safety net. And it's also a way of, people with that kind of diagnosis knowing that they are being listened to and therefore they are cared about. So, that's the real simplistic thing except for the fact that, that is perhaps more often than not all they need.

Validation is a powerful concept in accepting and recognising of a person's internal experience. It communicates acceptance, helps to regulate emotion, builds identity and relationships and shows that a person's feelings are important (Greenberg, 2014).

To conclude, the inclusion of peer support and experience-led people in services aids the effectiveness of services to meet the needs of those that require support. Inclusion challenges service cultures that hold negative attitudes or perceptions of the BPD diagnosis by promoting knowledge and understanding. People regain their identity instead of being seen as their diagnosis. It can provide a supportive network that offers a culture of ability rather than disability and connection with others to validate and share experiences and concerns with those who can understand the complexities of life. As a result, people become empowered to take control of their lives and contribute their knowledge to educate professionals and help others. Professionals have a unique opportunity to improve person centred care practice from the advice that participants shared.

Discussion

The main findings of this study present empirical data of the experiences of people with a BPD diagnosis and their interactions with frontline professionals in physical, mental health and public protection services. Placing the voices of those with a BPD diagnosis at the forefront, this research directly addresses the research question of stigmatisation, prejudice and inclusivity. The data demonstrates consistency with the literature reviewed in Chapter Two, supporting the findings of previous research highlighting the negative attitudes of and stigmatisation by professionals towards the diagnosis of BPD (Markham, 2003; Kealy and Ogrodniczuk, 2010; Sansone and Sansone, 2013). The main themes will be discussed in sequence beginning with stigmatisation.

Stigmatisation

This research demonstrates that people with a diagnosis of BPD can experience stigmatisation, negative attitudes, unequal treatment and lack of support. The diagnosis of BPD underpins recurrent stigmatisation and primes people to anticipate unfair and unjust treatment from professionals and services (Fallon, 2003). In similarity with Horn, Johnstone and Brooke's (2007) research of lived experience perspectives, the participants described how professional's stigmatisation left them feeling stereotyped, blamed for the way they were treated, and dehumanised. The participants' experiences demonstrated Mannarini and Rossi's (2019) finding that people withhold their diagnosis due to being fearful of discriminatory beliefs and attitudes when seeking treatment for physical issues or support at times of mental health crisis. Negative attitudes from professionals were not only directed at the person with the diagnosis but also their support networks in 'stigma by association'.

Professionals' in physical and mental healthcare services show high levels of stigma towards the BPD diagnosis. Physical health professionals receive no specific training on mental health or personality disorder diagnoses resulting in limited knowledge and understanding of this diagnostic group. However, this does not excuse healthcare service attitudes towards people with a BPD diagnosis who access services due to physical illness or at times of severe emotional distress. Negative views of BPD are reflected in the discriminatory practices of refusing or limiting the care and treatment of individuals, particularly if co-morbid conditions of addiction or self-harming behaviours were present. For example, despite national policy guidance on the management of self-harm (NICE, 2004), individuals experienced painful wound closures due to a lack of analgesia or were left with open wounds.

Diagnostic overshadowing of physical conditions by consultants and nurses often occurred when people presented with illness or injury in A&E or their general practitioners'. Conditions or non-self-harm injuries requiring investigation or treatment from professionals were questioned as to their authenticity, ignored and considered a 'symptom' of their mental health condition. People's experiences of stigmatisation by healthcare services compounded individual's negative internal feelings and thoughts and triggered crisis and self-harm. Stigmatisation amplifies the negative narratives used to describe individuals with the BPD diagnosis resulting in individuals withdrawing and self-excluding (Levitas et al., 2007). This places individuals at an increased risk of emotional distress, physical and chronic illness or risk to life.

Professionals working in mental health, despite expectations that they would have better knowledge and understanding of personality disorder diagnoses, are not exempt from discriminatory practice towards individuals as described by participants. There is a perception that mental health professionals are the 'experts', equipped to make the best decisions and should expect a level of cooperation from individuals, indeed some people who access mental health services also believe this. However, the findings here suggest that mental health professionals also have a lack of knowledge and understanding of the diagnosis. For those who question care, treatment and medication decisions can be seen as a challenge leading to the withdrawal of services. Psychiatrists and psychiatric nurses were shown to limit their interactions with individuals and showed less empathy and understanding towards them. Previous research (Chartonas et al.,2017; James and Cowman, 2008) suggest that mental health professionals appear to be more vocally discriminatory, limit interactions and display their dislike of the people with a BPD diagnosis in their care. For individuals who experience stigmatisation and negative attitudes from mental health services, this can be an emotional blow and be very damaging primarily during periods of crisis. This was particularly evident among participant's involved with Crisis Resolutions Teams where a lack of person-centred care and informed crisis intervention practice only added to distress.

Failure by mental health services to attend individuals in crisis means that police officers become the first responders to people in mental health crisis. However, police officers are not equipped to deal with a person in crisis (Mclean and Marshall, 2010) resulting in increased use of section 135/136 to detain people in custody due to a lack of other alternatives (Corrigan, 2014; Durcan, 2014). Baker and Pillinger's (2020) study identified that, police officers' limited knowledge of mental health conditions can mistakenly lead to an individual's presenting behaviour being understood as posing a threat to their own safety and others. For some individuals in crisis, this has resulted in the use of force such as physical restraint by police to control the situation, which can be humiliating, terrifying and cause trauma.

Participants' experiences identified that stigmatisation of the BPD diagnosis is present in all frontline services and highlighted the need to make specific mental health training compulsory to change the perceptions and attitudes towards and narratives used to describe people with a personality disorder diagnosis.

The power of language

Marginalising and discriminatory mental health narratives are influential in the interactions between professionals and people with a BPD diagnosis, identifiable by words like 'dangerous' and 'challenging' to describe the BPD diagnosis. Language is a very powerful tool both for those that use it and those it is directed towards. Mental health narratives are used as a way of maintaining hierarchical positions between the professional and the 'disordered' person to make known the authority and superiority they have over them. The participants' experiences of professionals and frontline services identified that the language used towards them reaffirmed their lower status and powerlessness (Benbow, 2009). Despite the RCPs' (2017) report addressing the use of derogatory narratives in mental health, which promoted the use of person-first language, participants described how they are identified as 'service users' rather than as an individual.

There were mixed opinions from participants about the 'service user' label; for some the label held strong connotations with drug addiction, as indicated by Rosa's view that it had association with heroin use or was seen as implying taking what you can get, feeding into discriminatory narratives used to describe people with the diagnosis as 'manipulative'. For others, the service user label provided membership to a community of people they could identify with. However, the label also implies a level of choice in the services people receive but participants' experiences identified this as misleading with limited or no choice possible.

Alternatives to 'service user' which was seen as creating a more equitable relationship with service providers, was the use of 'client' and/or 'patient'. 'Client' for some participants, still implied a certain 'user' element and choice within treatment provision and service accessibility. 'Patient' is associated with the medical model and can be viewed as maintaining professional dominance but was favoured by several of the participants as it implies a temporary status of being unwell and does not differentiate between a mental or physical illness and removes the focus on the diagnosis. The narratives used by physical and mental healthcare reflect how mental ill health and distress is conceptualised and influence how people with the BPD diagnosis are identified and treated which perpetuates the continued stigmatisation of the diagnosis.

Service provision

Mental health services are the gatekeepers to access resources and treatment but stigmatisation and negative belief systems towards the BPD diagnosis results in exclusionary criteria. Developments in policy and practice guidelines to improve service provision for borderline personality disorder, most recently NICE (2009b), have not increased accessibility to the therapeutic treatments identified as by Huxley and Thornicroft (2003) and Pilgrim and Rogers (2003). NIMH (2003a) *Personality Disorder: No longer a diagnosis of exclusion,* drew attention to services' exclusionary practices towards people with personality disorder diagnoses and identified the failure of healthcare trusts to provide a dedicated personality disorder service. Their findings identified that accessing relevant services was a 'postcode lottery' with most of the participants not being offered or being excluded from mental health support or treatment since they had received the diagnosis including at times of crisis. Several participants here also had comorbid diagnoses but found access to specialist treatment for these conditions also limited or not available because of their BPD diagnosis. The RCP (2020) statement highlighting that service provision was difficult to access for people with co-morbid diagnoses, highlighted that there are increasing exclusion criteria, which was also identified by several of the participants here. Exclusionary criteria for people with a BPD diagnosis or BPD traits were particularly noted for eating disorder services. Services claim that people with co-morbid BPD diagnosis have needs that are too complex or too serious to manage, and/or staff lack the necessary skills and knowledge. Often services refer them to another service who are also not able to meet the specific needs and that second service will refer back to the specialist services causing a cycle of rejection. People with comorbid diagnoses that have a personality disorder diagnosis are left with no option but to rely on mainstream services to get what treatment and support they can. This indicates that the gap between knowledge and practice in specialist and mainstream practice is growing.

Psychotherapeutic and trauma-informed therapies are the most suitable form of treatment but there are long waiting lists to get an initial assessment, one participant stated she had been waiting over a year and was still waiting for an initial assessment. For some, the only way to get therapeutic support is to pay privately which can cause a financial strain however delays in access to therapy or engagement by services amplifies distress and maladaptive coping methods such as self-harming or overdosing. Crisis support by mental health services was discussed by participants as poor and as disregarding the Mental Health Crisis care Concordant (2014) designed to support people before and during a period of crisis. Lack of access to timely and appropriate engagement by mental health services can mean people have no option but to seek help and support from other services such as A&E, sometimes by exaggerating their current situation in the hope of accessing the mental health team, but this further impacts an already strained service who are limited in their knowledge and understanding of BPD. Often the mental health team does not attend or will make appointments with no follow up if appointments are missed. When mental health crisis teams do attend, they were experienced as unsympathetic or unable to provide access to suitable support. Exclusion criteria or lengthy waits to access appropriate services results in suicidality and increased distress of people with a personality disorder diagnosis. Those who have sadly died by suicide were not receiving the support or treatment as recommended by the NICE guidelines.

The research has shown that people with a BPD diagnosis are experiencing enormous challenges in accessing appropriate support and treatment from a mental health system that is failing to meet the needs of people or provide a clear pathway to treatment. Services lack the knowledge, understanding or skills to support this diagnostic group and there is failure to provide crisis support or timely interventions, with long waiting lists for assessments and treatment with other support in the interim, which impacts distress and can result in people turning to maladaptive coping methods to manage. Lack of specialist personality disorder services in areas of England means that people are reliant on general mental health services who are unable to effectively work with and support people.

Professional power

Power is defined by Dahl (1957) as the intentional use of control and dominance to maintain a level of hierarchy over vulnerable and marginalised groups. The amount of power wielded varied between service professionals, with those in mental health services exercising an element of coercive control and manipulation to assert their authority. Authority was asserted through the use of language, restricting access to crisis support, suitable treatment, influence over others and compliancy. Authority was not just directed towards people in their care but also towards other colleagues and people's support networks to limit any challenge to the established framework of practice. Hierarchical service structures constrain those who work within them by removing their ability to challenge unhealthy practices which allows negative beliefs and stigmatising attitudes towards those with mental health diagnoses to remain.

Mental health professionals were primarily identified using their status as 'experts' to maintain power and authority over people in their care. Several of the participants' experienced an abuse of power from mental health professionals, particularly coercive and bullying tactics to remove individual care plans and support or to accept what was offered, even if it was unsuitable. One participant described the impact of a person's removal of support despite valid arguments about the risk of repeated crises and escalation of self-harming behaviour which was ignored and seen to challenge professional's expertise and authority. Awareness of the power dynamics between professionals and individuals with mental health diagnoses removes individual's autonomy to be involved in care decisions or express their needs for fear of losing support altogether (Connor and Wilson, 2006).

A number of 'cultures' were found to exist in the mental health sector including;

- Protecting professional reputations in the event of a person's fatality where errors of judgement or safeguarding have been made.
- Shifting blame over failures to meet the care and needs of vulnerable people, as evidenced by one participant's experiences of a professional attempting to manipulate vulnerability for financial gain and then attempting to divert blame onto their diagnosis.
- Diagnostic discrimination that perpetuates the continued stigmatisation of the BPD diagnosis in organisational and institutional practices.
- Manipulation of new colleagues to uphold the negative beliefs, attitudes and working practices that exist towards individuals with the BPD diagnosis.

The research has identified that practices and beliefs of professionals continue to add to the discrimination and stigmatisation of this diagnostic group. Mental health services appeared to be more concerned as Angela experienced, with 'arse covering if something goes wrong' in the care and support of people with a BPD diagnosis. Power and dominance of professionals in mental health services is authoritarianism and controlling, failing vulnerable members of society.

Reclaiming power and identity

Marginalised and vulnerable groups with mental health diagnoses have been challenging social injustice and discriminatory care systems for several years. Mental health activists have fought for their human rights, individual autonomy and inclusion in their own and others' care and support. Activism also extends to developing tailored care and treatment services to meet the needs of people. This study identified mental health services as not fit for purpose in the support and care of people with a personality disorder diagnosis.

Challenging services about their inadequacies in relation to the inclusion of people with lived experience, addresses power inequalities and empowers those who are often silenced by negative attitudes and stigmatising practices. Inclusion in mental and physical health organisations can sometimes be tokenistic and organisations can limit contributions to changes in policy and practice. Professionals can interpret inclusion as a challenge to the power of their status and role. Experience-led inclusion in frontline services has been proven to promote inclusivity and positively impact attitudes and practices of professionals as identified by participants here as it changes what professionals believe those with a BPD diagnosis are like and shows them that people are not their diagnosis but individuals with many attributes and skills and entitled to equal access to resources.

Inclusion of people with lived experience not only benefits services and professionals but also those accessing services by offering a shared understanding of mental health difficulties and experiences, acceptance and friendship (Nasland et al., 2014). Peer support is a valuable opportunity for the empowerment of people and the validation of their experiences. Peer support enables a shared understanding of distress which can make a difference in how that and what the person needs during that period is presented to professionals. It can change the culture of the mental health system from one of focusing on disability by actively encouraging focus on a person’s abilities and promotes a model of wellness emphasising strengths, recovery and a person’s ability to effectively function.

Changing the narratives about and perceptions of the BPD diagnosis was shown to be achieved in the re-education of professionals (Happell et al., 2014). The delivery of specific personality disorder training by lived experience trainers was found to dismantle preconceived judgements and expectations of someone with the diagnosis. For the participants who are in this role in physical and mental health services, it provided them with a sense of purpose, validation, recognition, empowerment and the ability to make a real change in how people with the diagnosis are treated and perceived. Although there may be initial resistance by professionals, lived experience trainers can address negative and stigmatising attitudes head on and expand professionals’ knowledge and understanding of the diagnosis and individuals’ behavioural representations of distress. People’s experiences and knowledge of their mental health can impart valuable opportunities for development of knowledge and understanding of professionals but also for the development of policy and practices to provide humanistic, person-centred care. The next chapter presents the new theoretical framework, the Dominant Identity Status (DISC).

Chapter 7. Theoretical Chapter

Dominant Identity Status Cycle (DISC)

This chapter introduces a new theoretical framework, the Dominant Identity Status Cycle (DISC) that emerged from the participants experiences of stigmatisation, discrimination and exclusion from frontline services. During the data analysis phase, it became apparent that there was a sequence of similar markers that occurred in the participants' experiences: diagnosis of the personality disorder; labelling effects; awareness of the negative attitudes towards the BPD label; withholding diagnosis from family, friends and professionals; loss of social status; being excluded from society and service provision because of the diagnosis and being stigmatised and discriminated against by professionals. Most of the research participants had been involved with frontline services thus giving a wide range of experiences pre and post diagnosis.

Participants' experiences showed no significant stigmatising or negative attitudes by professionals until the professionals became aware that they had received a formal BPD diagnosis or were assessed for BPD. Despite each participants' post-diagnosis experience being unique, the majority of them expressed noticing changes in professional's responses and gave detailed accounts of discriminatory treatment and lack of care from professionals as well as reduced access or exclusion from provision post-diagnosis. The development of DISC as a theoretical framework (figure 1) aims to present the interplay and integration of several theories once a diagnosis has been given. DISC places them into one coherent approach to aid explanation of why those with the diagnosis of BPD experience stigmatisation within health and social care settings and frontline services.

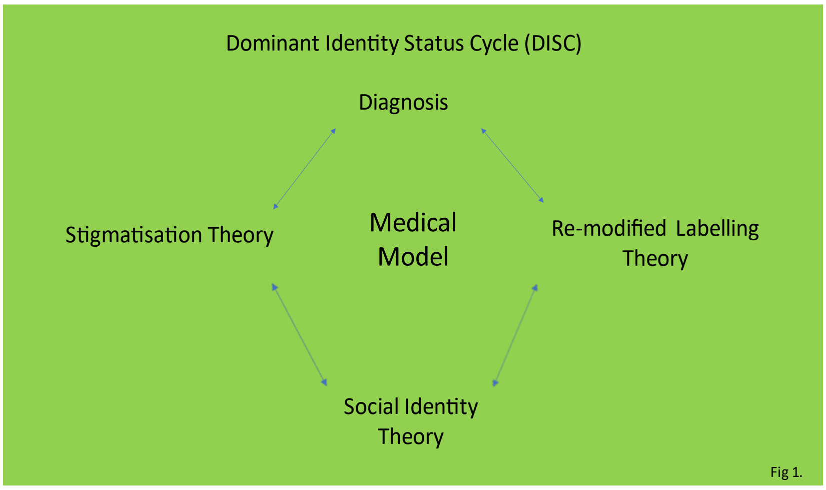


Figure 1: Dominant Identity Status Cycle

The theories proposed for integration are Link et al.'s (1989) Modified Labelling Theory, Social Identity Theory (Tajifel, 1970) and Goffman's (1963) concept of stigma to develop a theory of Stigmatisation. It presents a new way of thinking about Modified Labelling Theory which reflects how labelling influences the behaviour, thoughts, and beliefs of others in relation to a mental health diagnosis and this impacts the person as a result, rather than how a label influences the labelled person. It also proposes an addition to Social Identity Theory to consider the role that society can have in the devaluation and discrimination of those with a mental health condition, and the negative effects on the person.

The relevance of the integration of theories is that no single theoretical explanation, for example, Stigmatisation Theory, explains the phenomenon of why people with a diagnosis of BPD experience stigma, social exclusion, and discrimination. Each of the theories presented in the cycle co-exist and interplays with others in a loop from diagnosis. At the core of DISC is the medical model of mental health, which is the foundation upon which the other theories build. The medicalisation of mental health pathologizes natural human responses to difficult, abusive, or abnormal situations as 'disordered'. This pathologization results in a medicalised diagnosis (label) being assigned which sets DISC in motion. Each point and theory in the cycle has its own specific markers identified from participants' experiences and through the literature on BPD. Figure 2 presents each stage of the cycle and the anomalies that exist. Each section in the cycle will be discussed in more depth throughout the chapter.

Medical Model of Mental health	BPD Diagnosis	Re-modified Labelling Theory	Social Identity Theory	Stigmatisation Theory
Power entitlement	Dustbin diagnosis	Branded	Devalued as a useful member of society	Influences attitudes and behaviour
Control	Avoided	Perceived expectations on behaviour	Lost or fewer opportunities	Discrimination
Hierarchical system	Life experiences measured by tick box	Influences professional beliefs	Lower status in society	Social exclusion
Professional dominance	Trauma and distress pathologized	Influences professional attitudes	Media portrayal creates unfair representation	Secondary label stigma
Stigmatising culture	Life is measured by behaviour	Influences professionals treatment	Perceived as dangerous and deviant	Self-exclusion
Coercive treatment	Diagnosis dependant on another's opinion	Creates negative reactions	Judged	Low self- esteem
Professional v service user mentality	Become a statistic	Causes stigmatisation	Branded	Low self- worth
Authority over	Lose identity	Not 'normal' anymore	Social exclusion	Withhold diagnosis due to expected stigma
Coercion to conform	Put into a box	Prioritises MH over physical health concerns	Social injustice	Impacts on treatment seeking
Key holders to treatment and resources	Become invisible	Discriminatory attitudes	Inequality	Can increase distress
Loss of autonomy and choice	Diagnostic 'overshadowing'	Negative stereotype	Victimisation	Impacts on coping strategies

Figure 3 Dominant Identity Status Cycle Theoretical Framework

BPD Diagnosis

Psychiatry has firmly placed itself within diagnostic measures of mental health and is more concerned with cures and influencing pockets of society to believe that there is something wrong with them that requires fixing and that can be fixed (Conrad and Bergey, 2014; Ekman, 2016). People are pigeonholed into boxes through reliance on diagnostic categories that explain their ‘peculiarities’ to them and the rest of society. The diagnostic categories in the DSM and ICD manuals have become an essential tool in maintaining the medical model’s dominance over mental health (Smith, 2011). Individuals are negatively affected by the medicalisation of their natural and normal responses to their experiences based largely on social norms formalised in the DSM (British Psychological Society, 2011). The medical model framework of mental illness diagnosis deals with symptoms, not difficulties, and is based on the judgement of a person’s behaviour or communication (The British Psychological Society, 2011). Mental and emotional distress have always existed in human history however distress today, if prolonged or leading to maladaptive ways of coping which are deemed as ‘not normal’, is pathologized and labelled a severe mental disorder. The diagnostic system legitimises psychiatry’s claims of treating real diseases, which they define purely by symptomology without any regard to cause. This symptom-based tick box approach has allowed psychiatry to develop a visible and measurable framework that allows for the measure of mental illness and ways to silence scientific critics. Clinicians of all theoretical persuasion use this tick box approach to diagnose individuals, whilst also meeting the need of pharmaceutical corporations in having specific diseases listed and defined for their products to treat, providing enormous incentives to create new diagnoses and drugs (Grob, 1991; Mayes and Horwitz, 2005).

Blackburn (2006) has criticised the DSMs diagnosis of personality disorder for making people isolated and ignored with both Francis (2014), chair of the DSM-IV committee, and Hyman (2013), the former director of the National Institute of Mental Health, claiming that the new DSM-5 would recklessly and radically expand the boundaries of psychiatry with little basis in science. The recognition of the personality disorder diagnosis in the 1980 DSM was based on the clinical knowledge and aetiology at the time, to avoid the personality disorder diagnosis being absorbed by other diagnoses like depression which were believed to be short term conditions. The creation of the Axis 11 category as pervasive, enduring and psychiatrically untreatable in the DSM-IV-TR (1994) maintained the perception of personality disorder not as mental illness but as something inherently wrong with the internal construct of a person resulting in people being less deserving of support (Paris, 2003). This sets the basis for high rates of stigma from professionals and some of the poorest outcomes for treatment and health outcomes (Sheehan, Nieweglowski and Corrigan, 2016).

Personality disorder diagnoses generally, and BPD particularly, have poor reliability and validity as they are not based on objective criteria but on the subjective judgements of the thoughts, feelings, behaviour, and life experiences of an individual by the assessor. Psychiatric diagnoses, whether reliable or valid or not, have positive or negative impacts for those on the receiving end and can also provide access to services and treatment to manage the experiences of distress or associated symptomology. (Pitt et al., 2009; Cromby, Harper and Reavey, 2013; Allsop et al., 2019).

However, for some people who experience distress, diagnoses can be positive:

> Corrine: Having researched the condition and its triggers I immediately felt some relief as I realised it was not my fault for being like I am. Following my own research, I began to realise what all my symptoms meant, and I was finally able to start unpicking my past in order to understand my present.
>
> Louise: being diagnosed for me, was a fairly positive experience, it explained so much of what had been going on in my life. So, you're having a diagnosis that kind of explained my behaviours and my thought patterns, and that kind of thing, was a relief to me, it made me think well actually there is a reason that I'm finding this so hard, and it's not just me in the world that finds this hard there's a whole group of people that find this kind of thing hard.

For some people, having a diagnosis means that there is a shared sense of identity and community with others and access to support networks, literature and websites that offer understanding and support and that you are not alone. Additionally, mental health is commonly understood as something that cannot be helped, it just happens whether you want it to or not which can remove elements of guilt or blame.

Previous research has identified that for many given the BPD diagnosis, their subjective experiences differ significantly from the clinical descriptions used by professionals (Lester et al., 2020). An area of major concern, highlighted for those who are classed as having BPD, is that the assessment conducted by psychiatrists lacks insight into what they are diagnosing (Mulvany, 2000).

> Rosa: the symptoms that I was presenting with, although they matched up with a BPD diagnosis, they were the symptoms I was presenting with after an eighteen-month abusive relationship. So, it's so confusing, it's not how I would have presented without that abuse so, the links between complex PTSD and BPD get really blurry for me…BPD is so much harder and we don't know how to work with it and we're going to put it in this box over here because we don't know what we are doing.

Ramon, Castillo and Morant (2001) highlighted that 22% of their participants believed their diagnosis was given because professionals could not identify any other diagnostic label to give them, hence the idea of the diagnosis as a 'wastebasket' or 'dustbin' diagnosis and an 'easy option for we can't do anything for you' (Horn, Johnstone and Brooke, 2007. p.262; Nehls, 1999). This belief was also reflected in the participants of this study, like Carol who said, "BPD was just the dustbin in which the women were dumped".

Haigh (2002) identified that people with a personality disorder diagnosis felt labelled by mental health professionals and society, that professionals did not understand the diagnosis nor that it was treatable, and this results in professionals hiding the diagnosis from 'service users'.

> Rosa: I believe that I was diagnosed when I was 16. But I wasn't told about that diagnosis and also 16 is an unethical age to diagnose someone with BPD. So, I found out that that diagnosis was on my record when I was 20, but the last time I had seen a psychiatrist was when I was 16 so that's when I think the diagnosis got added to my record.

The diagnostic label of BPD sets the dominant identity status cycle in motion and exposes an individual to professionals' negative diagnosis belief systems. As David noted "The criteria of borderline personality disorder… It's very ugly reading because its, the criteria's are very, very negative, they are almost harmful aspects of living really". The diagnostic label of BPD is inherently linked to stigmatization and negative socio-cultural value judgements. Prejudices can be seen through diagnostic frameworks, for example homosexuality was classified as a mental disorder in the 1950s but removed from the DSM in 1973, not because it was never a mental health issue, but because it became politically and socially unacceptable to classify it as such due to campaigns for gay people's civil rights (Baughey-Gill, 2011).

The negative effects of a BPD diagnosis can bring personal feelings of shame and inadequacy based on societal stigmatisation of mental health conditions like personality disorders which are represented in such a way as to imply that people with the diagnosis have an internal badness as well as madness.

> Ash: So there is something wrong with who you are as a person. That's how I took it, at first, was that there is something wrong with your personality. You're just a shitty person was how I took it.

Compared to other mental health conditions, personality disorders have historically evoked considerable stigmatisation from within mental health services (Castillo, 2000; Sheehan, Nieweglowski and Corrigan, 2016). It can induce a sense of alienation from others and society whilst leaving them classed as 'disordered'. In addition, being told the diagnosis of a disordered personality has a profound effect on the identity of the self and hope for the future (Castillo, 2000). For David, receiving the diagnosis affected his ideas of future relationships and self-worth, "It kind of confirmed to me what I felt were my worst suspicions, that life was hopeless, I am worthless, this definitely now excludes me from having interpersonal relationships".

People given a BPD diagnosis encounter barriers to basic human rights and end up in a revolving door of care and having their past experiences of abuse, neglect or trauma ignored by services and professionals as irrelevant except as part of their psychiatric history. This means only the 'disordered' symptoms and not the problems or 'symptoms' are helped. Treatment may mean being trialled on numerous types of medications, some of which can have serious physical and mental effects, and which may not address the difficulties that brought them into contact with services in the first place or they may be moved from service to service. This is a common pattern which is initiated and maintained by a BPD diagnosis being made.

Psychiatric diagnoses have been extensively criticised for the impact on those who are labelled (Scheff, 1966; Rosenfield, 1997) and questioned about what the benefits of it are when individuals experience stigma, shame, worthlessness, and hopelessness (Rosenfield, 1997; Johnstone, 2014). Some individuals have campaigned against the dominance of psychiatry and to avoid the use of diagnosing altogether to reclaim ownership over their own life stories (Dillon and May, 2003; Johnstone, 2014).

Validity of Diagnostic labels

There has long been critical debate about how the diagnosis of BPD is constructed and it is argued to possess no core features and is a highly diverse diagnosis associated with multiple comorbidities (Coid et al., 2009; Troll, Distel and Carpenter, 2011; Oldham, 2015). The BPD diagnosis is complex with an unclear aetiology and epidemiology posing questions about its validity as a diagnosis. There have been calls for the BPD diagnosis to be abolished and these are gaining support from both those with the diagnosis and professionals (Personality Disorder in the Bin, 2016; A Disorder for Everyone, 2019; Watson, 2019; Warrender et al., 2020). People who receive the diagnosis generally dislike the diagnosis of personality disorder, because of the negative reaction of others, as highlighted by Nehls (1999) research on people's views of the diagnosis. Nehls' participants felt their personal experiences were invalidated by professionals, and their coping methods viewed as manipulative which limited their access to mental health services. It is suggested that BPD is a flawed diagnosis and a highly contentious label and synonymous with placing people into this diagnostic category even if their symptomology does not quite fit the criteria (Johnstone, 2014; Johnstone et al., 2018; Ring and Lawn, 2019; Lester et al., 2020).

> Louise: People see it as a label to give people who are just, you know, in the system, but people don't know what to do with them. so, it almost feels like, 'well we'll give them that, we don't know what else to do with them, and then once they've got that label then everybody will know that there is really nothing wrong with them' and you know, it's like, 'once we've given them that label it's a free ticket for everybody else to kind of pass them by and go, oh yeah we don't really need to know what's going on with them', when actually the people with BPD are often some of the most traumatized people that are ever going to be in the mental health system, and need the most, kind of, tailored care to stop that trauma being reignited constantly, and yet, we're not given it.

Some have campaigned for the diagnostic name to be replaced with something more representative of people's experiences to reduce the stigmatisation that people encounter and give a clearer understanding of the complex relational and emotional phases of someone's difficulties and individual identities (Johnstone, 2014; Johnstone, 2018; MIND, 2018). Some have suggested that due to the frequency of childhood abuse histories, the symptomology is a response to trauma (Johnstone, 2014; Johnstone et al., 2018) and should therefore be reclassified under Complex Post-Traumatic Stress Disorder. However, severe trauma histories have only been found in around a third of people with the BPD diagnosis (Herman and Van Der Kolk, 1987; Möeller, Bachmann and Möeller, 1993; Paris, 1998; Raven, 2009; Kuo et al., 2015; Porter et al., 2019).

The use of the word ‘disordered’ is loaded with negative associations and when combined with ‘personality’, implies that a person is intrinsically damaged from the core with little hope of achieving a normal functional life (Kulkarni, 2015; Johnstone et al., 2018). It instils a pre-determined judgment that people who are personality ‘disordered’ cannot be cured, just the symptomology managed, and they are problematic to treat (Magnavita, 1998; Tredget, 2001; MacManus and Fahy, 2008). Kinderman et al. (2012) states that ‘disorder’ should be dropped and instead acknowledge that psychological distress is a normal part of human life and each human responds differently to difficult circumstances or experiences. In response to the debates surrounding the removal of the BPD diagnosis, the recent edition of the ICD-11 changed the personality disorder categories to personality difficulty classifications instead (WHO, 2018). The new classification framework is not without criticism as regardless of the diagnostic framework used, clinical utility should be provided to reduce the risk of ongoing stigmatisation that people experience (Herpetz, Huprich and Bohus, 2017). Whether this change by WHO will alter the perceptions of the diagnosis is yet to be identified.

Considering debates on renaming the diagnosis and upon reflection of the voices of this study’s participants, changing the diagnostic label of BPD to Emotion Response Syndrome with/without associated complex trauma would be more reflective of the symptomology experienced and be representative of those who have or have not experienced trauma. The proposed diagnostic name change validates the person and reorientates the negative perceptions of the BPD diagnosis to focus on emotional responses rather than negatively perceived behaviours. Changing the perceptions of behaviours associated with BPD may alter the experiences that people have with how professionals in frontline services treat them, making service provision more focused and directed to the needs of individuals.

Psychiatric diagnostic assessment alternatives

Several alternatives to how a psychiatric diagnosis is given have been proposed, but one already practiced in the UK, and supported by the British Psychological Society is Psychological Formulation. It is the process of co-constructing a ‘best guess’ hypothesis on the origins of a person’s difficulties based on their relationships, social circumstances, life experiences and how the person has perceived them. Psychological formulation promotes co-production between the person and the professional with the person bringing their own expertise on and meaning from their own life. This is vastly different from standard psychiatric diagnostic assessment. Working together builds a narrative and provides the foundations of a plan tailored to meet the needs of the person.

> David: One of the nicest things I experienced with my psychologist that I’d done the Formulation with….I’ve got choices in this, you want to know what I think, not to just make an assumption on my case notes which only highlight the worst parts of what I have to live with….And I could write notes over the top and she put them in there verbatim as to how I would want that, she said, ‘this is your report, this is your life’. Yeah, allowed me to take such a huge amount of control and demonstrated so much respect for me as a person rather than being treated as a diagnosis and this is how we treat that diagnosis….they’re all the same person you know which can’t be further from the truth… that’s the approach that I think everybody should be working, anybody that works in any capacity supporting, providing care to people, that’s definitely a model they should be using, its together, not what you think is best, don’t underestimate who you are working with and their capacity to understand, to process, to learn.

Psychological Formulation is used additionally or alternatively to traditional psychiatric diagnosis (The British Psychological Society, 2011). In contrast to standard psychiatric diagnosis, Psychological Formulation removes the ‘expert’ power dynamics and presumptions of deficits in the person being diagnosed. Instead, it applies a Strengths Based and Trauma Informed Approach focusing on the resources of a person who has survived challenging life situations. Given the potential role of trauma, Trauma-Informed practices integrate such knowledge into intervention planning and consider how services might potentially compound difficulties by re-traumatising people through coercive and disempowering practices (Fallot and Harris, 2009). It approaches the expression of distress by assuming that it makes sense, that however frightening the thoughts, feelings, risky or harmful actions are, they are there to manage life experiences and that there is a way to create meaning out of them (Butler, 1998). However, Psychological Formulation may still involve some of the negative aspects of psychiatric diagnoses such as pathologization, exclusion or the imposition of an assessor’s view.

A diagnosis, whether from traditional psychiatric assessments or by Psychological Formulation results in a person being assigned a label to indicate their mental health status. The next part of the cycle focuses on Re-Modified Labelling Theory, and its comparison between Classic and Modified Labelling Theory and the use and effects of a stigmatising label being given to an individual.

Classic and Modified Labelling Theory

Classic Labelling Theory, such as the sociological ideas of Durkheim (1973), Mead (1934) and the Chicago School, was developed to highlight the social responses to crime and deviance. Becker’s (1963) research on use and control of deviance, questioned what the consequences of a label were on the person and what circumstances surrounded its application. Becker (1963) contended that social groups create the rules of deviance and if those rules are broken, a label of deviant is applied to the person resulting in social exclusion. Social exclusion, or as he termed ‘social leprosy’, was not due to the act committed but a consequence of social sanctions placed on a labelled person. Classic Labelling Theory posits that a person becomes a passive victim, compelled to accept stereotypes and display behaviours associated with the label.

However, Modified Labelling Theory (Link et al., 1989) proposed that for mental illness, negative beliefs are founded in the early stages of a person’s development through exposure to negative social conceptions from family, friends, and social media. Link et al. (1989) states that negative beliefs of mental illness are inconsequential until the point a person is officially labelled, then the label becomes personally relevant, and due to the associated meanings the labelled individual comes to believe that they will be socially rejected and either withdraw from society or challenge negative stereotypes by educating others (Link and Cullen, 1983. 1990). Link et al.’s Modified Labelling Theory (1989) has received evidential support from those with a mental health diagnosis and investigative research on the effects of labelling (Kroska and Harkness, 2006; Kondrat and Early, 2011). Link et al. (1989) conducted a series of sociological investigations using their modified approach to Scheff’s (1966) Labelling Theory of mental illness. Participants included people under psychiatric treatment, people experiencing psychotic symptoms but not in receipt of treatment and people without psychotic symptoms. All the participants were united in expecting social rejection due to their diagnostic label and had experienced negative aspects of labelling including vocational, interpersonal and economic functioning impacts (Link, 1987; Link et al., 1987; Link, 1989). According to Goffman (1963) people labelled with a mental health diagnosis expect to be devalued and rejected by those in society without a mental health condition. To protect themselves from this devaluation, people withhold their diagnosis, socially withdraw, and distance themselves from others involved in receipt of mental health service provision (Corrigan and Watson, 2002; Shih, 2004; Thoits, 2011). Link et al. (1989) findings confirmed that a mental health label disadvantaged people by placing them in a lower social status with fewer life opportunities.

This research proposes that negative beliefs are additionally fostered within educational settings and professionals' working environments. Modified Labelling Theory differs from Classic Labelling Theory as it does not make the same assumptions of people with a psychiatric diagnosis, instead, suggesting that a labelled person experiences difficulties created by being discredited which results in less favourable treatment and less support from frontline organisations. Negative characteristics associated with mental health disorders and becoming a diagnostic out-cast persuades people to maintain a secrecy of their mental health status. For example, Louise said "The last time I presented at A&E…they asked me my diagnosis I didn't tell them".

Labelling is at the heart of social victimisation in which those with power impose deviant identities on the powerless to maintain societal order in the interests of the powerful and the medical model (Becker, 1963). Sub-cultures of hereditary stigmatisation are filtered down through the hierarchical systems that operate in health and social care services. Eloise shared her experience of working on a psychiatric ward in an acute hospital as well as having a BPD diagnosis.

> Eloise: There is a culture within a service, and people may come into a service with absolutely no opinion's about it [BPD] but if everyone else is saying, 'oh you know, this is a particular difficult service user set to work with', everybody is going to start believing that and presuming that…I've definitely seen that…new members of staff

> start in units like that. They come in all bubbly with an idea and realize what the culture is like and they slowly turn into that.

Rosenfield (1997) and Link and Cullen (1992) argue that there are two sides to labelling, positive and negative. However, in the experience of the research participants, negative labelling affects outweigh the positives.

> Eloise: There's a lot of things you are counted out from, 'oh this is not appropriate because of your BPD', like I have other diagnoses as well…its actually shut a lot of doors and been something that sort of hangs around over your head as a flashing light.

Feelings of rejection and disappointment because of the BPD label, which resulted in some of them socially withdrawing and distancing themselves from services regardless of need, were frequently discussed by the research participants. As reported earlier, Carol said "over the years I've learned and understood that the best person to help me is me". Biased perceptions and behavioural discrimination towards people with a personality disorder label are determinants of professional and societal reactions. These can be elevated when a person's levels of distress and coping methods such as non-suicidal self-injury are evident or visible, the negative perceptions of BPD are heightened and enforced (Thoits, 2005).

> Corrine: Professional services see you as attention seeking persona with behavioural problems. Self-harming as well creates even more stigma from these people. I have been made to feel 'dirty' for self-harming. I don't want to self-harm but until I get the help I need this is my coping mechanism to get from one day to the next.

A mental health diagnostic label such as BPD is weighted with negative beliefs and ideas and is the pre-emptive mechanism of becoming a person's dominant identity status. Labelling Theory and Dominant Identity Status Cycle are intertwined and connected, for example Link et al., (1987) considered how mental health conditions and associated behaviour of a labelled person influences societal reaction. However, critics of Labelling Theory (such as Gove and Fain, 1973) state that it incorrectly suggests that societal reactions are primarily unaffected by behaviour. Social constructions of a mental illness label become a dominant identity status and determine the reactions of others irrespective of a labelled person's behaviour. Critics reject the effects of mental health labels based on research findings which do not show direct discrimination against labelled individuals, thus, they argue any rejection that occurs is based on a person's behaviour rather than the label they have (Gove and Fain, 1973; Myers and

Astrachen, 1974; Crocetti, Spiro and Siassi, 1974; Schwatrz, Lehman et al., 1976; Huffine and Classen, 1979).

This research strongly evidences disagreement with the critics of Labelling Theory. The research participants demonstrated through their experiences that people hold a priori judgements and beliefs about the BPD label irrespective of how they initially present themselves to others. This fuels negative reactions and impacts not only their personal well-being and self-worth but also affects the care, treatment, and support for their social and psychological well-being. If a person does not divulge their mental health label, then such expectations and beliefs are not formed.

Re-modified Labelling Theory

The proposal of Re-modified Labelling Theory is not to discount the past theorists of Classic and Modified Labelling Theory but rather to develop theoretical thinking and its application to mental health. Psychiatric labels that have been applied to people can place them into cultural categories, influenced by negative images of mental ill-health and creating a stigmatised identity (Rosenfield, 1997; Markowitz, 1998). Individual status characteristics that differ from normative expectations can make people vulnerable to being labelled with a mental health disorder (Horwitz, 1982; Rosenfield, 1984; Timimi, 2014; Rössler, 2016). People can experience rejection from and stigmatisation by others based on information that a label carries, and they may be placed into the role of ‘service user’ hindering their ability to socially and economically function due to limits imposed by others (Link, 1982; Garand et al., 2009; Timimi, 2014). Labelling Theory-based research has produced conflicting opinions on the positives and negatives of mental health diagnoses. The negative implications of mental health labels are that they enforce compliance to normative behaviours, medicalise natural human responses, stigmatise and alienate individuals (Szasz, 1960; Corrigan, 2004; National Health Executive, 2016). Gallo’s (1994) paper on their personal experience of psychosis and psychiatric hospitalisation highlighted how the negative conceptions of labelled people made her believe that she had been relegated to the social garbage heap.

Socially constructed images, language and media representations of personality ‘disorder’ labels repeatedly portray negative aspects which, as Goffman (1963) suggests, makes those with a label evaluated as not quite human. The combination of inaccurate dramatic portrayals, labelling and stigma of personality disorders heighten the negative stereotypes towards this group of people (Granello and Gibbs, 2016). Angermeyer and Matchinger's (2003) research into public attitudes found that serious mental health disorder labels influence public attitudes towards those with the diagnoses actively withdrew themselves from interactions with labelled individuals. In comparison, more common mental health diagnoses, for example depression, elicited no adverse attitudes. Regardless of a person's behaviour, the BPD label has a lasting effect of increasing the experience of discrimination towards the person from frontline services and professionals.

> Helen: I know that people who are diagnosed with BPD notoriously, amongst the people I know, have had dreadful treatment and it's almost been a diagnosis of exclusion. I know people have been discharged, told that it's untreatable, unfortunately, I know two people who had BPD who died by suicide…I can see how easy it is to go down that route because it is awful, it is harrowing and people can have such complex difficulties, to then be met with health care professionals either telling them that your problems are untreatable, intractable or whatever, why on earth would people have hope if they hear that?.

Positive opinions argue that labels set the standards of 'normality' by categorising what behavioural and emotional traits and experiences should be understood as 'disordered' (Timimi, 2014), they provide a succinct explanation to a person's difficulty, give an understanding as to the nature of their problems, a sense of hope towards a resolution of wellness and relief (Angermeyer and Matchinger, 2003) and can give a sense of identification as a patient (Angermeyer and Matchinger, 2003). This should result in an accepting, caring and non-judgmental response from health and social care professionals, however negative consequences of the BPD label experienced by the research participants, show that regardless of circumstances, interactions with frontline professionals result in experiencing negative attitudes, discrimination, neglectful treatment, societal and service exclusion. The BPD label is a determinant in the interaction and reaction of professionals, and regardless of people's behaviour is viewed through the lens of the negative aspects of the BPD label as 'difficult' to deal with.

In the development of Labelling Theory and its application to mental health, debates between Scheff (1966) and Gove (1975) focused on two particularly current relevant topics. The first considered who gets labelled and whether an individual's status characteristics, such as gender, exposes them to different labelling experiences. This is pertinent as BPD is a gendered diagnosis with women more likely to be diagnosed than men and women accounting for 70% of those diagnosed. Feminists (such as Simmons, 1992; Becker, 1997; Wirth-Cauchon, 1997; Kerr, 2004) have critiqued how the BPD diagnosis pathologizes women's expression of trauma and distress. Perceptions of feminine characteristics, including them being more emotional, hysterical, and needy, have favoured the application of the diagnosis even if past and present symptomology does not fit the criteria. Hence, the BPD diagnosis is argued to continue oppression and control of women (Shaw and Proctor, 2005; George, 2006).

> Carol: BPD has been used in a very derogative way, primarily for women, primarily for women with longstanding problems…that they are any better at understanding women…I knew other women that were going through the same system, who were as dismissed, they were dismissed with such contempt.

Scheff (1966) and Gove's (1975) second debate considered the consequences of labelling and whether institutionalisation is detrimental to a person's mental health (Townsend, 1976; Chow and Priebe, 2013) Forced in-patient care can be an option for people in prolonged periods of crisis resulting in chronic suicidality or serious self-harm. Although limited access to in-patient care is not unusual for other mental health diagnoses, for those with the BPD label, there is a clinical consensus that inpatient care should not be an option or should be minimised to a period of 24-48hrs for the management and escalation of self-injurious behaviours (Paris, 2002; Oldham, 2006). This is further impacted by professional's lack of knowledge of the diagnosis and negative and stigmatising attitudes towards this diagnostic group (James, 2007; Dickens, Lamont and Gray, 2016; Stapleton and Wright, 2019). Sarah experienced the detrimental effects of having the BPD label whilst staying at an inpatient facility.

> Sarah: I was in an acute ward and there was another girl at the time presenting relatively similar to me, quite severe self-harm, low mood things like that. She was diagnosed with bipolar…she was like, 'Sarah I don't understand why, when you have an incident they treat you like, their response is, like here you go, sort yourself out, off you go and distract somewhere'….when she had an incident she got time to sit and debrief with staff, she got time with the psychologist and stuff…the difference was that we had a different diagnosis.

Despite there being a body of research, which has demonstrated the psychosocial and pharmacological benefits of mental health treatment (Smith, Glass and Miller, 1980; Prien et al., 1984; Christiansen et al., 1987; Elkin et al., 1989; Kane, 1989;), the BPD label prevents and reduces opportunities to obtain benefits of treatment and therapeutic support. Scheff (1966) proposed that effects of labelling are primarily negative due to stigma and the dehumanising effects of psychiatric treatment. The negative consequence of receiving psychiatric treatment is that it is rooted in cultural definitions of 'mentally ill', which can influence the expectations and interactions of others of those receiving treatment which devalues and discriminates.

Individuals can experience rejection in physical and mental health care based on labelling information assigned to them (Link et al., 1987; Garand et al., 2009; Timimi, 2014; Munro, 2021). For David, his experience of rejection took place in A&E after a car accident in which he sustained quite severe injuries and suggested it was because of the BPD diagnostic labelling information and past addiction struggles in his medical notes.

> David: It was just complete contempt around that time…Yeah I'm an inconvenience to you, you've made that very clear, that I'm wasting your time and you've essentially said as much…I remember, I was having my thumb reattached, I'd gone through a car window and they were looking at my medical notes where I, had issues with addiction to opiates… 'we're not going to give you pain medication because we know you like that', like I was there for the medication.

Labelling Theory claimed that diagnostic labels lead to persistent and recurrent mental health problems, based on an individual's self-labelling concept (Link et al., 1987). However, participants here suggest that the self-labelling concept does not increase mental health problems, rather the label of BPD and negative perceptions attached to that label are an active block to therapeutic mental health services and heighten a person's emotional distress or maladaptive coping strategies.

The BPD label effect can make people with a diagnosis feel that they are not 'normal' anymore and are judged by professionals in physical and mental health services. David described how he believes that professionals view people with the diagnosis as "a cohort of dysfunctional people that clog up their system…taking up our time when we could doing much better things with our time". Additionally, it is the very services that people seek when in need of support which can be the most stigmatising and discriminatory towards those with the BPD label.

The next section will present Social Identity Theory and the role of negative mental health representation by the media in influencing societal stigma, exclusion, and discrimination.

Social Identity Theory

Human relationships are social and embedded in a network constructed on their identity associations (Stets and Burke, 2000). Associations are shaped in relation to skin colour, gender, country of birth, faith, socioeconomic class, disability, or other factors such as being a mental health service user. Social Identity Theory's core premise is traditionally centred around social situations and how people often think of themselves, and others, as members of a group rather than as individuals. Developed from Tajifel's (1970) early work, the theory attempts to apply cognitive grouping and Gestalt phenomena to social groups. Gestalt is the perceptual pattern which possesses qualities that cannot be described merely as a sum of their parts. The theory posits that social identity is underpinned by intergroup behaviour, as distinct from interpersonal behaviours, and that social identities become the main determinant of social perceptions (Hahn and Tapper, 2013). Stets and Burke (2000) proposed that social identity is developed through a process of self-categorisation; self-reflection and self-classification through identifying associations which seek associations with other social groups. Groups with which individual's align themselves determine their sense of self-worth as a member of society and the level of respect they receive as a member of a social group (Willetts and Clarke, 2014). People determine others' aptitudes for status and power in gaining insider group status of those that are deemed accepting and valued by society (McCall and Simmons, 1978; Turner et al., 1987). Critically, Social Identity Theory can help to develop insights into the social identity of discriminatory, prejudicial, and intergroup conflict resulting from group-based categorisation and motives for self-enhancement (Islam, 2014).

Hogg and Abram (1988) state that individuals are born into an already structured society in which they derive their identity, or sense of self, from the social category to which they belong. Individuals desire a social category based on which one will be powerful, provide status, prestige and rewards. Through such identification, people adopt the identity of the group that they categorise themselves as belonging to; they will begin to act in the ways that someone in the group should act and conform to the norms of that group (McLeod, 2019). As a result, a significant emotional attachment to being a group member is formed. Self-esteem becomes connected to group membership and to maintain it, the group must compare favourably with other groups. If two groups identify as rivals, they then compete to maintain their identity as well as the acquisition of social resources (McLeod, 2019). This is done through two important processes in Social Identity Theory, social comparison and self-categorisation, which yield different outcomes. Through social comparison, people who share similarities are categorised as 'in-group' members and those who differ are placed as 'out-group' members. Consequently, self-enhancement and self-esteem are targeted by evaluations that judge which groups are favoured and which are not. Applied to different social groups such as family, mental health status or social class, social comparison can be used to explain people's exaggerated and biased perceptions of difference (Tajifel, 1970; Tajifel et al., 1971).

> Rosa: The lower classes have personality disorder and middle classes have bipolar, and upper classes are just eccentric…you're more likely to have a diagnosis of bipolar if you're in a higher class and you're more likely to be treated like a person if you have a diagnosis of bipolar…BPD is related to working class oppression.

Self-categorisation emphasises similarities that people perceive between themselves and other members of an in-group and the perceived differences between in and out-groups (Tajifel, 1970). Assigning people to categories reveals characteristics about them and which appropriate behaviour is defined by the norms of the group they belong to. But assigning categories by behavioural norms can only be recognised via mutual identification of belonging to the same group. Emphasis occurs from the beliefs, values, behavioural norms, attitudes, and affective reactions believed to be correlated with intergroup categorisation. In testing the effects of emphasising difference, Tajifel (1970) conducted an experiment by dividing people into two groups and providing random information on group members. Group members with shared in-group identification on some dimensions exaggerated their positive qualities whilst exaggerating the negative qualities of out-group members. Past research has demonstrated social phenomena resulting from categorisation including negative evaluations of 'out-groups' (Dovidio, Gaertner and Validzic, 1998), stereotyping (Smith, 1999), and failure to allocate resources to 'out-group' members (Sidanius, Pratto and Mitchell, 1994). The social world then becomes divided into a 'them' and 'us' and the groups a person does not belong to are left with a negative self-image through the effects of active discrimination, negative views passed to existing group members.

The research findings here suggest that the Social Identity Status of people with a BPD diagnosis is determined by society and directly from psychiatric labels irrespective of how people present and live within the expected norms of society. Social prejudice towards and discrimination against people with mental health conditions are common and can be socially damaging. Such prejudice and discrimination can have substantial impacts on public health by adding to life and social inequalities (Clement, 2014; Heads Together, 2017). An individual who has a dominant identity based on a mental health diagnosis or as a 'user' of mental health services, is placed in a social role and social category in which their personal identity becomes the lowest level of self-categorisation. People's role and social category set them apart from other individuals and place them into the mentally ill role. Social comparisons and stereotypes are made by society which places people outside of the normative fit and functioning of others, continuing to override their personal identity (Stets and Burke, 2000). Society determines acceptable behaviour and more acceptable mental health conditions (those which cause the least disruption or risk to the rest of the population). Those branded with any other condition are labelled as outsiders. However, the more powerful a person's standing in society, the less likely an unfavourable diagnostic label and negative dominant identity status will be imposed upon them (Gove, 1970; Mummendey et al., 1999).

Generalisations about mental health diagnoses are formed based on the negative characteristics of the diagnosis. As Sarah described, "BPD, being over-emotional, can't simmer down sort of thing. So I get a lot of that, people expecting you to kick off at any moment". These generalisations can influence other members of the population to make judgments about whether people with different mental health diagnoses can become valued members of society. As noted by participants, there is a hierarchy of mental ill health whereby some conditions are more socially acceptable than others; Rosa said "I think BPD is the scary one and schizophrenia is the really scary one and depression is thing that we've all had at some point". Thus, depression or anxiety disorder are more socially accepted because most people have felt some aspect of depression or anxiety and they are considered short term problems that can be recovered from, unlike personality disorder symptoms. Social acceptance of mental ill-health could also be connected to the relatability of recent events of the Covid-19 pandemic and restrictions placed upon society with more people experiencing poor mental well-being.

People with mental health diagnoses who refuse to comply with, or are judged to not fit into those norms, are socially excluded. They become outsiders, out-group members with limited rights and denied opportunities that others are entitled to (Adams et al., 2007). Those who are excluded become identified and placed within a marginalised group. People with a BPD diagnosis do not have this entitlement as they, as a group, are depersonalised by society based on their diagnosis. Beliefs are developed about marginalised groups, passed on to others via various platforms such as literature or institutional culture, reinforcing negative perceptions and stigmatising attributes about someone with a BPD diagnosis (Tredget, 2001; Woollaston and Hixenbaugh, 2008; Warrender, 2015).

> Louise: You can't expect people to not be prejudiced when everything they are reading is all about how, you know, terrible the condition is and how you know, people are manipulative…just attention seeking and all of that kind of thing. That's what they are being fed, then they're never going to change their views are they?.

Additionally, negative perceptions can be formed by association to a label, which Eloise witnessed "I remember standing there once at the nurse's station and there was a new patient coming in, my colleague turned to me and said, 'oh it's one of those borderlines, brace yourself'". Thus, labels, generalisations, evaluations, and stereotypes of people with a BPD diagnosis contribute to their social identity which creates their social experiences of devaluation and discrimination (Jones et al., 1984; Crocker and Major, 1989; Link and Phelan, 2001; Major and O'Brien, 2005).

Role identities are organised into hierarchies and devalued role identities, such as being mentally ill, are prioritised as more important than other role identities leading to discrimination (Stryker, 1980; Tajifel and Turner, 1986; Thoits, 1992; Taylor and Moghaddam, 1994). For example, health and social care professionals will express dominance over unfavoured mental health diagnostic group members who should display subordination to maintain the status quo of social status.

> David: Yeah, you better suck it up and you better put a smile on your face and don't show any outward signs if you're struggling or not coping because that'll be the threat to your, us going, 'we'll take away the thing that might actually help you'. And it feels incredibly like that power dynamic as well, that we're holding all this power, we've got the keys.

Amir (1969) and Jackson (1993) suggest that if an encounter is superficial when applied through the dominance context, it lacks understanding and is not genuine, leaving those involved reminded of their subordinate status and place. Dominant in-groups, such as the medical or psychiatric professions, as discussed above and in Chapter 6, favour their own group at the expense of others; beliefs and attitudes that already exist within the group will be adopted by new members and those who challenge the power of the in-group will be excluded (Mental Health Foundation, 2021). As noted above, Eloise reflected on her experiences delivering mental health training saying:

> Eloise: There was a sister who I'd met before…when I'd been in the hospital and she was quite aloof and not interested, and she was in the same training, she was sort of sitting there, like went out to the loo part way through…and all the people, the nurses and support staff who worked with her followed suit, because she was a senior who wasn't interested, they come in all bubbly…and then they realize what the culture is like and they slowly turn into that. There is a culture within a service…people come into a service with absolutely no opinions about it [BPD], but if everyone else is saying, 'oh you know, this is a particular difficult service user set to work with', everybody is going to start believing that and presuming.

Actions by dominant in-group leaders influence other group members to follow and uphold their superiority and maintain their dominance over the subordinate out-groups (such as people with a BPD diagnosis). This can occur even if the subordinate out-groups' behaviour does not reflect a priori beliefs about them and this enables in-group members to remain within their social collective (Tajifel, 1978, 1982; Tajifel and Turner, 1979, 1986; Goar, 2007). Interactions between professionals and those with a BPD diagnosis are mediated by group identities; that is, an individual with BPD is viewed through the lens of their dominant social identity, as a member of the BPD group (and associated activated stereotypes), rather than an individual. Professionals reinforce this social identity by maintaining interaction through the medical model structures of treatment and the continued pathologisation of a person's distress and emotional (in)stability.

> Sara: I think a lot of the judgement isn't on what you're saying, because a lot of people can say its lies, they usually judge people on what they look like and how they seem…the kind of image of personality disorder that everyone has in their head, whether its subconscious or unconscious is like, the crazy ex-girlfriend kind of thing…I'm very very wary of telling anyone, friends…like most of my closest friends wouldn't even know.

Toynbee and Walker (2008) suggest that the UK has become a more divided and unequal place with greater disparities between those with mental health problems and those without. Social exclusion is traditionally understood to apply in terms of poverty and hardship with political and moral undertones relating to justice, equality, human rights and citizenship. In terms of mental health, the central concepts of social exclusion proposed by Boardman (2011) align to social capital, recovery, citizenship, choice and access, participation, stigma and discrimination. The effects of social exclusion from society conflicts with the values of social justice and solidarity and emphasises the importance fairness plays in our society as it removes choice and opportunity which the population majority take for granted.

Johnstone (2001) suggests that societal abuse is a cruel injustice in the denial of people's moral entitlements. Disadvantages that people with a mental health diagnosis experience reveal unjust social structures that prevent them from reaching their full potential and meeting basic human needs (Benbow, 2009). Overton and Medina's (2008) review of literature on stigma and mental illness identified social discrimination which included negatives attitudes, physical abuse, homelessness, and continued difficulty in obtaining a good standard of life. Social oppression and the inequality of people with a BPD diagnosis primarily exists in terms of structures that are linked to their social identities and their relation to status and power in society. Social exclusion can deny them the basic level of citizenship, wealth and happiness that is potentially available for those without a severe mental illness diagnosis (Nicki, 2001; Pilgrim, Rogers and Pescolido, 2011). Socially devalued out-groups are aware that their social mobility is blocked, they withstand the discrimination directed towards them and challenge the social devaluation and stigmatisation been placed upon them (Thoits, 2011; Cruwys and Gunaseelan, 2016).

Influence of media on society

Jorm (2000) and Gaebel and Baumann's (2003) research into public attitudes towards people with mental health conditions suggests that the general population hold preconceived judgements on the nature of mental illness and how these people should be treated. They are influenced by factors such as media reports, personal contact with someone with mental ill-health and/or knowledge about the mental health system (Wahl and Lefkowits, 1989; Rossler and Salize, 1995; Kolodziej and Johnson, 1997; Corrigan, River and Lundin, 2001). The general public's knowledge of mental illness commonly derives from mass media as its main distributor of information highlighted by a survey conducted by the Daniel Yanklovich Group (1990) in which 87% of the survey's respondents quoted news and non-fictional programs as a source of information about mental illness. Nunally (1957), the first researcher to investigate mental health in the media, compared the views of the public, mental health experts and the mass media, and concluded that the mass media's portrayal of mental health was far removed from the views of professionals or the general public. Diefenbach and West (2007) suggest that some positive knowledge is acquired through media, but that much of the content presented perpetuates negative stereotypes (see also Abelman, 1985; Brown and Cody, 1991; Rada, 2001; Dixon and Linz, 2002; Minnebo and Van Acker, 2004). The media's depiction and reporting of mental health in the UK continues to reinforce negative beliefs and stigmatisation (Atanasova et al., 2019; Li et al., 2021).

Bissell and Parrott (2013) propose that the media shapes prejudice via two routes: the dissemination of inaccurate information about social groups and the provision of information to viewers about society's beliefs which inform actions towards members of social out-groups. Media coverage linking mental illness to violent crimes has served to perpetuate negative social attitudes.

> Rosa: I currently do therapy with 7-year olds…sometimes she's younger than 7 and sometimes she's an adult…she has trauma from when she was about 2…I was saying about the two sides of her…he [dad] was saying to me, 'we need to nip that in the bud before it becomes a multiple personality or something like borderline personality disorder',…the majority of the public that doesn't work in the mental health industry, doesn't know these terms, sees the phrase BPD and equates it with dissociative identities and dissociative identities means bad. And means like, those horror movies…that's the link he makes.

The tabloids unfairly give false and negative views of mental illness and grant prominence to stories associated with mental illness and violence. Acts of violence committed by a person with mental illness has a greater possibility of being reported by the media than other reports of mental illness containing no violence (Nunally, 1957; Matas et al., 1986; Mehta et al., 2009).

> Helen: I think I prefer people being informed in some ways, as long as they are correctly informed…they might have heard horror stories or occasional things in the press about somebody with BPD who has stabbed somebody.

Negative depictions of mental illness in films and television influences the attitudes of viewers as found by Wahl and Lefkowitz's (1989) experimental study where participants that were exposed to movies of murderers with mental illness developed negative attitudes toward mental illness and community care and Goldstein (1979) and Diefenback (1997) who both found that prime time fictional police dramas were found to associate more negative labels with criminals with mental health conditions and present them as more dangerous.

> Rosa: I've just finished watching some British mystery where there was a Munchausen's by proxy plot twist…I just wished that hadn't happened because it's a mental health problem…you take…it's easy to take it in…you are a lot more likely to be like, 'okay this is what people with BPD are like'.

The diagnosis of BPD has not been spared fictional representation but is consistently portrayed in a negative and stigmatising way; female characters who are dangerous, psychotic and chaotic in films such as Girl Interrupted (1999), Single White Female (1992), Monster (2003) and Fatal Attraction (1987). Inaccurate stereotypes of mental health conditions influence society's reality of individuals that are distressed or suffering from trauma. People with mental health conditions are identified as being dangerous, aggressive, impulsive and not to be trusted.

> Helen: There's quite high rates of abuse, people having been abused…they'll [society] have these awful preconceptions…if it was actually, correctly informed…this person could probably be a bit more vulnerable than the average person, might have had something traumatic happen.

Negative stereotypes of mental illness that are fed to society are integrated into society's cultural narratives making people with a mental health condition scapegoats whilst diverting attention away from policy makers in addressing issues of equality, fairness, justice and health and social care. Pescolido, Manago and Monahan's (2019) research of public views on violence committed by those with mental illness identified that public perceptions were found to have a greater concern about the danger they posed in violence to others. Becker (1991, pp.8-9), describing the social beliefs of mental health deviance, suggests that it is society which creates this belief system but not in the way that it is generally understood as cause and effect of social factors that influences a deviant act. Public attitudes towards people with mental illness have indicated an anticipation or perception of social deviance and violent behaviour. However, people with mental health problems are more likely to be targeted and face discrimination, hostility and violence from different population groups identified as young adults, strangers, colleagues, family members and professionals within health and social care (Kumar, Guite and Thronicroft, 2001; Berrins, Petch and Atkinson, 2003; Sin et al., 2009).

Other determinants that have been identified as increasing the risk alongside mental health diagnoses are sexuality, and physical disabilities (MIND, 2007; Clement et al., 2011). Hate Crime and harassment are recognised as significant factors in the discrimination that those with mental health problems face (Thornicroft et al., 2007). A survey across twenty-seven countries to identify the levels of discrimination that people with varied mental health diagnoses experienced found that of 732 participants 26% had experienced verbal or physical abuse because of their mental health and 29% had experienced unfair treatment in their community (Thornicroft et al., 2009). Similarly, Deponte, Bird and Wright's (2000) study into the level of stigma experienced by people with a mental illness identified that 47% of their participants had been abused or harassed in public.

To address how society perceives those with mental illness and reduce discrimination, inequalities and exclusion, anti-stigma campaigns in England have become more pronounced in targeting the general population or specific groups to reduce negative attitudes and promote understanding. *Time to Change*, created by mental health charities MIND and Rethink, have been consistently challenging discrimination since 2007 in a series of phased advertising targeting of different population groups (Henderson, Potts and Robinson, 2019). The key emphasis of Phase 3, active since 2016, has been targeting individuals aged 25-44 years with a focus on men's mental health in an effort to create more openness in discussing mental health difficulties. However, there is currently no measure of societal perception of mental health that determines whether society has developed a more informed acceptance and understanding. Stigmatisation Theory, the next phase in the DISC framework, will be presented next.

Stigmatisation Theory

Social justice theory as discussed in Chapter 3, proposes that all people are equal and have the right to dignity and respect. Its application to stigmatisation expands an understanding of the problem and explores the means to target efforts to eliminate it. Framing stigmatisation as an issue of social justice reminds others that people with mental ill health are, in fact, just people. The stigmatisation of mental ill-health and the impact it has on those at the receiving end, such as a barrier to receiving or seeking treatment and poor care, have been well documented over the last half century (Overton and Medina, 2008; Da Silva et al., 2020). Stigmatisation is a major cause of exclusion and discrimination and global barrier to seeking help and getting effective care from physical and mental health organisations (Corrigan et al., 2003; Martin, Lang and Olafsdottir, 2008; The World Health Organisation, 2013). Mental health stigma sustains social inequalities and influences health outcomes (Hatzenbuehler, Phelan and Link, 2013; Stangi et al., 2019). Research into public health considers the role of stigma as a fundamental driver for population health disparity through mechanisms such as unequal distribution of resources for stigmatised groups (Lamont et al., 2016). Membership of a stigmatised cohort of people amplifies the negative effects of stigma when seeking clarification, treatment, or referral for specialised health advice (Lam, Salkovski and Hogg, 2016; Lam et al., 2016; Chartonas et al., 2017).

> Louise: I have a chronic physical condition as well and I had to go to the hospital to deal with it…there was physically something wrong that needed fixing the doctor kept coming and saying to me, ‘well no I’m not, I’m not going to do that because I don’t think, I think you’re exaggerating the symptoms…I think, because he found out what my mental health condition was. So, you can’t win, even if you present as a normal physical patient, if people find out, you know, everything is just, you know, it changes.

The effects of diagnostic overshadowing occur not only for people in the general population but also for those who work within health and social sectors. Gold et al. (2016) research, focused on women working in the medical profession, identified that stigmatisation of mental health impacted their willingness to disclose and seek treatment through fear of losing their status and ability to practice. Stigmatisation of personality disorders acts as a deterrent in maintaining a good standard of living, pursuing life opportunities and affects self-worth (Clement, 2014).

Previous researchers of stigmatisation, such as Gove (1982), believed that the effects of stigmatisation were small and temporary and did not appear to pose a severe problem downplaying the importance of stigma due to individuals still being offered and in receipt of beneficial treatments. Scheff (1966) contended that because of stigma, individuals are treated negatively and made to endure dehumanising experiences from psychiatric institutions, or as he called them ‘agents of control’. Stigma is a matter of degree in that what sets a person apart can vary; the person can have a strong or weak association to undesired characteristics which in turn determines the rejecting responses.

> Helen: All the things I’d read that people might experience once they’ve been given this diagnosis, it just suddenly, I just suddenly realized, when professionals had been very rude or very dismissive and tended to just ignore what I was saying, massive fear of me ever becoming over-dependent on services, the neediness, things like that. I just started to piece together, oh this is how they’ve framed me; this is how, the lens they’ve been seeing me through.

Corrigan and Kleinlein (2007) suggest that stigmatisation in healthcare is not just limited to the treatment system but also a place where people’s experiences of professionals are less favourable particularly at times of crisis and distress.

> Angela: I saw her hanging herself twice so, I had to help the police cut her down on one occasion. She was sent home from hospital after two of those incidences…they let her walk home from [anonymised] hospital… [The mental health] Trust blamed the hospital, but they were aware of the fact that she was in crisis and they did nothing…she went into hospital for self-harming she was in such a disturbed state and…. got two nurses who really didn’t give a shit about her…she was allowed to walk home, but then the trust blamed the hospital for allowing her to go…We live 24 miles away from [anonymised] hospital and you’ve got 8 miles on unlit rural roads.

People with a BPD diagnosis are more likely to be viewed by professionals as responsible for their own problems, in control of their behaviour and symptomology, but also less likely to recover from their diagnosed condition. Their ‘behaviour’ is misinterpreted as manipulative rather than as portraying their level of distress (Warner and Wilkins, 2004; Aviram, 2006; Commons Treloar and Lewis, 2008; Rogers and Dunne, 2011; NG et al., 2019; Baker, Edwards and Beazley, 2021). Professionals attach blame to people’s mental ill health and coping methods used in periods of distress.

The level of stigmatisation and negative attitudes towards the BPD diagnosis has remained relatively stable over time. Stroud and Parsons’ (2013) interpretative phenomenological analysis of attitudes towards the diagnosis indicated that professional’s attitudes were on a sliding scale between dread and a desire to help those with the diagnosis. It is unsurprising then professionals carry stigmatised beliefs towards those with a diagnosis of BPD and actively discriminate despite awareness of treatment and support barriers that are created as a result (Barlow, Miller and Norton, 2007; Horn, Johnstone and Brooke, 2007; Campbell, 2008).

> David: It wasn't until I'd got the diagnosis of BPD, it was ah, this is a catch all you know. Anyone that presents at hospital with a history of self-harm, then they're called PD's, we're not people anymore…I have lost my identity.

People are described as high consumers of services, having repeated emotional crises with recurrent threats of self-harm and the ability to cause conflict between staff which do nothing to assist in reducing the negative way that the BPD label is interpreted amongst frontline professionals (Gallop, 1985; Linehan et al., 1991; WHO, 1992). Interactions with this diagnostic group are described as emotionally blackmailing, rule-breaking, threatening, dangerous, evoking heightened emotional responses and beliefs that people are bad not distressed (Markham, 2003; Wilstarnd et al., 2007; Woollaston and Hixenbaugh, 2008; Westwood and Baker, 2010; Chartonas et al., 2017). The belief that those with the diagnosis are bad is an important part of the development of stigmatisation frequently referred to in literature (Corrigan et al., 2001; Feldman and Crandall, 2007). Attitudes by professionals, such as psychiatrists, mental health nurses and psychologists do not differ greatly from the general population, pre-empting social distance and avoidance (Nordt et al., 2006). Additionally, discomfort and fear can arise due to social cues ascribed to an individual, highlighting symptoms such as physical appearance or unease at being around or interacting with others (Link et al., 1987; Corrigan, 2004, 2007).

Link and Phelan (2001) propose that stigmatisation and the theory of labelling are connected in the way stigmatisation is defined. The personality disorder label has been and is a contemptuous label with people with the BPD diagnosis stereotyped as a 'therapist's nightmare' and perceived as challenging due to 'disturbed' behaviours (Kaplan, 1986; SANE Australia, 2001; Felton and Stickley, 2004; McCann et al., 2006; Goodwin and Happell, 2007a). Similar research on professional perceptions in healthcare identified they believed people with the diagnosis were less ill than other inpatient groups, eliciting less compassionate responses and perceived as more responsible for their actions (Gallop, Lancee and Garfinkel, 1989).

Challenging behaviour, a term originally introduced to offer social explanations of people's behaviour, was soon adopted by health and social care professions to refer to the negative characteristics of an individual and their diagnosis (Hayman, Swain and Gillman, 1998).

> Corrine: It felt as if I had a "Mickey Mouse" condition that was not worth their effort to help me with …I have taken overdoses as well as severely cutting myself that has required myself attending A&E. On all occasions the police became involved. When I am in such a state I am usually confused and scared and on each of these times the police have handcuffed me despite some protest from my then CPN. I have been sectioned a few times and have had different experiences with the police in attendance…Very few are understanding they simply see me as someone having behavioural problems.

Self-harm behaviours (or more correctly coping methods to manage distress or grounding techniques to balance emotion or to bring oneself back to the present if in a state of dissociation) are still believed to be manipulative actions (McAllister et al., 2002; Gunderson, 2008; Gibb et al., 2010). Although negative beliefs have been steadily changing, altering perspectives and highlighting the experiences of people with the diagnosis is difficult. Fallon's (2003) research analysing lived experience of BPD, identified reluctance to disclosing their diagnosis to mental health professionals. In agreement with Fallon's findings, this occurrence was highlighted by a small number of those who participated in this study.

> Eloise: There were people who were just like, you know, 'because of your diagnosis you are choosing to do this to yourself' [self-harm], 'silly little girl, you need to grow up', all this sort of stuff, which just, was really like, when you're in that place when you're really lost and you don't know what's going on and people are telling you that, and most people with personality disorder are pretty under-confident in themselves and there's all these people telling you that sort of stuff from the outside, it really doesn't help. It doesn't help.

Professionals' viewpoints gathered by Commons Treloar's (2009) research of health services in Australia and New Zealand, identified similar attitudes from staff. One professional's comment was that 'BPD is just an excuse for bad behaviour and nastiness' (p.131). Lawn and McMahon's (2015) study identified that 57% of people with BPD were shunned by service providers in comparison to 29% of people with other mental health diagnoses.

The challenging of stigma attempts to change people's views or behaviour and to engage with biased attitudes, by contradicting the stereotyped expectations. A campaign launched in 2016 by Heads Together, an umbrella organisation of eight UK mental health charities, sought to challenge and end the stigmatisation of mental health in England. The aim was to raise awareness of the inequalities that still existed for those with mental health conditions and to provide help for people with mental health challenges. The organisations believed that stigma was still a key issue preventing people from getting the help and support they need (Heads Together, 2017). Challenges to the concept of stigma include cognitive resistance through rejecting the identity of a ‘mental health patient’ or a ‘personality disordered’ person (Link and Phelan, 2001). Although raising awareness of stigma is always a positive intervention, it can fail to address the broader context of mental health stigmatisation, diminishing the positive outcomes of successful campaigns over time (Link and Phelan, 2001; Gronholm et al., 2017). Link and Phelan (2001, p. 356) suggest that investigating stigma processes can be challenging and those that study it ‘do so from the vantage point of theories that are uniformed by the lived experience of the people they study’ creating a misunderstanding of the experiences of the stigmatised and the perpetuation of unsubstantiated assumptions.

To bring this chapter to a close, the Dominant Identity Status Cycle theoretical framework, demonstrates the various stages that explain the stigmatisation, discrimination, and social exclusion of those with a BPD diagnosis. The DISC framework is versatile and can be applied to other mental and physical health diagnoses that experience stigma and discrimination including, but not exclusively, other personality disorders, schizophrenia, dissociative identity disorder, eating disorders, HIV and Aids, Tourette’s, sexual health conditions and addiction (drug, alcohol, sex etc). The framework can be used as a concept outside of the medical model in considering hate crimes, discrimination and stigma of a person’s lifestyle or culture (sexual identity, orientation, race, religion) with the central point and start of the cycle replaced with the appropriate topic under investigation. The next chapter will present the final discussion of the research.

Chapter 8. Conclusion

Chapter Overview

This study has provided an examination of the experiences of people with a diagnosis of borderline personality disorder who access and participate with frontline services. It has explored how stigmatisation by and negative attitudes of frontline professionals towards this diagnostic group results in discriminatory practices, influences policy and the service and social exclusion of individuals. In doing so, it has illuminated that, despite mental health stigma campaigns and a greater social awareness of mental ill-health in England since the covid-19 pandemic, individuals with the BPD diagnosis are the least accepted or understood by professionals.

This final chapter opens with the contribution to literature and research, a summary of the main findings, followed by recommendations for future policy, practice and research before concluding comments that draw the thesis to a close.

Contribution to academic literature and research

People's experiences of accessing and participating with frontline services in England has been largely overlooked by research literature, thus one contribution of this work has been to focus on this topic. Research on the BPD diagnosis has predominantly been taken from the perspectives of professionals which show negative and stigmatising attitudes towards this diagnostic group (Deans and Meocevic, 2006; Munro and Baker, 2007). The stigmatisation of mental health is an antecedent for discriminatory practices and is a barrier to accessible care and treatment which impacts on an individual's quality of life and life choices. The language used by professionals towards individuals captured in this research and in literature, label individuals in derogatory terms such as manipulative, dangerous, difficult to treat and communicate with and less deserving of care and treatment (Markham, 2003; James and Cowman, 2008). Professional's belief systems towards this diagnostic group create adverse effects on individuals and directed 'stigma by association' towards their support networks. The level of stigmatisation from services towards this diagnostic group has made some of the psychiatric community question the continuing use of this stigmatising diagnostic label. For some members of the psychiatric community, resistance to or non-disclosure of the diagnosis during diagnostic assessments reaffirms the high level of associated stigmatisation and awareness of stigmatisation of the BPD diagnosis. This research has theorised that people are unwillingly given a dominant identity status as a result of having the diagnosis which is underpinned by the medical model of mental health.

Research on the lived experience of the BPD diagnosis is minimally represented in scientific and academic research. Placing lived experience at the forefront of academic research, addresses the prejudicial beliefs and attitudes inherent in physical health care and public protection services. Studies of BPD diagnosis stigmatisation in lived experience accounts identify dehumanization, patronisation, shame, stereotyping and blame in professionals' attitudes towards the diagnosis. This study adds to the literature on the lived experience of mental health to show that inclusion in and by frontline services can have a positive impact in the re-education of professionals of the BPD diagnosis to improve organisational policy, understanding, working practices and challenge negative discourses.

Furthermore, this study contributes to the critiques of the application of the medical model to mental health which allows for the construction of psychiatric disorder through the pathologization of emotional and behavioural states that are deemed to be 'abnormal'. Dominant ideologies embedded in the medical model allow medical and psychiatric professionals to maintain their 'expert' power and control over people with mental health diagnoses. The medical model devalues the diversity of individual experience to support the continuation of injustice and inequality of people through exclusion, oppression, disempowerment and stigmatisation.

Summary of key findings

The aim of this study has been to highlight the experiences of people with a BPD diagnosis in relation to stigmatisation, prejudice and inclusivity whilst accessing and participating with professionals in frontline services in England. The key findings of the research are that:

- The diagnosis of BPD results in people experiencing stigmatisation, negative attitudes and exclusion from frontline services and professionals. Physical and mental health services demonstrated a high level of stigmatising experiences leading to discriminatory practices and the refusal or limitation to care and treatment.

- The language used by physical and mental health care professionals reflected how the BPD diagnosis was negatively conceptualised and influences how individuals are identified and treated perpetuating the continued stigmatisation of this diagnostic group.
- People with a BPD diagnosis experience barriers to accessing appropriate support and treatment which is often compounded by exclusionary criteria of services. Individuals with comorbid diagnoses face further exclusion due to lack of professional knowledge or skills resulting in a cycle of rejection.
- There is a failure to provide specialist personality disorder services in some parts of England. Mainstream services fail to provide a clear pathway to treatment with waiting lists for treatment more than one year, with the start of treatment in excess of a two year wait.
- Professional hierarchy and power results in an abuse of that power with coercive and bullying tactics to either accept the treatment and support offered or have individual care plans removed. Toxic cultures of power show that professionals blame and discriminate against this diagnostic group and challenges to ‘expert’ cultures result in inter professional manipulation to maintain the power balance, belief systems and practice towards individuals.
- Lived experience inclusion in services challenges the cultures, beliefs, stigmatisation, knowledge, understanding and working practices of frontline professionals. It addresses the power dynamics that exist between professionals guided by the medical model framework of mental health and those that access their service. Inclusion provides validation and empowerment of people who have been marginalised and discriminated against because of the diagnosis.

Dominant Identity Status Cycle (DISC) model

The DISC model was developed as a direct result from analysing participants experiences and their thoughts in accessing and participating with frontline services and professionals. The foundation upon which services and professionals respond to and understand mental health is via the medical model of disease and disability rather than acceptance and ability.

The DISC model begins at the point of diagnosis, with which the medical model cannot exist or maintain its dominance. Reframing how services are structured towards diagnostic prominence and how professionals interact with people with 'diagnoses' is the first phase in restructuring beliefs and working practices in mental health. As a result of diagnoses, labels are made and applied to people which then take the forefront of their identity and influence how they are treated and responded to by frontline services. Of course, this is dependant on what label they have and if their diagnosis is interpreted as one which is not considered a challenge, dangerous or difficult to work with such as BPD.

Mental health labels then influence the social context within which frontline services and society react to and understand those with a diagnosis of BPD. Negative perceptions of the diagnosis held by dominant in-groups in services can not only be adopted by new professionals entering their services but also limit the rights, opportunities and exclude those with the diagnosis placing them within a marginalised group. Negative perceptions, stereotyping and beliefs are further reinforced by portrayals in the media and the tabloids.

The outcome is the stigmatisation of the BPD diagnosis which is a major cause of exclusion and discrimination resulting in social inequalities. In aiding positive and non-discriminatory future practice and policy within services, this model with further development, could provide a foundation in which to reduce the stigmatisation and inequality of mental health.

Recommendations for future research

This study identified the following lines of enquiry for future research that would benefit the knowledge and understanding of the BPD diagnosis from gaps in existing literature:

The male perspective

Identified as a limitation of this study was a lack to recruit equal or proportionate male and female participants. This meant an under representation of lived experience from the male perspective. Pertaining to the literature, the diagnosis of BPD is considered gendered with women accounting for 70% of those diagnosed. Whilst there is a wealth of literature on BPD, this too highlights a limitation to show that the male perspective is vastly underrepresented (Johnson et al., 2003). Research that has been conducted is generally focused on the criminal justice system (Black et al., 2007; Wetterborg et al., 2015). Although research identifies that the diagnosis of BPD in prison and forensic settings is not uncommon, it does not determine why there is a high correlation of men with the diagnosis involved with the criminal justice system. Gendered specific research could explore this correlation and provide space to address why men with the diagnosis show high comorbidity rates with other personality disorders (Grant et al., 2008), more contact with drug and alcohol services, and less likelihood to seek out help and support from mental health services at times of crisis (Sansone and Sansone, 2011b). It could also ascertain whether the male experience of frontline services is similar to that of women, and if not, how are they different. Adding this study to the field of research would assist towards providing a measurement of the number of males diagnosed with BPD in England.

BAME and the BPD diagnosis

BAME communities experience repeated social disadvantages and racism which means that they can be at a higher risk of developing mental health problems (Mental Health Foundation, 2019). Mental health conditions vary in BAME communities and these groups experience inadequate service provision and care (Rethink, 2020; National Collaborating Centre for Mental Health, 2019). BAME groups can experience stigmatisation and racism from mental health services which has a negative impact on them seeking support when needed (Bhui, 2018; National Collaborating Centre for Mental Health, 2019a). However, a gap exists in research on the lived experience of ethnic minority groups with a diagnosis of BPD which future research should consider.

Practical implications

The focus of this research has been the experiences of individuals, due to the favoured approach of placing the professional’s perspectives at the forefront of the BPD diagnosis in existing research. However, there are some practical recommendations proposed that may benefit individual’s future experiences of frontline services.

Experience-led inclusion

Experience- led inclusion in services gives people the opportunity to share their experiences with professionals in the development of good practice and the reduction of discriminatory attitudes towards personality diagnoses. Service inclusion can aid in the development of organisational policy and frameworks shaped by individuals whose knowledge places them at the forefront of what is and is not best practice. Services that promote inclusion show improvements in supporting individuals and in professional attitudes and perceptions towards mental ill-health (The National Survivor User Network and Together for Mental Wellbeing, 2014). Inclusion can influence policies towards alternative approaches to access support and can aid service improvement in the delivery of care to others in the future.

Education of professionals

Education of frontline service professionals is identified as a necessary strategy in reshaping the belief systems around mental health conditions, particularly personality disorder diagnoses. Identified in previous research with organisations that have applied this shows that it breaks down negative and stigmatising attitudes (Happel, Moxham and Platania-Phung, 2010; Byrne et al., 2013). The knowledge and understanding framework of personality disorders (KUF) was designed to support frontline professionals in a variety of sectors challenge the misconceptions about this diagnostic group and to gain practice-based knowledge of different working and support approaches to support people (Personality.org, no date). The training is delivered via co-production by non and lived experience trainers offering unique perspectives. The KUF training should be a compulsory requirement for frontline service professionals and should also be included in educational curriculums of professional courses such as mental and physical health nursing, paramedic sciences, trainee psychiatrists and psychologists as a small example.

Concluding Statement

The experiences of people with a diagnosis of BPD in accessing and participating with frontline services and professionals has been shown to be stigmatising, negative, prejudicial and exclusionary. This study suggests that these experiences with services and professionals can be challenging and can also prolong periods of distress and maladaptive coping methods. However, more work needs to be done in challenging stereotypes belief systems as well as assisting professionals and services to eradicate these from practice. This study has also provided insight into the potential benefits and opportunities for people with a diagnosis of BPD and for professionals to work together in providing best working practices that work to support the needs of individuals.

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Appendices

Appendix 1. DSM-5 Diagnostic criteria for Borderline Personality Disorder

A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

1. Frantic efforts to avoid real or imagined abandonment. (Do not include suicidal or self-mutilating behaviour covered in criterion 5.)
2. A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation.
3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
4. Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). (Do not include suicidal or self-mutilating behaviour covered in Criterion 5.)
5. Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour.
6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).
7. Chronic feelings of emptiness.
8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).
9. Transient, stress- related paranoid ideation or severe dissociative symptoms.

Diagnostic Features

The essential feature of borderline personality disorder is a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity that begins by early adulthood and is present in a variety of contexts.

Individuals with borderline personality disorder make frantic efforts to avoid real or imagined abandonment (Criterion 1). The perception of impending separation or rejection, or the loss of external structure, can lead to profound changes in self-image, affect, cognition, and behaviour. These individuals are very sensitive to environmental circumstances. They experience intense abandonment fears and inappropriate anger even when faced with a realistic time-limited separation or when there are unavoidable changes in plans (e.g., sudden despair in reaction to a clinician's announcing the end of the hour; panic or fury when someone important to them is just a few minutes late or must cancel an appointment). They may believe that this "abandonment" implies they are "bad". These abandonment fears are related to an intolerance of being alone and a need to have other people with them. Their frantic efforts to avoid may include impulsive actions such as self-mutilating or suicidal behaviours, which are described separately in Criterion 5.

Individuals with borderline personality disorder have a pattern of unstable and intense relationships (Criterion 2). They may idealise potential caregivers or lovers at the first or second meeting, demand to spend a lot of time together, and share the most intimate details early in a relationship. However, they may switch quickly from idealising other people to devaluing them, feeling that the other person does not care enough, does not give enough, or is not “there” enough. These individuals can empathise with and nurture other people, but only with the expectation that the other person will “be there” in return to meet their own needs on demand. These individuals are prone to sudden and dramatic shifts in their view of others, who may alternatively be seen as beneficent supports or as cruelly punitive. Such shifts often reflect disillusionment with a caregiver whose nurturing qualities had been idealised or whose rejection or abandonment is expected.

There may be an identity disturbance characterised by markedly and persistently unstable self-image or sense of self (Criterion 3). There are sudden and dramatic shifts in self-image, characterised by shifting goals, values, and vocational aspirations. There may be sudden changes in opinions and plans about career, sexual identity, values, and types of friends. These individuals may suddenly change from the role of a needy supplicant for help to that of a righteous avenger of past mistreatment. Although they usually have a self-image that is based on being bad or evil, individuals with this disorder may at times have feelings that they do not exist at all. Such experiences usually occur in situations in which the individual feels a lack of a meaningful relationship, nurturing, and support. These individuals may show worse performance in unstructured work or school situations.

Individuals with borderline personality disorder display impulsivity in at least two areas that are potentially self-damaging (Criterion 4). They may gamble, spend money irresponsibly, binge eat, abuse substances engage in unsafe sex, or drive recklessly. Individuals with this disorder display recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour (Criterion 5). Completed suicide occurs in 8%-10% of such individuals, and self-mutilative acts (e.g., cutting or burning) and suicide threats and attempts are very common. Recurrent suicidality is often the reason that these individuals present for help. These self-destructive acts are usually precipitated by threats of separation or rejection or by expectations that the individual assumes increased responsibility. Self-mutilation may occur during dissociative experiences and often brings relief by reaffirming the ability to feel or by expiating the individual’s sense of being evil.

Individuals with borderline personality disorder may display affective instability that is due to marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days) (Criterion 6). The basic dysphoric mood of those with borderline personality disorder is often disrupted by periods of anger, panic, or despair and is rarely relieved by periods of well-being or satisfaction. These episodes may reflect the individual's extreme reactivity to interpersonal stresses. Individuals with borderline personality disorder may be troubled by chronic feelings of emptiness (Criterion 7). Easily bored, they may constantly seek something to do. Individuals with this disorder frequently express inappropriate, intense anger or have difficulty controlling their anger (Criterion 8). They may display extreme sarcasm, enduring bitterness, or verbal outbursts. The anger is often elicited when a caregiver or lover is seen as neglectful, withholding, uncaring, or abandoning. Such expressions of anger are often followed by shame and guilt and contribute to the feeling they have of being evil. During periods of extreme stress, transient paranoid ideation or dissociative symptoms (e.g., depersonalisation) may occur (Criterion 9), but these are generally of insufficient severity or duration to warrant an additional diagnosis. These episodes occur most frequently in response to a real or imagined abandonment. Symptoms tend to be transient, lasting minutes or hours. The real perceived return of the caregiver's nurturance may result in a remission of symptoms.

Associated Features Supporting Diagnosis

Individuals with borderline personality disorder may have a pattern of undermining themselves at the moment a goal is about to be realised (e.g., dropping out of school just before graduation; regressing severely after a discussion of how well therapy is going; destroying a good relationship just when it is clear that the relationship could last). Some individuals develop psychotic-like symptoms (e.g., hallucinations, body-image distortions, ideas of reference, hypnagogic phenomena) during times of stress. Individuals with this disorder may feel more secure with transitional objects (i.e., a pet or inanimate possession) than in interpersonal relationships. Premature death from suicide may occur in individuals with this disorder, especially in those with co-occurring depressive disorders or substance use disorders. Physical handicaps may result from self-inflicted abuse behaviours or failed suicide attempts. Recurrent job losses, interrupted education, and separation or divorce are common. Physical and sexual abuse, neglect, hostile conflict, and early parental loss are more common in the childhood histories of those with borderline personality disorder. Common co-occurring disorders include depressive and bipolar disorders, substance use disorders, eating disorders (notably bulimia nervosa), posttraumatic stress disorder, and attention-deficit/hyperactivity disorder. Borderline personality disorder also frequently co-occurs with other personality disorders.

Prevalence

The median population prevalence of borderline personality disorder is estimated to be 1.6% but may be as high as 5.9%. The prevalence of borderline personality disorder is about 6% in primary care settings, about 10% among individuals seen in outpatient mental health clinics, and about 20% among psychiatric inpatients. The prevalence of borderline personality disorder may decrease in older age groups.

Development and Course

There is considerable variability in the course of borderline personality disorder. The most common pattern is one of chronic instability in early adulthood, with episodes of serious affective and impulsive dyscontrol and high levels of use of health and mental health resources. The impairment from the disorder and the risk of suicide are greatest in the young-adult years and gradually wane with advancing age. Although the tendency toward intense emotions, impulsivity, and intensity in relationships is often lifelong, individuals who engage in therapeutic intervention often show improvement beginning sometime during the first year. During their 30s and 40s, the majority of individuals with this disorder attain greater stability in their relationships and vocational functioning. Follow-up studies of individuals identified through outpatient mental health clinics indicate that after about 10 years, as many as half of the individuals no longer have a pattern of behaviour that meets full criteria for borderline personality disorder.

Risk and Prognostic Factors

Genetic and physiological. Borderline personality disorder is about five times more common among first-degree biological relatives of those with the disorder than in the general population. There is also an increased familial risk for substance use disorder, anti-social personality disorder, and depressive or bipolar disorders.

Culture-Related Diagnostic Issues

The pattern of behaviour seen in borderline personality disorder has been identified in many settings around the world. Adolescents and young adults with identity problems (especially when accompanied by substance use) may transiently display behaviours that misleadingly give the impression of borderline personality disorder. Such situations are characterised by emotional instability, “existential” dilemma, uncertainty, anxiety-provoking choices, conflicts about sexual orientation, and competing social pressures to decide on careers.

Gender-Related Diagnostic Features

Borderline personality Disorder is diagnosed predominantly (about 75%) in females.

Differential Diagnosis

Depressive and bipolar disorders. Borderline personality disorder often co-occurs with depressive or bipolar disorders, and when criteria for both are met, both may be diagnosed. Because the cross-sectional presentation of borderline personality disorder can be mimicked by an episode of depressive or bipolar disorder, the clinician should avoid giving an additional diagnosis of borderline personality disorder based only on cross-sectional presentation without having documented that the pattern of behaviour had an early onset and a long-standing course.

Other personality disorders. Other personality disorders may be confused with borderline personality disorder because they have certain features in common. It is therefore important to distinguish among these disorders based on differences in their characteristic features. However, if an individual has personality features that meet criteria for one or more personality disorders in addition to borderline personality disorder, all can be diagnosed. Although histrionic personality disorder can also be characterised by attention seeking, manipulative behaviour, and rapidly shifting emotions, borderline personality disorder is distinguished by self-destructiveness, angry disruptions in close relationships, and chronic feelings of deep emptiness and loneliness. Paranoid ideas or illusions may be present in both borderline personality disorder and schizotypal personality disorder, but these symptoms are more transient, interpersonally reactive, and responsive to external structuring in borderline personality disorder. Although paranoid personality disorder and narcissistic personality disorder may also be characterised by an angry reaction to minor stimuli, the relative stability of self-image, as well as the relative lack of self-destructiveness, impulsivity, and abandonment concerns, distinguishes these disorders from borderline personality disorder. Although anti-social personality disorder and borderline personality disorder are both characterised by manipulative behaviour, individuals with antisocial personality disorder are manipulative to gain profit, power, or some other material gratification, whereas the goal in borderline personality disorder is directed more toward gaining the concerns of caretakers. Both dependent personality disorder and borderline personality disorder are characterised by fear of abandonment; however, the individual with borderline personality disorder reacts to abandonment with feelings of emotional emptiness, rage, and demands, whereas the individual with dependent personality disorder reacts with increasing appeasement and submissiveness and urgently seeks a replacement relationship to provide caregiving and support. Borderline personality disorder can further be distinguished from dependent personality disorder by the typical pattern of unstable and intense relationships.

Personality change due to another medical condition. Borderline personality disorder must be distinguished from personality change due to another medical condition, in which the traits that emerge are attributable to the effects of another medical condition on the central nervous system.

Substance use disorders. Borderline personality disorder must also be distinguished from symptoms that may develop in association with persistent substance use.

Identity problems. Borderline personality disorder should be distinguished from an identity problem, which is reserved for identity concerns related to a developmental phase (e.g., adolescence) and does not qualify as a mental disorder.

Appendix 2. BPD support groups

Durham BPD Group – Waddington Street Centre, 3 Waddington Street, Durham DH1 4BG. Age Group 18-85+ Meet every 2nd Thurs of month. Tel: 07930158724
E: Durhambpdsupportgroup@rethink.org

Time to change – 15-19 Broadway, London, E15 4BQ Tel: 02082152356 E: info@time-to-change.org.uk (Led by Mind and Rethink).

Changes Bristol – Barton Hill Settlement, 41-43 Ducie Road, Lawrence Hill, Bristol, B55 OAX Tel: 0117 9411123 E: info@changesbristol.org.uk

Derbyshire BPD support group – Saints parish centre, church way, chesterfield S40 1XJ meet 1st & 3rd Mon each month Tel: 07597 644558 E: derbyshireborderlinepd@gmail.com

Mental health forum –Suite 223-266 Banbury road, Oxford, OX2 7DL E: forum@mentalhealthforum.net

Mind – Norwich and Central Norfolk – 50 sale road, Norwich NR7 9TP Tel: 01603 432457 E: headoffice@norwichmind.org.uk

Suffolk User Forum Tel: 01473 907087 E: hello@suffulkuserforum.co.uk

Wirral Pathfinders – Peer support group Tel: 0151 334211 E: support@wirralpathfinders.org.uk

Take off – East Kent (Canterbury) peer support groups Online contact form

Self Injury support – Bristol Tel: 0117 9279600 E: info@selfinjurysupport.org.uk

BPD Relief – support group in Portsmouth Contact form online – organiser called lou

Richmond Fellowship Pele Tower – therapeutic housing service for BPD – North Shields Tyne & Weir E: northtyneside.peletower@richmondfellowship.org.uk

Waves – pd support group – Bury St Edmunds & Ipswich E: waves@suffolkmind.org.uk

BPD World – Silicon House, Farfield park, Manvers Rotherham S63 5DB Online contact form

Personality disorders Plymouth – support group E: meercats19@hotmail.com

The Haven Project – 10 St peters court Colchester Essex CO1 1WD Tel: 01206 572215 E: the.haven@thehavenproject.org.uk

Leeds survivor -led crisis service E: survivor.led@lslcs.org.uk

Enigma – emotional regulation peer support group Suffolk/Norfolk

Emergence – online contact form

Mind CPSL – Cambridgeshire, Peterborough & South Lincs peer support groups

Bridging the gap St Neots, Huntingdon and Cambridge E: enquiries@cpslmind.org.uk

Borderline Arts – 119 Osmaston Road, Derby DE1 2GD Tel: 07754 806814 E: contact@borderlinearts.org

Suicide Crisis Cheltenham – Tel: 07889 420200 E: joy.hibbins@suicidecrisis.co.uk

Appendix 3. Introductory email

Donna Bradbury E: [email redacted] T: [mobile number redacted]

Dear Sir or Madam,

My name is Donna Bradbury. I am currently undertaking my Doctorate at the University of Gloucestershire in which my research is to gather the experiences of people diagnosed with Borderline Personality Disorder that have used or worked with frontline services in England. This research has been approved by the University's Ethics Committee, and I am now seeking interview participants who would like to share their experiences with me.

I am passionate about this topic as research consistently highlights that frontline professionals repeatedly display or hold negative attitude towards people with a diagnosis of BPD. This can result in stigmatising or pre-judgemental behaviour often reflected in the care or support they provide which causes individuals to exclude themselves from seeking care or support. Despite an increase in mental health awareness and media campaigns to reduce the stigma of mental health conditions within England, there is still a resistance to change in attitude towards this diagnostic group.

BPD is a condition that has been the focus of much research, however the perspective has been from a professional viewpoint rather than from the viewpoint and experience of individuals with the diagnosis. Only a small percentage of studies have been undertaken with individuals with BPD and none that specifically relate to all frontline services in England.

Participation is completely voluntary, if you or your colleagues, friends or clients would be interested in taking part, I have enclosed information on my research, interview questions you/they will be asked and my contact information. I will happily travel to your/their location and can meet wherever you/they will feel most comfortable to conduct the interview which will last no more than one hour.

Thank you for your time and I look forward to hearing from you.
Kindest regards
Donna

Appendix 4. Participant information letter

Researcher: Donna Maria Bradbury MSc. BSc. Donna Bradbury E: [email redacted] T: [mobile number redacted]

Title of Study: What are the experiences of people with Borderline Personality Disorder on accessing and participating with frontline services in England in relation to stigma, prejudice and inclusion.

Dear participant,

I am a PhD researcher at the University of Gloucestershire. I would like to invite you to take part in a research study which is exploring the experiences of people with a diagnosis of borderline personality disorder who have accessed frontline services (A&E departments, police, mental health crisis teams, mental health services, GP's, street triage, suicide crisis support etc.). In particular I am looking at stigma and prejudice from frontline professionals and whether this impacts on inclusion to services, support and seeking treatment. I have many years of experience in mental health and drug and alcohol addiction as a support worker as well as 13 years of personal relationship experience of borderline personality disorder, pmdd, self-harm, eating disorder, dissociation and suicide ideation.

The intention is to publish the results of the research in the hope of highlighting the difficulties that this diagnostic group can face arising from negative attitudes of professionals and to inform policy and practice on engagement.

Interview participants:

- must be at least 18 years of age.
- have a professional/personal support network accessible.
- have been without a period of crisis for a minimum of one month

If you would like to take part, I would like to do a research interview with a duration of 90 minutes – this isn't like a job interview, it's a friendly and informal conversation about your experiences. You are free to stop the interview at any time and can withdraw from the study up to 14 days from the date of the interview. The interview will be audio recorded so that I can transcribe it (write it out) and then analyse it by looking at the other interview transcripts for example).

All data will be securely held on a password protected computer and secured premises. Audio recordings and interview transcripts will be held by the researcher to further analyse or use for future research projects and or publication. Participants will be anonymous in the transcripts and identified only by the name you choose to be known by. You can also receive a copy of your interview if you want.

The University of Gloucestershire Research Ethics Committee has approved this study. For any ethical concerns the Chair of Research Ethics Committee Dr Emily Ryall can be contacted on [contact details redacted].

If you would like further information on the study then you can contact the studies supervisory team Dr Louise Livesey E: [email redacted] or Dr Pauline Dooley E: [email redacted].

If you would like to participate in this study, please contact me on the above email or telephone number at the top of this letter. I will email or ring you (if you state your preference) a week later where we can have an initial chat and answer any questions you may have plus arrange an interview date and location that is convenient for you.

On the morning of the interview only, if you could take 30 minutes to think about an experience you may have had when engaging with services that might be a positive or negative one it would be very helpful.

On the day of the interview an informed consent form will be given to you to read and sign before the interview takes place.

Please retain a copy of this information sheet for contact information along with the Research Participants Privacy Notice which will be given to you.

Many thanks and I look forward to hearing from you.

Donna Maria Bradbury MSc. BSc.

Appendix 5. Informed Consent Form

UNIVERSITY OF
GLOUCESTERSHIRE
at Cheltenham and Gloucester

Informed Consent Form

(Two copies of this form will be signed, one retained by the participant and one by the Researcher)

Title: What are the experiences of people with Borderline Personality Disorder on accessing and engaging with frontline services in England in relation to stigma, prejudice and inclusivity.

Researcher: Donna Maria Bradbury MSc. BSc.

I have read and understood the information sheet and have had the opportunity to ask questions and understand I can ask further questions at any point. Please Circle: **Yes** **No**

I understand I am free to withdraw from the study within the time limits outlined in the information sheet and can refuse to answer any question. Please Circle: **Yes** **No**

I agree for the research interview to be tape recorded, for it to be used for this study and then destroyed after 5 years. Please Circle: **Yes** **No**

I agree that extracts from the interview, in which I will only be identified by the name I have chosen, can be used in

The research findings	Please Circle: **Yes** **No**
Presentations about the research	Please Circle: **Yes** **No**
Academic publications	Please Circle: **Yes** **No**
Future research projects	Please Circle: **Yes** **No**

Do you understand the possible psychological risks in taking part in this research particularly that it might involve remembering upsetting experiences you may have had? Please Circle: **Yes** **No**

Would you like to receive a copy of the interview transcription via post or email?
Please Circle: **Yes** **Post**
Yes **Email**
No

I agree to take part in this interview.

Name of participant Date

Signature