

**Addressing Misdiagnosis: Towards a Better Understanding of how to Clinically  
Differentiate Autism and Borderline Personality Disorder**

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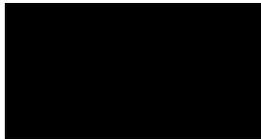
## **Declaration**

### **UCL Doctorate in Clinical Psychology**

#### **Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:



Name: Kimberley Guest

Date: 18/06/2021

## Overview

This thesis considers autism and the diagnostic entity of borderline personality disorder (BPD) together.

Part one, a conceptual introduction, reviews the literature to discuss the ways in which autism and BPD are similar and the ways in which they are different. Shared traits, particularly regarding emotion regulation, mentalising, self-harm and suicide rates, and challenges in interpersonal relationships are highlighted. The lack of literature on how to differentiate the conditions is noted. To better understand how autism and BPD are conceptualised today, the origins and evolution of the two diagnoses are outlined and compared. The impact of receiving either an autism or BPD diagnosis is explored, including the way in which individuals are responded to by professionals in healthcare services.

Part two, the empirical paper, aimed to establish expert consensus on how to differentiate autism and BPD. The three expert panels consisted of 18 experts by experience, 16 research and clinical experts in autism and 17 research and clinical experts in BPD. Responses from a questionnaire were used to develop statements regarding how to differentiate autism and BPD. Via a two-round Delphi study, expert consensus was reached on 22 statements which 80% or more of 51 panellists rated as extremely useful or useful.

Part three, the critical appraisal, reflects on how the project was developed in the context of the scientist-practitioner model and on the complexities of using the term, “borderline personality disorder”. It also considers the challenges of using the Delphi method as well as the strengths and limitations of the empirical paper.

## **Impact Statement**

Whilst there is increasing recognition of the overlap between autism and BPD, almost no systematic research has been conducted to investigate how the conditions can be differentiated from each other. The empirical paper aimed to establish expert consensus on what helps to differentiate autism and BPD via a Delphi study. Twenty-two statements were produced which were endorsed as useful for differentiating autism and BPD. These statements can contribute to improved assessment for individuals where it is unclear if they are autistic, have BPD or are autistic with co-occurring BPD.

The empirical paper will be submitted to a research journal. The publication of the paper may help to raise awareness of the fact that autism and BPD share traits which can result in misdiagnosis and, in turn, risks inappropriate care being given. Thus, the empirical paper in and of itself can inform clinical practitioners of the importance of differential diagnosis and may prompt conversations regarding the differentiation of autism and BPD.

The specific statements which were agreed upon as useful by experts can help clinicians to disentangle autism and BPD. The statements are not intended as a diagnostic tool. However, the current study is the most systematic research in this area and thus its results offer some guidance on differentiating autism and BPD where there has previously been very little. Clinicians can refer to the endorsed statements to inform clinical discussions regarding service-users who present with characteristics which could be explained by either BPD or autism.

The differentiating statements can also support better recognition of autism in adult mental health services, particularly in women. This identification may result in referrals to autism services and thus contribute to minimising the time before an autism assessment is offered to autistic individuals whose autism has previously been missed by services.

Furthermore, the 22 statements which met consensus may help clinicians to identify autistic individuals with co-occurring BPD, who are at higher risk of suicide and who may have unique needs regarding their healthcare.

The results of the study also have implications for research. The endorsed statements about differentiating autism and BPD are testable and can act as hypotheses for future studies. This is of particular importance due to the current dearth of literature on this topic, most of which is based on clinical opinion not sought in a systematic way.

It is also possible that the endorsed statements can be used to develop a questionnaire or measure which could indicate whether someone's difficulties are more indicative of autism or BPD.

On a separate note, and more broadly, the conceptual introduction highlights that many professionals misunderstand autistic people and people with BPD. The discrimination encountered by individuals with BPD as a result of this diagnosis being stigmatised is also highlighted. This review reinforces that clinicians and researchers need to commit to understanding the difficulties of both groups, to destigmatising the difficulties of those diagnosed with BPD, and in doing so, improving patient care.

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## **Part One: Conceptual Introduction**

**How are Autism and Borderline Personality Disorder Similar and Different?**

## **Abstract**

Autism and borderline personality disorder (BPD) are conceptually different and have different aetiologies. Yet, the conditions share traits. These include difficulties with emotion regulation and mentalising, high rates of self-harm and suicide attempts, and challenges within relationships. Shared traits mean that the conditions are difficult to differentiate which can lead to misdiagnosis. Although the diagnostic overlap is increasingly being acknowledged, few studies have considered the conditions together. This review discusses the way in which autism and BPD are similar and different. Looking at their respective histories elucidates that the conditions have been conceptualised and researched differently; autism has been historically associated with males and children and BPD with females and adults. Both autistic individuals and those with BPD may experience barriers in accessing appropriate healthcare services. Whilst both conditions are misunderstood amongst professionals, BPD is more stigmatised by professionals which may impact care. At the level of shared traits, almost no systematic research has investigated how BPD and autism can be differentiated. Yet, there is a need for better differential diagnosis to ensure that appropriate interventions are offered and to help identify autistic individuals with co-occurring BPD, who may have unique needs. A Delphi study could be a first step to establish expert consensus on what helps to differentiate autism from BPD.

## **Introduction**

Autism Spectrum Disorder (hereafter 'autism') and borderline personality disorder (BPD) are conceptually different. Autism is a neurodevelopmental condition largely related to genetic differences (Dias & Walsh, 2020) historically seen as being driven by social cognition (Baron-Cohen et al., 2008) and characterised by differences in sensory processing (Robertson & Baron-Cohen, 2017). By contrast, although genetics influence vulnerability (Amad et al., 2014), BPD is thought of as developing in adolescence or early adulthood and in response to adverse experiences (Porter et al., 2019), an invalidating environment (Linehan, 1993) or in the context of attachment difficulties (Fonagy, 2000).

However, it is increasingly being acknowledged that the two conditions can be difficult to differentiate (Lai & Baron-Cohen, 2015). This is linked to important shifts regarding autism being recognised more in those with normal-range IQ (Charman et al, 2010) and in women (Gould & Ashton-Smith, 2011). There is a need to better understand autism and BPD, and how they are similar and different, both conceptually and practically (Gordon et al., 2020). Despite this, there is limited literature directly comparing them.

In this Conceptual Introduction, after defining autism and BPD, the issue of misdiagnosis will be described, and the overlap between the conditions will be outlined. The origins and evolution of autism and BPD will then be considered and compared. Latterly, the consequences of being diagnosed with autism or BPD will be discussed and contrasted, considering access to services, misunderstanding amongst professionals, and stigma.

### **Autism & Borderline Personality Disorder**

Autism and BPD are both common diagnoses, with prevalence rates of .39-11.6% (Baird et al., 2006) and 5.9% (Grant et al., 2008), respectively.

## Autism

Autism Spectrum Disorder (ASD), as described in DSM-5 (see text box), is defined by the core traits of persistent and pervasive deficits in social communication and interaction, and restricted and repetitive patterns of behaviour (American Psychiatric Association, 2013). Although named “autism spectrum disorder” in diagnostic manuals, the paper will use the term autism to reflect the idea that this is better considered a condition than a disorder. In recognition that many people prefer identity-first language (Kenny et al., 2015), this group of people will be referred to as autistic individuals. Whilst autism will be discussed generally, our focus on its differentiation from BPD will likely result in considering autistic individuals with normal-range IQ, functional language and more subtle difficulties. This is because it is likely easier to identify autism in those who have more pronounced traits, possibly paired with a lower IQ and lack of spoken language.

### *DSM-5 criteria for Autism Spectrum Disorder*

“A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history (examples, are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or

deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature,

adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.”

### **Borderline Personality Disorder**

Borderline Personality Disorder (see text box) is one of ten personality disorders and is described as “a pervasive pattern of instability in interpersonal relationships, self-image, and emotion” and impulsivity (American Psychiatric Association, 2013). To receive this diagnosis, individuals must meet five out of nine criteria (see below). Its counterpart is termed, “Emotionally Unstable Personality Disorder” with either a “borderline” or “impulsive” subtype in the International Classification of Diseases-11 (ICD-11) (World Health Organisation, 2019).

*DSM-5 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.
2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization 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).
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.”

***The BPD Term***

This study uses the term, BPD, for reasons outlined below, despite the difficulties and

controversy regarding it. Many service-users, and professionals, suggest that the term BPD itself contributes to the stigma of the diagnosis, and that this should be changed (Recovery In the Bin, 2019). Indeed, some suggest that complex post-traumatic stress disorder (CPTSD) (World Health Organisation (WHO), 2018) – included as a new diagnosis in the ICD-11 in 2018 - should subsume the BPD diagnosis, both because it is very similar to BPD, and as it clearly references trauma in its title (Kulkarni, 2017). However, not all agree that such constructs can be merged and argue that CPTSD is nosologically distinct from BPD (Cloitre et al, 2014; Jowett et al., 2020 Ford & Courtois, 2021).

The term BPD, despite its shortcomings, has been used in the current study as alternative terms, such as complex trauma or complex emotional needs, are not agreed upon or used consistently, nor are they concretely defined. Using one of these alternative terms would be especially challenging in the current study whereby the comparison of two entities requires them to be clearly defined. Furthermore, there are documented instances of misdiagnosis between autism and BPD (i.e., Takara, 2015) which has the potential to cause harm; therefore, in order to address an important and under-researched clinical area, in a way which has clinical utility, the term, BPD is used.

### **Autism or BPD? Misdiagnosis, Shared Traits & Differentiation**

#### **Misdiagnosis**

Although conceptually different, autism and BPD share traits (Trubanova et al., 2014). Thus, there is confusion regarding how to make a differential diagnosis (Lai & Baron-Cohen, 2015). Indeed, BPD has been cited as particularly difficult to differentiate from autism by psychiatrists and psychologists who are experienced in assessing women for autism (Cumin, 2020). Lack of clarity regarding differentiation may result in service-users being misdiagnosed (Takara et al., 2015). The clinical observation that many autistic women are first perceived as

having BPD is beginning to be documented in the academic literature (Casanova et al., 2020; Driver & Chester, 2021). Documented examples refer to autistic individuals being misdiagnosed with BPD prior to receiving an autism assessment, which often occurs years later (Takara et al., 2015). In contrast, to the author's knowledge, there are no examples of individuals in the scientific literature with BPD being misdiagnosed as autistic.

The issue of misdiagnosis is important as research indicates that being given a diagnosis of autism, even in late adulthood, can be helpful in making sense of one's experience of the world (Bargiela et al., 2016). Thus, being given an incorrect diagnosis could deprive individuals of this clarity and understanding. Furthermore, the support appropriate to those with BPD and those with autism differs; for example, whilst group interventions are often offered to those with BPD (McLaughlin et al., 2019), this setting may not be the most beneficial for autistic people, who may be more likely to experience groups as overwhelming and find them more difficult to navigate socially (Babb et al., 2021). Inversely, - if individuals with BPD are being misdiagnosed as autistic, they may also not be offered appropriate interventions that are clinically indicated, such as dialectical behavioural therapy or other long-term therapies (National Institute of Health and Care Excellence, 2009).

### **Shared Traits**

Specific similarities between autism and BPD noted in the literature include: difficulties in mentalising; feelings of emptiness; intense emotions; difficulty naming one's own and others' emotions; acting out emotions instead of verbalising them; suicidal and self-injurious behaviours; unstable sense of identity; transient stress-related paranoid ideation; interpersonal difficulties such as intense relationships and incorrect assumption of others' intentions (Dudas et al., 2017; Fitzgerald, 2005; Dell'Osso et al., 2018; Ryden et al., 2008; Gordon, Lewis & Knight, 2020). Executive function and impulse control have also been

suggested as possible areas of overlap between autism and BPD which are worthy of investigating (Vegni et al., 2021). To gain insight into the similarities and differences, four key areas of overlap are highlighted below.

### ***Emotion Regulation***

Both autistic individuals and those with BPD may experience difficulties in regulating their emotions. Emotion regulation refers to the ability to influence what emotions one has, when they are experienced, and how these are expressed (Gross, 1998). Emotion dysregulation is seen as a core feature of BPD (Chapman, 2019) and is referred to in diagnostic criteria with marked reactivity of mood and difficulty controlling anger (American Psychiatric Association (APA), 2013). Emotion regulation difficulties may partly explain engagement in self-harm (Brereton & McGlinchey, 2019) and improving emotion regulation is perceived as a key mechanism of change (Rudge et al., 2017) in dialectical behaviour therapy, which was developed specifically for individuals with BPD (Swales et al., 2000).

There is a growing emphasis on emotion regulation difficulties in autism (Mazefsky, 2015). Autistic individuals have more emotion regulation difficulties than the general population and less adaptive emotion regulation strategies (Cai et al., 2018). Indeed, dialectical behaviour therapy has been trialled with this group (Cornwall et al., 2020; Huntjens et al., 2020). Due to both conditions involving emotion regulation difficulties, it may be unclear whether someone presenting with these challenges, amidst other shared traits, is autistic or has BPD (Trubanova et al., 2014). However, it has been suggested that, in contrast to autism, abrupt shifts in mood are generally linked to interpersonal relationships in those whose difficulties are described by BPD (Cox et al, 2019).

### ***Suicide & Self-harm***

Non-suicidal self-injury and suicide attempts are prevalent in both those with BPD and autistic adults. Non-suicidal self-injury is present in up to 90% of adults with BPD (Klonsky, 2011) and up to 75% of this group attempt suicide (Black et al., 2004) with two to five per cent going on to complete suicide (Tomas et al., 2019). Whilst the self-harm literature in autism has typically focused on self-injurious behaviour in the context of repetitive behaviours (Cassidy et al., 2020), non-suicidal self-injury generally is more prevalent in autistic adults than the general population, particularly in women (Maddox et al., 2016). Autistic adults are also at higher risk of suicide: one systematic review found that suicidal ideation is experienced by 72% of autistic adults and that suicide is attempted by between seven and 47% (Hedley & Uljarević, 2018). Autistic adults are also substantially more likely to die by suicide than neurotypical adults (Hirivikoski et al, 2016), with females being most at risk (Kirby et al., 2019). It has been suggested that self-harm is often connected to interpersonal conflict in BPD but more likely associated with sensory overload in autism (Gordon et al., 2020) although this is based on clinical opinion. However, that autistic individuals self-harm partly to relieve inner tension caused by sensory overload has been endorsed by research (Duerden et al., 2012).

### ***Mentalisation & Theory of Mind***

Both autistic individuals and individuals with BPD may find it challenging to understand others' thoughts and feelings as well as their own. In BPD, this difficulty has been referred to as difficulties in mentalising, i.e., struggling to understand the mental states and processes of oneself and others (Bateman & Fonagy, 2010). It is hypothesised that individuals develop mentalising difficulties due to not having had their mental states, i.e., emotions and cognitions, reflected back to them as children (Fonagy et al., 2010).

Mentalisation-based therapy was developed specifically to promote the development of mentalising in adults with BPD (Bateman & Fonagy, 2010).

In autism research, difficulty in understanding others' mental states has been understood within the theory of mind framework (Baron-Cohen, 2000). Theory of mind is the ability to attribute mental states to others in order to help explain and predict their behaviour (Baron-Cohen et al., 1985). Impaired theory of mind is thought to account for some of the social and communication difficulties experienced by autistic people (Frith, 1994). Despite different conceptualisations, difficulty understanding others' mental state is a defining feature of both BPD and autism.

In fact, these concepts have recently been considered together in the context of overlap between autism and BPD (Vegni et al, 2021); it was suggested that, in contrast to autistic people, individuals with BPD might hyper-mentalize, i.e., excessively interpret others' mental states. It has also been proposed that mentalising is largely stable in autism but fluctuates according to level of emotional distress in BPD (Gordon et al., 2020).

Vegni et al. (2021) also states that there is no consensus on the theoretical and conceptual distinction between mentalising and theory of mind and that there is overlap in how these terms are referred to and researched in the current literature. However, on comparison, mentalising is an affect-driven process (Fonagy et al., 2015), developed in the context of the parent-child dyad (Luyten & Fonagy, 2014) whereas theory of mind is a developmental cognitive capacity (Wellman, 2018). However, theory of mind is also likely affected by states of high emotion and affected by parenting, whilst mentalising may also be influenced by genetics. Therefore, there are overlaps and imprecisions between the theory of mind and mentalising. To the authors' knowledge, there are currently no studies which take an empirical approach to understanding to what extent these constructs are similar and different.

## ***Relationships***

Difficulties regarding relationships are cited in the diagnostic criteria for both BPD and autism (APA, 2013). Relationships are referred to as unstable and intense in BPD, whereas autism is characterised by difficulties in developing, maintaining, and understanding relationships (APA, 2013). Whilst a lack of interest in social relationships has historically characterised autism (Chevallier et al., 2012), it has become clear that many autistic individuals, particularly women, do desire social relationships (Jaswal & Akhtar, 2019; Tierney et al., 2016;) but lack an implicit understanding of social rules to navigate them (Sosnowy et al., 2019). In contrast, interpersonal difficulties in BPD have been linked to emotion dysregulation (Herr et al., 2018), difficulties mentalising (Berenson, 2018) and concerns about being abandoned (Palihawadana et al., 2018).

## ***Feeling Different & Identity***

Other characteristics might present as shared or similar on the surface but are theoretically different constructs. For example, many autistic individuals describe a felt sense of difference in comparison to neurotypical people (Bargiela et al., 2016; Kanfischer et al., 2017). Although there is a wealth of literature on this phenomenon in autism research, this is not reflected in the BPD literature. Identity diffusion, including not having a cohesive sense of self and experiencing feelings of emptiness, is definitive of BPD (Jørgensen & Bøye, 2021). However, this construct is conceptually and theoretically different from feeling different to others. Empirical evidence suggests that a felt sense of difference, and differences in identity and sense of self are in fact quite distinct between the two conditions. Therefore, after reviewing the literature, felt sense of difference was not seen to be a key area of overlap, in contrast to theory of mind and mentalising, relationships, self-harm and suicide rates and emotion regulation.

## **Differentiation**

Despite the acknowledgement of autism and BPD sharing traits, there is a lack of systematic research on how to differentiate the two conditions. Some differences can be inferred from diagnostic criteria; for example, impulsive behaviours demonstrated in BPD (APA, 2013) contrast with a need for routine in autism (APA, 2013). Furthermore, the repetitive behaviours and sensory sensitivities characteristic of autism are not necessarily present in individuals with BPD.

Non-verbal communication has been suggested as another possible differentiator, as deficits in this area are rarely present in BPD but are integral to the autistic profile; other such markers may be narrow interests, repetition, and an insistence on sameness (Lai & Baron-Cohen, 2015). It has also been stated that the process of differentiation should involve consideration of developmental history including social communication, interpersonal relationships, history of trauma or maltreatment, and attachment (Lai & Baron-Cohen, 2015). However, such indicators are not based on empirical research, but clinical observation.

The two publications specific to the differentiation between autism and difficulties associated with BPD are also largely based on clinical opinion (Cox et al., 2019; Gordon et al., 2020). For example, Gordon et al. (2020) proposes guidelines for differentiation of autism spectrum disorder and BPD based on the clinical opinion and experience of a group of clinicians following incidences of misdiagnosis in an NHS trust; this does not represent empirical research. Meanwhile, Cox et al. (2019) provide suggestions on how to differentiate autism from complex trauma, a term sometimes used to refer to BPD. Suggested differentiating factors include childhood abuse or neglect; although this may have been experienced by autistic individuals, it is not seen as causal to difficulties, in contrast to BPD (Gordon et al., 2020). It is also suggested that autistic people may show reduced sharing of

emotions whereas those with BPD may be particularly likely to share emotions and disclose past experiences (Gordon et al., 2019).

However, such differentiators are not based on clinical data and systematic research has not yet investigated how to differentiate autism from the diagnosis of BPD. Therefore, in order to aid differential diagnosis, there is a need for empirical research to investigate how autism and BPD are different. Furthermore, it is challenging to conduct empirical research comparing autism and BPD until the two groups can be reliably differentiated; therefore there is a need for initial research to investigate areas of differentiation in order to lay the foundations for future studies.

### **Diagnoses: Origins & Evolution**

Differentiating autism and BPD, and indeed diagnosing individuals with one or both of these conditions, impacts the way in which a person's difficulties are understood, the interventions offered, and the way in which they are responded to by healthcare professionals. It is therefore important to understand how the respective histories of the diagnoses of autism and BPD impacts how they are differentially perceived, for example, why BPD is generally seen as a more stigmatised condition than autism. Diagnoses are not wholly objective, scientific constructs; they are shaped by the time they were conceived, the nature of the people researching such constructs, and wider social influences. The paper will now outline the trajectories of both diagnoses, both in tracing their genesis, and exploring how the conceptualisations of BPD and autism have evolved over time.

#### **Autism**

##### ***From Rare to Common***

Presentations of what is now recognised as autism were first documented in 1943.

Kanner (1943) published 11 case studies of children he had worked with, stating that they presented in a different way to those with other diagnoses. Distinctive characteristics of these children included impaired ability to communicate, lack of reciprocal interaction, and repetitive behaviours such as rocking. The first widely accepted account of the aetiology of autism was environmental. Specifically, autism was attributed to cold, rejecting, and distant ‘refrigerator mothers’; ‘symptoms’ of autistic children were even likened to the behaviours shown by prisoners in Nazi concentration camps (Bettleheim, 1972). The idea that autism was caused by such environmental factors was subsequently discredited as evidence became available that autism was, in fact, a highly heritable condition (Mandy & Skuse, 2008).

Between the 1960s and 1980s, autism was considered as “rare and obscure” (Langan, 2011). Subsequently, there has been a huge increase in diagnosed prevalence (Newschaffer et al., 2005) and this is likely due to an increase in awareness, increased diagnosis of people with normal-range IQ and lowering of diagnostic thresholds (Prior, 2003). From the 1990s, the conceptualisation of autism, and research focus, began to move away from seeing it as always paired with intellectual disability and language impairments (Happe & Frith, 2020).

### ***Neurodivergence Movement***

Another shift in autism discourse relates to the neurodiversity movement. First coined by Judy Singer in the 1990s, neurodiversity refers to the notion that conditions such as autism should be considered as “naturally occurring cognitive variations with distinctive strengths” (Silberman, 2015, p. 17). Whilst the neurodivergence concept opposes medical models of disorder, it does not deny that autistic individuals may be disabled; however, autistic people are seen as being disabled by an unaccommodating world built for neurotypical individuals, rather than being disabled by the autism itself (den Houting, 2019). Whilst autism is still frequently conceptualised as a disorder, the neurodivergence movement has contributed to the

strengths-based narratives often used when referring to autistic individuals (Baron-Cohen, 2017).

### ***Autism & Gender: Males***

Historically, autism has been associated with boys and men; it is still seen, and theorised to be, an exaggeration of male traits (Baron-Cohen, 2002). For many years, the gender discrepancy was thought to be 4:1 (Fombonne, 2009). However, in a meta-analysis, where only studies of prevalence (in children) with high methodological quality were included, the gender ratio changed to lower than 3.5:1 (Loomes et al. 2017). Even this may be an overstatement; it is known that girls tend to be diagnosed later than boys (Begeer, et al., 2013), including during adulthood, (Rutherford et al., 2016) meaning that gender ratios based on children are likely to be overstated.

A higher prevalence of autism in males is also likely inflated by historical research (Lai & Baron-Cohen, 2015). Early autism research was androcentric (i.e., focused on men) (Happé & Frith, 2020); this set a precedent, with research into autism consistently recruiting more males than females (Shefcyk, 2015). Thus, diagnostic tools based on this research may not be adequate in identifying autism presentations which do not fit the male stereotype, which has prompted recent development of female-specific autism measures (e.g., Brown et al., 2020). It is plausible that a cyclical effect was created, whereby male-based diagnostic criteria caused more boys than girls to be diagnosed which, in turn, created androcentric research samples, which further ‘confirmed’ the male phenotype of autism.

### ***Autism & Gender: Females***

Over the last decade, research into the female experience of autism has increased. Characteristics of autism in women, not encapsulated by current diagnostic measures, include motivation for friendship, more “typical” special interests, greater social attention and

linguistic abilities, and more camouflaging than in autistic males (Lai & Szatmari, 2020). “Camouflaging” refers to “using learned social communicative behaviours” (Lai et al., 2017) and may manifest by telling learnt jokes, using gestures copied from previous interactions and imitating others’ facial expressions. Camouflaging is associated with increased psychological distress (Beck et al., 2020), including depression and anxiety (Bargiela et al., 2016; Hull et al., 2021). The use of this strategy paired with a lack of gender-specific research, likely contributed to autism being largely unseen in girls and women. Only when autism in women began to receive due attention did the relevance, and conundrum of differential diagnosis, of BPD come into view.

## **BPD**

### ***Early Conceptualisation: Roots of Stigma & of BPD as “Untreatable”***

The history of BPD illuminates the roots of its stigmatisation. Prior to the 1970s, when a psychoanalytic way of thinking predominated, those seen as neurotic were deemed treatable via psychoanalysis, whereas those labelled as psychotic were not (Gunderson, 2009). The term “borderline” was given to refer to a group of patients who sat at this border between neurosis and psychosis. Whilst some analysts believed that such patients could be supported through long-term psychoanalytic psychotherapy, others did not. For example, as noted in Gunderson’s (2009) paper, people diagnosed with BPD were referred to as “fickle, egocentric, irresponsible, love-intoxicated” in 1972 (Gunderson, 2009, p. 302). Coupled with this, Gunderson (2009) quotes Houck’s (1972) statement that such individuals were “intractable, unruly” (p. 59) patients who used hospitals to escape from responsibilities’ (Gunderson, 2009, p. 302). When it is considered that the language first used to describe those considered, “borderline” was pejorative, judgemental, and moralising, it is unsurprising that those with BPD remain one of the most stigmatised groups in mental health, including by health professionals themselves (Aviram et al, 2005; Kealy & Ogrodniczuk, 2010; Sheehan et

al., 2016). Furthermore, that being on the border of psychosis equated to possibly being untreatable exposes the foundations of those with BPD being considered as “heartsink” patients (Pérez-López, 2010), for whom nothing can be done.

In 1980, BPD was added to the DSM-III (American Psychiatric Association, 1980). The context in which BPD was being considered was changing. Since the 1970s, psychiatric diagnoses had become more descriptive, with operationalised definitions of disorders that prioritised reliability of diagnostic categories, and a more evidence-based psychiatry began to predominate over a psychoanalytic paradigm (Gunderson, 2009). Research into the construct of BPD increased; it was found that around 70% of those with a BPD diagnosis had been subject to physical and sexual abuse (Herman, 1992). Throughout the 1990s, more attention was paid to childhood development, including attachment (Agrawal et al., 2004), inability of the parent to mirror emotions (Bateman & Fonagy, 2004), and Linehan’s (1993) invalidating environment.

That the designation of the term borderline occurred before widespread acknowledgment of the abuse, neglect and trauma in the lives of many of those who received this diagnosis is pertinent. It is plausible that operationalising how BPD presents in adults, divorced from a context of early childhood experiences – which may explain many of its characteristics - contributed to the stigmatised and unempathetic stance still held by many towards those who receive the diagnosis.

The way in which those with BPD (and other personality disorders) were responded to by services was highlighted by the governmental white paper, “Personality disorder: No longer a diagnosis of exclusion” (NIHME, 2003). In recognition of the fact that many of those with personality disorder (not specifically BPD) were unable to access secondary mental health services, funding was made available for the development of dedicated

personality disorder services. Whilst a welcome step, the paper and funding were needed due to findings that many with personality disorders were treated “at the margins” (p. 5), for example, in A&E, on community caseloads where they were not the priority, or in inappropriate admissions to hospital. The paper also spoke to the perception of BPD as untreatable, which was seen as one of the reasons for services excluding those with BPD.

### ***Gender & Feminist Critiques***

Over recent years, both service-users and professionals have called for BPD to be reconceptualised, as neither the term nor the diagnostic criteria refer to the early experiences which contribute to the difficulties encapsulated by BPD. Although research suggests that there is no gender difference in true prevalence there is a higher diagnosed incidence of BPD in women (Grant et al., 2008). This gender discrepancy is likely due to sampling and diagnostic bias in research and clinical practice, respectively (Skodol & Bender, 2003).

Feminist critiques suggest that the term BPD pathologises survivors’ understandable responses to, often sexual, abuse. This critique argues that the construct of BPD operates in much the same way as “hysteria” did in the 19<sup>th</sup> century; labelling reactions to abuse and powerlessness as, essentially, “madness” (Shaw & Proctor, 2005). BPD has also been criticised for situating women into a double bind; their outbursts of emotion are hyperfemale, whilst unfeminine expressions of anger and impulsivity are seen as deviations from the norm (Berger, 2014).

### **Comparison of Historical Development of Autism and BPD Diagnoses**

Reviewing the histories of both diagnoses shows several differences in the conceptualisation of the conditions: autism research has predominantly focused on children, with less attention on autistic adults; in BPD, adults were the focus, and early childhood

experiences were neglected for many years. These differences are reflected in current service provision, i.e., fewer services for autistic adults and the histories of individuals with BPD not always being considered.

Both diagnoses have been gendered: there is a focus on males and masculine traits in autism and on females and feminine characteristics in BPD. However, in terms of our understanding and the differential diagnosis rates between genders, the gap is narrowing across both conditions. Another difference is that, inspired by the neurodivergence movement, autism is moving towards being conceptualised as a difference rather than a disorder; strengths of autistic people are often cited. In contrast, there is a movement of people wanting to get rid of the BPD diagnosis. This suggests that the autistic identity is sometimes embraced, and an identity characterised by BPD is often rejected. This review of the diagnoses' histories demonstrates that the way in which the conditions were first perceived and studied has differentially impacted their reception today.

### **Consequences of Diagnosis: Access to Services, Misunderstanding & Stigma**

We will now consider how the diagnoses are perceived by the recipients of them, as well as by healthcare professionals. This consideration is important to a) understand why individuals may seek one diagnosis over the other, and b) understand the impact that these diagnoses have on service-users. Indeed, understanding the different impact of the diagnoses may also help clinicians to consider whether a formal diagnosis is helpful or not. It will be argued that both groups experience difficulties in accessing services and that both conditions are often misunderstood by professionals. However, individuals with BPD seem to face more stigma whilst autism is perceived more favourably.

## **Consequences of Diagnosis**

The consequences of being given a formal or suspected diagnosis for an individual differ; in contrast to BPD, being diagnosed as autistic in adulthood has been described by some people as liberating and sense-making (Bargiela, et al., 2016). Individuals who receive late diagnoses of autism often report that they have felt dissimilar to others for a long time and are relieved at a long-awaited explanation; that they are not “weird”, but neurodivergent (Punshon et al., 2009, p. 277). An autism diagnosis may enable people to connect with others who were diagnosed in adulthood and to find comfort in shared experiences (Leedham et al., 2020). In this way, receiving a diagnosis of autism may give people a sense of identity.

If receiving an autism diagnosis yields clarity, and resolves confusion, being diagnosed with BPD is commonly reported to do the opposite. The meaning of BPD is frequently not explained to patients (Stalker et al., 2005), which understandably often results in confusion for service-users (Horn et al., 2007), including that “borderline” means that they ‘sort of’ have a personality disorder. Others report feeling that there is something globally wrong with who they are as a person (Stalker et al., 2005).

## ***Delivery of Diagnosis***

The way in which autism and BPD are diagnosed also commonly differs. Autism diagnoses are typically delivered after a thorough and standardised assessment process. Although it does not always happen, people are often given space and time to understand what autism means, and are sometimes offered post-diagnostic support (Crane et al., 2018). In contrast, individuals with BPD may be given this diagnosis without being informed (Sisti et al., 2016). Some individuals report finding out about a diagnosis in a hospital discharge letter or from professionals using euphemistic terms such as “cluster B symptoms” and “borderline traits” (Sulzer, 2016). Realising that a diagnosis has been withheld is likely to reinforce the negative connotations associated with BPD and patients who discover their

diagnosis has been withheld are more likely to leave treatment (Sulzer, 2016). When individuals *are* explicitly informed about their diagnosis, BPD may be spoken about as untreatable (Morris, 2014).

Such poor practice is particularly concerning because the way in which a diagnosis is communicated influences how people feel about having BPD (Lester et al., 2020). For example, being diagnosed during a course of therapy and simply being given information about the diagnosis is likely to have advantages such as instilling hope, and increasing understanding of oneself (Morris, 2014). Indeed, when individuals are diagnosed with BPD following a thorough assessment, the diagnosis may provide containment, validation, and recognition (Bilderbeck et al., 2014). Feeling supported following diagnosis is also important yet seems to be the exception rather than the norm (Bilderbeck et al., 2014). This contrasting picture suggests that the consequences of being assigned “autism” or “BPD”, may differ, but also raises that it may be how the diagnoses are communicated, rather than the designation of the diagnosis itself, which matters most.

### **Access to Services**

Whilst an adult autism diagnosis may provide clarity and understanding, autistic adults experience many barriers in accessing support. Such barriers exist at three levels: signs of autism being unrecognized, particularly in women (Fusar-Poli et al., 2020); long waiting lists for assessment (NHS digital, 2021), and lack of support for co-occurring mental health difficulties following a diagnosis of autism (Crane et al., 2018). Even after signs of autism are recognized, and an individual is referred for an assessment, there are still long waits: between July and September 2021, the average number of days between referral and diagnosis was 221 for 18-24-year-olds, and rose steadily with age, to 472 days in over 65s (NHS Digital, 2021). This long wait list for autism assessments was representative of previous years, and is replicated across the lifespan (Dowden, 2012; NHS Digital, 2021).

As autism is neither a learning disability nor a mental health problem, autistic individuals (without co-occurring learning disabilities) may fall through the gaps in services (Barber, 2017). Some autistic individuals report that services have not accepted their referral due to the co-occurring autism and mental health difficulties being perceived as too “complex” by services (Camm-Crosbie et al., 2019). Others experience being “bounced between” systems and also experiencing a sudden “disappearance” (p. 486) in support after turning 18 (Crane et al., 2019).

Whilst there has been an increase in UK personality disorder services since the turn of the millennium (Dale et al., 2018), the BPD diagnosis can also act as a gatekeeper, i.e., obstructs access to services. Historically, many services have excluded individuals with a BPD diagnosis, citing reasons such as individuals being untreatable or not suited for their specific provision. The governmental white paper, “Personality Disorder: No longer a diagnosis of exclusion” (NIMHE, 2003) exposed that many people whose primary diagnosis was a personality disorder were unable to access secondary mental health care, with specialist services being the exception in the context of a postcode lottery. Clinicians also reported reluctance in working with this group, citing lack of training, resources, or hope that they could help (NIMHE, 2003).

Eighteen years on, people with a personality disorder diagnosis are perhaps still treated “at the margins”. For example, UK-based GPs describe often seeing patients with personality disorders, and not only lacking knowledge about the condition, but not knowing which services to refer to or what treatment in secondary care would look like (French et al., 2019). GPs also reported such patients being deemed too risky for primary care (Improving Access to Psychological Therapies (IAPT)) but not risky enough for secondary services, and thus having to revise up or down a patients’ risk status in order to secure them access to a service; “you know if you mention personality disorder there will be nowhere at all for them

to go” (French et al. 2019, p. 4). This experience is echoed by Faith (2020) who provides a first-person account of her rejection from services for being “too complex” (p. 157) for IAPT but not “high-risk” enough for secondary care; such exclusions resulted in deteriorating mental health and frequent A&E admissions followed. As demonstrated, both autistic individuals and those with BPD may be excluded from services.

### **Misunderstood by Services**

Both groups are impacted by lack of understanding amongst professionals. Regarding autism, lack of understanding may manifest in autism not being identified or interventions and care generally not being adapted even when autism is recognised (Camm-Crosbie et al., 2019). Lack of understanding in BPD may manifest as healthcare staff lacking knowledge about the reasons behind individuals’ difficulties. In a sense, autism is unseen and BPD is overly seen, i.e., in BPD all behaviours are interpreted as a symptom of the diagnosis and sometimes without considering the underlying understandable reasons.

Autistic individuals, especially women, may suffer due to health professionals’ ignorance regarding how an autistic person might present (Camm-Crosbie et al., 2019). To demonstrate, healthcare professionals may wrongly dismiss patients’ suggestions that they could be autistic, for example, because they have good eye contact or are in successful relationships (Tint & Weiss, 2017). Services’ lack of knowledge often means that autism is not considered when it needs to be, for example, in individuals with diagnosed anorexia (Adamson et al., 2020).

For individuals with BPD, ignorance may manifest when staff do not understand the foundations of “difficult” behaviours. This can lead to prejudice towards this group. For example, self-harm could occur as someone in distress struggles to regulate their emotions (Brereton & McGlinchey, 2018), as their emotional states were seldom mirrored back to them

as children (Fonagy, 2000). However, self-harm may be pejoratively coined, “manipulative” or, “attention seeking” by healthcare staff (Veysey, 2014).

In this way, the BPD diagnosis seems to move people, in the eyes of some clinicians, from unwell and distressed, to difficult and to blame for their problems (Morris, 2014). Indeed, some mental health professionals expressed higher levels of social rejection towards those with BPD when compared to service-users with schizophrenia and depression (Markham, 2003). This demonstrates how ignorance of the origins of the behaviours associated with BPD risks perpetuating discrimination in the very places that those with BPD are encouraged to seek help.

### **Stigma & Discrimination: BPD**

Discrimination from healthcare staff towards those with BPD is well-documented. Individuals who have stayed in inpatient wards described staff dismissing their psychotic experiences as not real (Rogers & Dunne, 2011), despite psychotic experiences being well-documented in BPD, particularly under stress (D’Agostino et al., 2019). People with BPD have also been told that they are unworthy of a bed space (Fallon, 2003), and that their behaviour is attention-seeking (Veysey, 2014). Such communications are reiterated by accounts given in other qualitative research: individuals with BPD reported perceiving messages from health professionals that they were manipulative, liars, untreatable, and taking resources away from more deserving clients (McGrath & Dowling, 2012; Veysey, 2014). Indeed, that those diagnosed with BPD are sometimes not treated well in services is endorsed by Krawitz & Batcheler’s (2006) survey where 85% of healthcare professionals admitted that, in regards to individuals with a BPD diagnosis, they were not working in line with best practice.

Autistic individuals do not seem to face equivalent levels of stigma and discrimination by healthcare professionals. However, stigma and discrimination for this group may sit more

in the public response. Indeed, worrying that neurotypical people are prejudiced towards autistic people may be one of the reasons that some individuals use camouflaging, which in turn can have burdensome consequences including anxiety and depression (Hull et al., 2021). Fears of being judged for autistic behaviours may be founded. In one study, participants observing both neurotypical and autistic individuals interacting with others were more likely to form negative first impressions of autistic adults, and to be less inclined to socially engage with them (Sasson et al., 2017). However, a follow-up study showed that first impressions of autistic individuals were more favourable when they were labelled as autistic compared to when no label was provided, particularly when observers had an understanding of autism (Sasson & Morrison, 2019). Although conclusions from single studies cannot be widely generalised, it could be that, unlike BPD, disclosing diagnosis improves social response, rather than increases negative social evaluation.

### ***Attribution of Responsibility***

Another key difference between autism and BPD, which may influence stigma, is the attribution of responsibility. If someone has an autism diagnosis it is generally agreed that they have different needs which require others to adapt, even if this does not translate into practice. In contrast, the message given to those with BPD is often, “you need to take responsibility for changing” (Pickard, 2011). Whilst this message may not be wholly unhelpful in and of itself, it is likely damaging when change is expected to occur without sufficient support, services, and empathy from others. Indeed, clinicians may act on the assumption that patients have emotional and cognitive capacities which, because of their experiences, they do not possess (Bateman & Fonagy, 2004).

The review of the literature suggests that, whilst those with autism are partly let down because they are not given a diagnosis, those with BPD may be let down because they are. For autistic individuals, especially women, not having a diagnosis is often spoken about as

being an injustice, as it deprives people of understanding and knowledge of their condition and potentially support (Zener, 2019). However, the injustice for those with BPD, in some cases, is being *given* this diagnosis. When those with BPD do access services, as the diagnosis is heavily stigmatised, it is possible that care is negatively impacted by the attitudes and behaviours of healthcare staff. In autism, having a diagnosis may be more welcome but does not necessarily lead to appropriate care. Individuals with BPD and autistic individuals share the experience of mental health services being somewhat impenetrable and frequently failing to meet their needs.

### **Conclusion**

Whilst a formal diagnosis of BPD may not always be helpful, knowing how to differentiate autism and BPD has clinical utility. First, understanding which diagnostic criteria most accurately describes someone's difficulties helps to ensure that the appropriate care is offered; interventions for autistic people and those with BPD largely differ. Moreover, a formal diagnosis does not have to be given, but having an understanding of the explanatory diagnostic framework is typically necessary in order to determine which service someone should be signposted or referred to.

Second, although the BPD diagnosis is controversial, some people do find a diagnosis of BPD helpful, particularly if it is explained well and in a non-stigmatising way (Bilderbeck et al, 2014). In fact, it should not necessarily be concluded that the BPD diagnosis should not be used, but that there is a need for the BPD diagnosis to be explained better, and for service-users to be given choice about whether the term is formally used in their health records.

Third, being able to differentiate between BPD and autism will help to prevent autistic individuals, particularly women, from being misdiagnosed. This is especially important as many adults who receive an autism diagnosis describe it, overall, as a positive experience

(Punshon et al., 2009). Indeed, inversely, until clear guidance exists on differentiation, it may not be clear if there are individuals misdiagnosed as autistic who actually have BPD.

Fourth, until clear guidance exists on differentiating autism and BPD, it will likely be difficult to identify autistic individuals with co-occurring BPD. Knowing that someone meets criteria for both conditions is important for planning interventions (Takara et al., 2015).

Furthermore, initial research suggests that those with co-occurring autism and BPD have lower global functioning (Ryden et al., 2008) and are at higher risk of suicide (Dell’Osso et al., 2018; Ryden et al., 2008). Guidance on differentiating autism and BPD is therefore needed as a first step towards identifying and appropriately supporting autistic individuals with BPD.

Although initial studies (Cox et al., 2019; Gordon et al., 2020) have suggested markers of differentiation, there has been almost no systematic research in this area. As a first step, a Delphi study – a design utilised when there is a dearth of research in a topic (Iqbal & Pison-Young, 2009) - could be used to establish expert consensus on how to differentiate autism and BPD.

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**Part Two: Empirical Paper**

**Towards a Better Understanding of how to Clinically Differentiate Autism and  
Borderline Personality Disorder**

## **Abstract**

### **Aims**

Autism and borderline personality disorder (BPD) share traits. This can lead to diagnostic confusion between the two conditions. Almost no systematic research has been conducted which investigates how autism and BPD can be differentiated. The current study aims to establish expert consensus on what helps to differentiate autism from BPD.

### **Method**

A Delphi design was used. A pre-Delphi questionnaire asked participants to give their opinion on how to differentiate autism and BPD. Subsequently, in a two-round Delphi study, the usefulness of these statements was rated on a five-point Likert scale by 51 panellists (18 experts by experience, who had been misdiagnosed or had both diagnoses; 16 research or clinical experts in autism; and 17 research or clinical experts in BPD).

### **Results**

One-hundred-and-sixty-one statements regarding how to differentiate autism from BPD were developed from free text answers given in the pre-Delphi questionnaire. In round one, consensus was reached on sixteen statements which were rated as useful or extremely useful by 80% of panellists in round one. An additional six statements reached consensus in round two. Differentiating statements refer to autistic individuals having more sensory sensitivities and processing difficulties than those with BPD. Statements also indicate that autistic individuals' preference for routine differentiates from the impulsivity which characterises BPD. Delphi consensus also suggested that relationship difficulties for autistic people are driven by not understanding the social rules whereas fears of rejection or emotion dysregulation are associated with relationship difficulties for those with BPD.

## **Conclusions**

Clinicians can use the 22 endorsed statements to inform clinical discussions regarding differentiating autism and BPD. The statements can also be used as hypotheses to be tested by future studies.

## **Introduction**

Borderline Personality Disorder (BPD), otherwise referred to as Emotionally Unstable Personality disorder (World Health Organisation (WHO), 2019)), is defined by patterns of unstable relationships, impulsivity, affect dysregulation, and unstable self-image (American Psychiatric Association, 2013). Diagnostic criteria refer to recurrent suicidal behaviours and self-harm, feelings of emptiness, and attempts to avoid abandonment (WHO, 2019). BPD has a lifetime prevalence of around 6% (Grant et al., 2008) and, although diagnosed more often in women, has equal true prevalence in men and women (Grant et al., 2008). Its development is attributed to an interaction of genetic (Skoglund et al., 2019) and environmental factors, such as adverse early life experiences (Porter et al., 2019), including attachment disruption (Fonagy, 2000) and trauma (Ball & Links, 2009).

Autism spectrum disorder, henceforth referred to as “autism”, is a neurodevelopmental condition, characterised by difficulties in social interaction, social communication, and restricted and repetitive behaviours (APA, 2019). Its features include reduced or increased sensory sensitivity, difficulties in maintaining and understanding relationships, and a preference for sameness and routine (APA, 2019). Autism is highly heritable (Sandin et al., 2017) and symptoms typically present in early childhood.

As the definition of autism has shifted (Happé & Frith, 2020) to focus more on individuals with normal-range IQ and women with subtle difficulties (Green et al., 2019), the clinical problem of differentiating autism and BPD has been brought into view.

## **BPD & Autism**

Few studies have considered BPD and autism together. To my knowledge, their shared characteristics were first documented in the scientific literature by Pelletier in a letter to the Journal of the American Academy of Child and Adolescent Psychiatry in 1998. The

letter noted several shared traits, including difficulties in relationships, intense anger, and identity problems, and that such similarities might mean that many individuals diagnosed with BPD may actually have “a subtle form of Asperger’s disorder” (p. 1128) (a historical subtype of autism with normal-range IQ). Pelletier (1998) also included a case example where two children had been inaccurately diagnosed with BPD before a diagnosis of Asperger’s was given. The letter also hypothesised that the poor response to medication and psychotherapy sometimes seen in individuals with BPD may be because such individuals in fact met criteria for Asperger’s. Fitzgerald (2005) later stated that the conditions were sometimes confused due to their symptomatic overlap, including difficulties in social functioning and chronic feelings of emptiness, particularly in adult psychiatric settings. Yet, research into the relationship between BPD and autism has only started to increase in recent years.

### **Shared Traits**

Studies comparing the two conditions have found evidence for overlapping traits. For example, of 41 consecutively referred females with BPD, 15% were judged to meet criteria for autism, with an additional 42% showing autistic traits (Ryden et al., 2008). Inversely, of 41 autistic individuals, 10.6% were identified as meeting criteria for BPD, as did 14.8% of those with both autism and attention deficit hyperactivity disorder (ADHD) (Anckarsater et al., 2006). Another study found no significant difference between autism and BPD groups on self-report measures assessing systemising ability and autistic traits despite both groups being significantly different to a control group; this suggests diagnostic overlap (Dudas et al., 2017). In addition, Dell’Osso et al. (2018) found that autistic traits were elevated in a group of individuals diagnosed with BPD, and that this was significantly higher than a control group. Such findings demonstrate that, although clearly distinct conditions with different aetiologies, BPD and autism do share traits.

Specific similarities between the two diagnoses have also been documented. The shared traits include: difficulties in interpersonal relationships; superficial friendships; difficulty with separation; identity disturbance; feelings of emptiness; intense anger; impulsivity; suicide attempts and self-injurious behaviour; transient, stress-related paranoid ideation; difficulty verbalising emotions; inaccurate interpretation of others' emotions; incorrect assumption of others' intentions; and, difficulties in mentalising (Dell'Osso et al., 2018; Fitzgerald, 2005; Gordon et al., 2020; Ryden et al., 2008; Vegni et al., 2021). Indeed, parallels have been drawn between Theory of Mind (Baron-Cohen, 2000) and mentalisation (Fonagy & Luyten, 2009) in explaining the challenges in understanding another's mental state in autism and BPD respectively. Interventions designed for BPD, such as Mentalisation Based Therapy, and Dialectical Based Therapy have also been proposed for implementation with autistic individuals (Huntjens et al., 2021; Thevenet et al., 2017); this reinforces the idea that similarities exist between the conditions.

### **What do Shared Traits Suggest about the Relationship Between BPD and Autism?**

It is unclear to what extent such findings support 1) the existence of symptomatic overlap between conditions, 2) superficial similarities, i.e., apparently similar presentations with different underlying explanations, or 3) higher than chance rates of co-occurrence. Indeed, it could be that being autistic renders children more vulnerable to risk factors for going on to develop BPD (Anckarsater et al. 2006), such as bullying (Campbell et al., 2017), physical abuse (McDonnell et al., 2019) and childhood sexual abuse (Ohlsson Gotby et al., 2018). It is important to be able to identify individuals with co-occurring autism and BPD as initial research suggests that this group has lower global functioning (Ryden et al., 2008) and is at higher risk of suicide (Dell'Osso et al., 2018; Ryden et al., 2008). Understanding how to differentially diagnose autism and BPD may also elucidate how an individual with both

diagnoses may present. A better understanding of the differentiation between the two conditions is needed before rates of their co-occurrence can be established.

### **Misdiagnosis**

The need for clinical guidance differentiating autism and BPD is demonstrated by evidence of misdiagnosis within healthcare services (Takara et al., 2015; Au-Yeung et al., 2019). For example, one study includes an account of an autistic individual whose self-harm, and apparent sudden expression of emotion, was interpreted as BPD; the ‘sudden’ expression of emotion was due to hiding feelings in social situations until it became unbearable, paired with others not noticing this build up due to lack of facial expressions indicating distress (Au-Yeung et al., 2019). In a case series detailing autistic adults with normal-range IQ being misdiagnosed, one individual, whose autism was unrecognised at the time, was diagnosed with BPD following an incident of self-harm. To the author’s knowledge, there are no instances documented in the scientific literature of someone being misdiagnosed as autistic, before being diagnosed with BPD. It is plausible that BPD is diagnosed before autism more often because adult mental health services are sometimes poor at identifying autism, especially in women (Lai & Baron-Cohen, 2015).

### **Why Misdiagnosis Matters**

Even if a formal diagnosis is not desirable in and of itself, being able to differentiate autism and BPD is important as the suspected diagnosis determines how an individual’s difficulties are understood and the nature of care offered. Interpreting individuals’ difficulties using the incorrect explanatory framework may lead to inappropriate care; for example, groupwork is typically offered for those with BPD, which may be experienced as overwhelming and difficult to navigate for autistic individuals (Babb et al., 2021). Furthermore, an incorrect autism diagnosis may preclude an individual who has BPD from exploring how their early life experiences relate to their current difficulties. Giving someone

an incorrect diagnosis will also result in a poor understanding of their difficulties by themselves, their support network, and health services (Cox et al., 2019).

## **Differentiation**

At the time the current study was designed, there were no publications specifically focusing on differentiating autism and BPD, however some recognised the need for more information on the topic. In 2005, Fitzgerald stated that taking a detailed childhood history was central to differentiation as, in contrast to BPD, features of autism would be noticeable from early childhood. Lai & Baron-Cohen (2015) endorsed taking a thorough developmental history, including regarding social communication, attachment, history of trauma or maltreatment, and interpersonal relationships. Difficulties with non-verbal communication, in addition to narrow interests, repetition and insistence on sameness were suggested as indicators of autism rather than BPD (Lai & Baron-Cohen, 2015). It has also been suggested that, for those with BPD, individuals who were also autistic may be less likely to misuse substances than those who had BPD and were not autistic (Ryden et al., 2008). However, these suggested areas of differentiation are largely based on clinical opinion and have not been investigated with systematic research. The aforementioned factors therefore represent a low standard of evidence and are limited in the extent to which they should inform care.

In the last two years, two publications have focused specifically on differentiating autism and BPD. In 2019, Cox et al. adapted the Coventry Grid (Moran et al. 2010), guidance on differentiating autism from attachment problems in children, for adults. The adapted Coventry Grid for Adults (Cox et al. 2019) lists identifying traits of autism and complex trauma (a term sometimes applied to BPD), under various categories of presentation, which are relevant to both conditions. For example, under the category, ‘unusual mood patterns’, sudden mood change in autism is attributed to changes in the environment, such as miscommunication or sensory information; in BPD, sudden mood change is listed in

reference to changes in internal states (such as flashbacks) or perceived emotional demands (Cox et al. 2019).

Whilst a welcome step, the authors note that participants' expertise was skewed towards autism. Furthermore, the adapted grid was reviewed by only seven clinicians; this is indicative of the uncertainty surrounding the differentiation process, as 100 clinicians were asked but many declined because of insufficient confidence in the area. Finally, the authors also note that descriptions of autism do not include nuanced autistic traits more commonly seen in women, which is particularly relevant when differentiating from BPD due to the higher BPD diagnosis rate in women (Sansone, & Sansone, 2011). For example, a trait listed as descriptive of autistic individuals: "prefer(s) to pursue interests alone, or only alongside others, in a parallel fashion" (p.82), does not take into account that many autistic people, particularly women, do desire friendships and social interaction (Tierney et al., 2016; Jaswal & Akhtar, 2019).

More recently, Gordon et al. (2020) developed guidelines specifically for differentiating autism and BPD. The guidelines were developed following incidences of misdiagnosis and subsequent ineffective support for individuals with autism and BPD in an NHS trust. The guidelines list shared traits as categories, next to examples of differences in presentations and questions to facilitate discussion. For example, under "visual cues", it is stated that people with BPD are generally able to perceive subtle signs of emotion, whereas autistic individuals may only be able to identify emotions after stronger visual demonstrations of an emotional state; adjoining questions include, "does the person recognise subtle signs of emotion?" (p. 25).

Although these guidelines are likely a helpful reference point for clinicians, they are based on clinical opinion and the statements were not developed in a systematic, transparent

and replicable way. Thus, almost all of what is known about differentiating autism and BPD is based on the opinions of experts, compiled in a non-systematic way.

The current study further develops this area via a Delphi study, whereby expert panels will be asked what factors they believe help to differentiate autism and BPD from each other. Experts' views will be sought in a systematic way. Delphi studies have advantages including: anonymity, whereby not knowing who else is taking part prevents group dynamics from biasing group opinion; and diversity of experience, i.e., involving different types of experts (Jorm, 2015). By collating individuals' responses, the Delphi method also offers a way of reaching group consensus.

The study is unique in that it seeks the opinions of a relatively large group of experts, with equal numbers of autism and BPD experts. It is also the first study to include the opinions of experts by experience, (i.e., those who have received both diagnoses, or been misdiagnosed with either BPD or autism before being diagnosed with the other condition); this is important as both groups have felt misunderstood by professionals (for example, Tint & Weiss, 2017; Veysey, 2014), and it is experts by experience who are most likely to be adversely affected by an inaccurate diagnosis.

### **Aims**

The current study aims to establish expert consensus on what factors help to differentiate autism from BPD.

### **Method**

The study is comprised of three phases: a pre-Delphi questionnaire and a two-round Delphi study.

## **The Delphi Method**

A Delphi study aims to establish expert consensus on an issue where there is little information in the academic literature (Jorm, 2015). Consensus is achieved through an iterative process (two or more rounds) of seeking feedback from a panel (or panels) of experts. Typically, panellists use a Likert scale to rate individual items (i.e., statements) based on how useful they believe them to be. If items are rated as useful or extremely useful by 80% of panellists, consensus is deemed to have been reached, and such items are included in the final list of endorsed items. Items rated as useful or extremely useful by 70-79% of panellists are re-rated in a subsequent round; each panellist's individual score is presented next to the group score, so that panellists can choose whether or not to change their answer in light of the group response. Although there is no conclusive guidance on thresholds for consensus (Diamond et al., 2014), a cut-off point of 80% is widely used (e.g., Kelly et al., 2008; Langlands et al., 2008; Petros et al., 2019; Seidler et al., 2019) and is similar to the median threshold of 75% identified in a systematic review of consensus thresholds used in Delphi studies (Diamond et al., 2014).

The Delphi technique is rooted in the idea that groups, under specified conditions, make more accurate decisions than an individual (Surowiecki, 2004). These conditions include: making decisions independently; the 'decision-makers' having diversity of experience between them (as diverse groups will make better decisions than homogenous ones); expertise being held by individuals working in a decentralized way; and aggregation i.e. responses are collected and collated (Jorm, 2015). The Delphi technique contains these characteristics.

In addition, Delphi studies afford anonymity. Namely, panellists do not know who is on the panel; this safeguards against those assuming that well-known researchers or clinicians must be right, and therefore changing their feedback accordingly. The anonymised online

process also prevents group dynamics from affecting the results i.e., prevents more vocal or confident panellists from biasing group opinion.

### **Ethical approval**

Ethical approval was received from University College London (Ref 17119/001).

### **Participants**

#### *Type of Experts*

Three groups of experts were recruited: (1) clinical and research experts in autism; (2) clinical and research experts in BPD; and (3) experts by experience.

#### *Inclusion Criteria*

Clinical and research experts in autism needed to have either worked in autism for three years (for at least three days a week) and have some clinical or research experience of BPD or have three or more publications in autism with some research or clinical experience of BPD. Clinical and research experts in BPD needed to have either worked with those diagnosed (or diagnosable) with BPD for three years (for at least three days a week) and have some clinical experience of working with autistic individuals or have three or more publications on BPD with some research or clinical experience of autism. Although it would have been ideal, in terms of nature of expertise, to recruit experts who had three years' or more experience working with autistic individuals *and* those diagnosed with BPD, this subgroup is likely very small and would have significantly impacted recruitment. Therefore, panellists were required to only be an "expert" in one area, but with some experience of, or exposure to, the other area. Clinical or research experts who were conducting, or had published, research looking at BPD and autism together were also eligible to participate.

Experts by experience were eligible to take part if they self-reported: having been misdiagnosed with either autism or BPD before being diagnosed with the other; or received

formal diagnoses of, or have been told that they are likely to have, both autism and BPD. Those who have received a diagnosis of either autism or BPD but believe they should have the other were also eligible for participation. The inclusion criteria were broadened out to this group as: a) many women with autistic traits may not meet threshold for ASD as diagnostic criteria have been developed and validated based on androcentric samples; b) individuals may not have a formal diagnosis, in part, due to long waiting lists for autism assessments; c) some individuals with personality disorder traits are not given a formal diagnosis due to perceived stigma from either the professional or patient, or because they do not need a diagnosis in order to access services; d) individuals' reasons for disagreeing with their diagnosis are interesting in and of themselves, and may highlight areas not considered by clinical or research experts.

All panellists reported proficiency in English, although English did not have to be their native language. As the Delphi was conducted online, panellists could be recruited from any country.

### ***Recruitment Strategy***

Information about the study and contact details of the research team were circulated on social media. Research and clinical experts known to the research team were also sent information about the study and were invited to take part. Invitees were asked to inform other eligible candidates about the study, or to provide the research team with their contact details; this led to recruitment via a snowballing strategy. It is possible that recruiting in this way meant that the panels of experts are not representative of all experts in this field and that it is not known how many experts were contacted but did not participate. However, a snowballing strategy was nonetheless used in order to maximise the number of experts on each panel.

The authors of a recent literature review (Gordon et al., 2020) on the similarities and differences between BPD and autism, and the authors of the six studies reviewed, were

invited to participate via email, and asked to invite their co-authors. The authors of the Coventry Grid for adults (Cox et al., 2019) were also invited to participate. Recruitment through these three different channels was decided upon in order to maximise the number of participants and therefore reduce the impact of attrition throughout the different rounds, which typically occurs in Delphi studies (Hsu & Sandford, 2007).

For the experts by experience, individuals known to the research team were contacted and asked to share details. The study details were also shared online via social media. The snowballing process occurred organically with experts by experience sharing information on online groups or with peers.

Individuals who expressed interest in participating confirmed that they met inclusion criteria and returned signed consent forms via email.

## **Procedure**

The pre-Delphi questionnaire and the two Delphi rounds were hosted on Qualtrics, a web-based survey tool (<https://www.qualtrics.com>). Experts by experience were paid £5 for each stage completed.

Delphi studies differ in the way in which items for the Delphi are generated (Jorm, 2015). Items may be generated by: synthesising relevant literature; extracting items from existing guidance; conducting focus groups; or via a pre-Delphi open-text questionnaire (Jorm, 2015). As there is limited literature on the overlap between BPD and autism, and to ensure that the views of experts by experience were represented, this study utilised a pre-Delphi questionnaire. Clinical and research experts, in addition to experts by experience, were recruited to participate.

## **Pre-Delphi Questionnaire**

A pre-Delphi questionnaire was chosen to develop the items for the first round of the Delphi. This ensured anonymity of answers to both the researcher and other participants, with the effect that power dynamics which may have been present in an in-person discussion were minimised. For example, an anonymous questionnaire may have allowed experts by experience to express their opinions without having to navigate or be concerned about the answers from research and clinical experts. A questionnaire was also more feasible than a focus group or discussion given the relatively large number of participants, and the fact that this research took place during the Covid-19 pandemic.

The aim of the pre-Delphi questionnaire was to gather participants' opinions, based on their experience, on the similarities and differences between autism and BPD in adults.

Participants were first asked to state, based on their experiences, how autism and BPD were similar and then how they were different. The question was asked in the following categories: presenting difficulties; core features; co-occurring difficulties; early life experiences; associated risks; relationships with others; ability to mentalise and empathise; impact on everyday life; other factors (see appendix D for full pre-Delphi questionnaire). These prompts were used, rather than asking one open-ended question, as it was hypothesised that, due to the lack of research and guidance on this topic, experts might struggle to generate differentiating factors. Indeed, in a study researching the differences between autism and complex trauma (a term sometimes applied to BPD), only seven experts out of 100 participated, with many citing insufficient confidence in the area as a reason not to participate (Cox et al., 2019). The prompts were chosen as they represent areas commonly asked about in clinical assessments (e.g., impact on everyday life) and areas of overlap noted in the literature (e.g., ability to mentalise and empathise). The prompts were deemed to be broad enough not to heavily bias answers but helpful enough to scaffold answers.

### ***Questionnaire Distribution***

In January 2021, links to the pre-Delphi questionnaire were sent to all individuals who consented to participate in the study. Participants were informed that they could log out and log back in again, without losing their answers, to complete the study.

Reasonable adjustments were made, for example, the questionnaire was reformatted to allow for dictation, and phone call support was offered to anyone who asked for clarification on the meaning of the questions asked. The questionnaire was posted to those who struggled with computer use or had limited access to the internet.

### ***Preparation of Data for Round One***

Data were excluded for the following reasons: unrelated, or peripheral to, the question of how BPD and autism are similar and different; ambiguous or hard to understand; could be considered offensive. Data generated by participants in the pre-Delphi questionnaire were then sorted according to content topic (e.g., co-occurring conditions). After this, the data were sorted according to subtopics (e.g., statements about co-occurring anxiety were grouped together, and statements regarding higher prevalence of learning difficulties in autism compared to BPD were grouped together etc.). Statements were written so that all of the points made under each subgroup were included in the final list of statements. It was ensured that each statement only made one point (so that panellists could easily rate usefulness). Duplicated statements were only included once. Based on these free text answers, 309 statements were initially developed.

In order to reduce participant burden and therefore prevent attrition, which is a huge threat to Delphi studies, as participants are required to participate in multiple rounds (Hsu & Sandford, 2007), it was agreed that round one needed to comprise fewer items. Statements were excluded for the following reasons: referred to similarities between the conditions rather

than differences (n = 68); statements which, upon re-reading, were peripheral to the question (n = 6); statements which were more conceptual in nature, i.e., referred to the differing causes of difficulties in autism and BPD, which were deemed by the research group not to be central to differentiation (n = 5)

Two-hundred-and-thirty items remained. In order to ensure quality of the items, to omit the least useful items, and to further reduce participant burden and therefore attrition, both supervisors – one an expert in BPD and one an expert in autism, reviewed all the items and marked those they deemed as definitely not useful. Items which both supervisors rated as definitely not useful were omitted. One-hundred-and-sixty-one statements remained and were presented to panellists in the first round of the Delphi study.

### **Delphi Round One**

The online link to Round One of the Delphi was sent to everyone who consented to participate, even if they had not started or completed the pre-Delphi questionnaire. Online links were also sent to individuals who had asked to participate in the study after the pre-Delphi questionnaire had closed. The link to the questionnaire – with participant information sheets and consent forms embedded into it, was also sent to individuals who were known to meet the inclusion criteria but had not participated in the pre-Delphi questionnaire. Panellists were sent a link to Round One of the Delphi study, containing a list of the items developed in the pre-Delphi questionnaire. Panellists were asked to rate each item, in terms of how useful they believed it to be in differentiating autism and BPD, on a Likert scale (definitely not useful; probably not useful; don't know/it depends; useful; extremely useful).

### **Round One**

#### ***Defining Consensus***

Items endorsed (rated as 'useful' or 'extremely useful') by 80% or more of panellists,

across the three groups, were included in the final item list. Items endorsed by 70% - 80% of panellists were included in round two for re-rating. Items endorsed by 80% by only one or two panels (i.e., groups), but not by the panels' aggregate score, were also included for re-rating in round two. This was considered especially important for ensuring that the views of specific groups, in particular the experts by experience, were considered. All other items were excluded. This criteria for re-iterating items are in line with other studies (e.g., Kelly et al., 2008),

## **Round Two**

In Round Two, only panellists who participated in round one were sent the link to the second round of the Delphi. The items to be re-rated were presented together with the overall endorsement rate, and the endorsement rate by group (i.e., BPD expert; autism expert; expert by experience). Qualtrics was also programmed to show individuals their ratings from the first round, next to each item. This allowed panellists to consider adjusting their endorsement rating of an item in light of the group response, which is in line with good practice in Delphi studies (Khodyakov & Chen, 2020).

## **Data Analysis**

Results from rounds one and two were analysed using Excel. After each round, spreadsheets were used to calculate the descriptive frequencies of the items and, whether or not consensus had been met.

## **Odds Ratios**

Odds Ratios with 95% confidence intervals were calculated (BPD experts vs autism experts; autism experts vs experts by experience; experts by experience vs BPD experts) using the frequencies data from the first round of the Delphi, to see if there were any significant differences in endorsement rates between panels (i.e., groups). Differences

between panels were investigated because a) experts by experience were included, who may have different opinions to the research and clinical experts, and b) this Delphi study is unusual in that the clinical and research experts only have expertise in part of the research topic, i.e., either autism or BPD, and thus the clinical opinion of the autism experts and BPD experts may differ. In order to compute odds ratios, scores were dichotomised by categorising ratings of ‘useful’ and ‘extremely useful’ as endorsing an item and considering ratings of, ‘don’t know/it depends’, ‘probably not useful’ and ‘definitely not useful’ as not endorsing an item. Odds ratios were calculated for the sixteen items that met consensus in the first round, and the 40 items that were re-rated in the second round.

### **Sensitivity Analysis**

Throughout the study, the threshold for consensus was set at 80%. Although this cut-off is widely used, it is arbitrary, and it is possible that it distorted the results. At the end of Round Two, a sensitivity analysis was performed; the threshold for consensus was lowered to 70% to see if any categories of statements subsequently met consensus which were not represented in the initial analysis. The sensitivity analysis shows which items would have met consensus for being useful or extremely useful when the threshold is lowered by 10%.

### **Participants**

Sixty-five people consented to participate in the study and were sent a link to the pre-Delphi questionnaire. Of this group, 52 participated by filling out the initial, pre-Delphi questionnaire. In the first round of the Delphi, the panel was comprised of 51 participants. In the second round, the panel was comprised of 43 participants.

## Participation

Table 1 shows the number of experts, by group, in each round.

**Table 1**

*Participation in Pre-Delphi Questionnaire and Two-round Delphi*

	Sent pre-Delphi questionnaire	Completed pre-Delphi questionnaire	Sent Round One	Completed Round One	Completed Round Two
Experts by experience	25 (36.2%)	22 (42.3%)	22 (32.8%)	18 (35.3%)	17 (39.5%)
Clinical & research experts in autism	23 (33.3%)	16 (26.2%)	24 (35.8%)	16 (31.4%)	13 (30.2%)
Clinical and research experts in BPD	21 (30.4%)	14 (26.2%)	21 (31.3%)	17 (33.3%)	13 (30.2%)
Total	65	52	67	51	43

## Participant Characteristics

Participant characteristics in the pre-Delphi questionnaire are displayed in Table 2. Participant characteristics for Round One and Round Two in the Delphi study are displayed in Table 3. In all three stages of the study, the nature of the expertise (e.g., misdiagnosed or received both diagnoses), was based on self-report. Throughout the three stages the majority of experts by experience were women.

**Table 2**  
*Pre-Delphi Questionnaire: Participant Characteristics*

<b>Panel</b>	<b>Variable</b>	<b>Variable category</b>	<b>Pre-Delphi questionnaire</b>
<b>Experts by experience</b>	N		22
	Gender	Female	19 (86.4%)
		Male	2 (9.1%)
		Non-binary	1 (4.5%)
	Ethnicity	White British	15 (68.2%)
		Black British	1 (4.5%)
		Mixed Other	1 (4.5%)
		British Asian	1 (4.5%)
		White American	1 (4.5%)
		Black American	1 (4.5%)
		White Other	1 (4.5%)
		Prefer not to say	1 (4.5%)
	Country of residence	United Kingdom	20 (90.9%)
		Netherlands	1 (4.5%)
		United States	1 (4.5%)
Type of expert by experience	Both diagnoses	8 (36.4%)	
	Misdiagnosed with BPD and then given autism diagnosis	6 (27.3%)	
	Diagnosed as autistic and then misdiagnosed with BPD	2 (9.1%)	
	Diagnosis of BPD but believe I am autistic	0	
	Diagnosed as having BPD. PD service / myself querying	0	

		autism but don't believe I am autistic	
		Diagnosis of BPD AND believe I am autistic	4 (18.2%)
		Diagnosis of autism and believe I / other services believe I have BPD	1 (4.5%)
		Prefer not to say	1 (4.5%)
	Age at diagnosis	BPD diagnosis (n = 18)	
		Mean	29.17 (SD=10.22)
		Range	16-55
		Median	28
		Autism diagnosis (n = 16)	
		Mean	30.44 (SD=12.59)
		Range	7-53
		Median	29
<b>Clinical and research experts in BPD</b>	N		14
	Gender	Female	9 (64.3%)
		Male	4 (28.6%)
		Prefer not to say	1 (7.1%)
	Ethnicity	White British	11 (78.6%)
		White Other	1 (7.1%)
		Prefer not to say	2 (14.3%)

<b>Clinical and research experts in autism</b>	Country of residence	United Kingdom	13 (92.9%)
		Canada	1 (7.1%)
	Years worked with people with BPD	Mean	17 (SD=8.51)
		Median	14
		Range	7 – 35
	Number of publications in BPD	Mean	2.83 (SD=6.12)
		Median	0
		Range	0 – 19
	N		16
	Gender	Female	9 (56.3%)
Male		7 (43.8%)	
Ethnicity	White British	7 (48.8%)	
	White Dutch	3 (18.8%)	
	Indian	1 (6.3%)	
	East Asian	2 (12.5%)	
	White Other	1 (6.3%)	
	Prefer not to say	2 (12.5%)	
Country of residence	United Kingdom	9 (56.3%)	
	Netherlands	3 (18.8)	
	Canada	4 (25.0%)	
Years worked with autistic individuals	Mean	15.64 (SD = 10.54)	
	Median	11	
	Range	4-40	
Number of publications in autism	Mean	9.17 (SD = 11.65)	
	Median	4.5	
	Range	0-35	

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**Table 3**  
*Delphi Rounds One and Two: Participant Characteristics*

Panel	Variable	Variable category	Round 1	Round 2
<b>Experts by experience</b>	N		18 (35.3%)	17 (39.5%)
	Gender	Female	17 (94.4%)	17 (100%)
		Non-binary	1 (5.6%)	0
	Ethnicity	White British	9 (50%)	9 (52.9%)
		Black British	1 (5.6%)	1 (5.9%)
		White American	1 (5.6%)	1 (5.9%)
		White Dutch	1 (5.6%)	1 (5.9%)
		Prefer not to say	2 (11.1%)	1 (5.9%)
		Missing	4 (22.2%)	4 (23.5%)
	Age	Mean	38.6 (SD=12.99)	39.63 (SD=12.66)
Range		19-66	19-66	
Country of residence	UK	17 (94.4%)	16 (94.1%)	
	Netherlands	1 (5.6%)	1 (5.9%)	
Type of expert by experience	Both diagnoses	9 (49.7%)	8 (52.67%)	
	Misdiagnosed with BPD and then given autism diagnosis	4 (22.2%)	4 (23.5%)	
	Diagnosed as autistic and then misdiagnosed with BPD	1 (5.7%)	0	
	Diagnosis of BPD but believe I am autistic	3 (16.7%)	3 (17.6%)	
	Diagnosed as having BPD. PD service / myself querying autism but don't	1 (5.7%)	1 (5.57%)	

		believe I am autistic		
<b>Clinical and research experts in BPD</b>	Age of diagnosis	BPD diagnosis	27.1	27.1
		Mean	(SD = 9.11)	(SD = 9.08)
		Median	26.0	26.5
		Range	15-50	15-50
	Autism diagnosis	Mean	34.2	36.33
			(SD = 14.4)	(SD = 12.72)
		Median	38.0	39.50
		Range	8-53	13-53
		N	17 (33.3%)	13 (30.2%)
Gender	Female	9 (52.9%)	9 (69.2%)	
	Male	8 (47.1%)	4 (30.8%)	
Ethnicity	White British	16 (94.1%)	11 (100%)	
	White Other	1 (5.9%)	0	
Age	Mean	49.87	47.42	
		(SD = 11.92)	(SD = 9.58)	
	Range	33-80	33-65	
Country of residence	UK	17 (100%)	13 (100%)	
Profession	Clinical Psychologist	3 (17.6%)	3 (23.1%)	
	Psychiatrist	1 (5.9%)	1 (7.7%)	
	Occupational Therapist	1 (5.9%)	1 (7.7%)	
	Team Manager/Lead	3 (17.6%)	3 (23.1%)	
	Psychotherapist	1 (5.9%)	1 (7.7%)	
	Medical			
	Psychotherapist	1 (5.9%)	1 (7.7%)	

		DBT Therapist	1 (5.9%)	1 (7.7%)
		Psychiatrist	5 (29.4%)	2 (15.4%)
Years worked with people with BPD	Mean		17.07 (SD = 8.27)	15.64 (SD = 6.05)
	Median		17	15
	Range		3-34	7-25
Number of publications in BPD	Mean		4.13 (SD = 6.206)	3.31 (SD = 5.47)
	Median		1.00	1.00
	Range		0-18	0-18
<b>Clinical and research experts in autism</b>	N		16 (31.4%)	13 (30.2%)
	Gender	Female	8 (50%)	7 (53.8%)
		Male	8 (50%)	6 (46.2%)
	Ethnicity	White British	10 (62.5%)	9 (69.2%)
		White American	1 (6.3%)	1 (7.7%)
		White Dutch	1 (6.3%)	1 (7.7%)
		East Asian	1 (6.3%)	1 (7.7%)
		White Irish	1 (6.3%)	1 (7.7%)
		Indian	1 (6.3%)	0
		Prefer not to say	1 (6.3%)	1 (7.7%)
Age	Mean		44.81 (SD = 9.04)	42.69 (SD = 7.23)
	Range		31-66	31-52
Country of residence	UK	13 (81.3%)	10 (76.9%)	
	Netherlands	1 (6.3%)	1 (7.7%)	
	US	1 (6.3%)	1 (7.7%)	
	Canada	1 (6.3%)	1 (7.7%)	
Profession	Clinical Psychologist	5 (31.3%)	5 (38.5%)	
	Psychiatrist	2 (12.5%)	1 (7.7%)	

	Occupational Therapist	1 (6.3%)	1 (7.7%)
	Academic Clinical Psychologist	1 (6.3%)	1 (7.7%)
	Reader	2 (12.5%)	2 (15.4%)
	Research Fellow	1 (6.3%)	1 (7.7%)
	Lecturer	2 (12.5%)	1 (7.7%)
	Professor	2 (12.5%)	1 (7.7%)
Years worked with autistic individuals	Mean	16.57 (SD=6.32)	16.67 (SD=6.65)
	Median	20	20
	Range	7–26	7-26
Number of publications on autism	Mean	33.33 (SD=40.86)	26.80 (SD=29.08)
	Median	17.50	17.50
	Range	0–130	0–90

## Epistemological Position

This research takes a critical realist approach, which posits that a real world exists but that it can never be known with certainty, and that our attempts to understand it must be tentative (Barker et al., 2016). This study also takes a pragmatist approach (Barker et al., 2016): Although I believe that being given a diagnosis is not always helpful, especially regarding BPD, I also believe that the diagnostic constructs of autism and BPD do reliably describe groups of people and are therefore useful. As this is the framework that is currently used in healthcare services, and because autism and BPD are clearly defined constructs, if we do not use the diagnostic system, the primary research question cannot be investigated.

## Results

### Items

#### *Generation of Items*

One-hundred-and sixty-one items were developed and included in the first round of the Delphi (see appendix H).

### **Round One**

In Round One, 16 out of the 161 statements reached consensus (were rated as useful or extremely useful by 80% of panellists) (see Table 4). These statements referred to: sensory/processing difficulties; rules, repetition, and routine; impulsivity; change; mentalising; emotion regulation; relationships; social communication; co-occurring difficulties and childhood indicators. One-hundred-and-six items were excluded as they did not reach consensus for being useful (see appendix H). Twenty-six items attained 60 - 79% consensus and so were reiterated in Round Two for re-rating. Fourteen items were rated as 80% or above by one or two groups and were reiterated in round two for re-rating. No new items were included in Round Two; few additional items were suggested and none of these were deemed to be sufficiently distinct from pre-existing items by the research team.

### **Round Two**

Of the 40 re-rated items, consensus was reached (i.e., the items were rated as useful or extremely useful by 80% or more of the panellists) on six items. These were included in the final set of endorsed statements, alongside the 16 items which met consensus in the first round (see Table 4). Overall, 22 items met consensus. The fate of all items can be seen in the flow chart in Figure 1.

**Table 4***Items Reaching Consensus (80%): Final List of Endorsed Items*

Category	No.	Item	Round included	Endorsement rate
Sensory / processing	1	Autistic individuals are more likely to experience sensory difficulties (i.e., hypersensitive to sound, light, touch, smells, visual cues) to the extent that it is overwhelming, contributes to co-occurring mental health problems and leads to restrictions in activity, compared to BPD.	1	86.27%
	2	Autistic people often have stimming habits such as repetitive hand movements, humming or pacing. Individuals with BPD are much less likely to show this.	1	82.35%
	3	Autistic individuals are more likely to have processing difficulties, for example, may be slower to process and comprehend information, and struggle with verbal instructions. This is not characteristic of BPD.	2	88.37%
Rules, repetition & routine	4	Autistic individuals are more likely to adhere strictly to rules than those with BPD.	1	82.35%
	5	Autistic individuals show insistence on sameness, inflexible adherence to routines, and a preference for structure to a greater extent than individuals with BPD, whereas someone with BPD may change their habits more often.	1	82.35%

	6	In autism, eating behaviours may be driven more by rules, rituals and routines, such as wanting to eat the same thing every day, fear of trying new food, or only eating from a particular plate, than in BPD.	1	88.24%
Impulsivity	7	Individuals with BPD are much more likely to be impulsive than autistic individuals, including in regards to behaviours that may be self-damaging, i.e., overspending, unsafe sex, substance misuse, reckless driving, binge eating. Impulsive actions that do occur in autism may be due to having struggled to process information or plan.	2	86.05%
	8	Individuals with BPD may be more likely to engage in other risky behaviours in an impulsive way (i.e., sexually risky behaviour; gambling; overspending) compared to autistic individuals.	1	80.39%
Change	9	Another person changing plans at the last minute may be difficult for individuals in both groups, and trigger emotions which are difficult to regulate. For individuals with BPD this could be due to perceived rejection or fears of abandonment; for autistic individuals, this may be due to disliking change (but may be misinterpreted by services).	1	84.31%
Mentalising	10	For individuals with BPD, mentalising skills may be lost when highly emotional or when feeling vulnerable. For autistic individuals, difficulty mentalising is more consistent across time and situations (although, feeling distressed, tired, anxious, or overwhelmed may exacerbate mentalising difficulties for autistic individuals).	1	84.31%
Emotion regulation	11	In BPD, emotion regulation difficulties are likely to be triggered by an interaction involving perceived rejection or invalidation. In autism, emotion regulation difficulties are more likely due to other factors, like sensory overload, social exhaustion, or unexpected changes.	2	86.05%

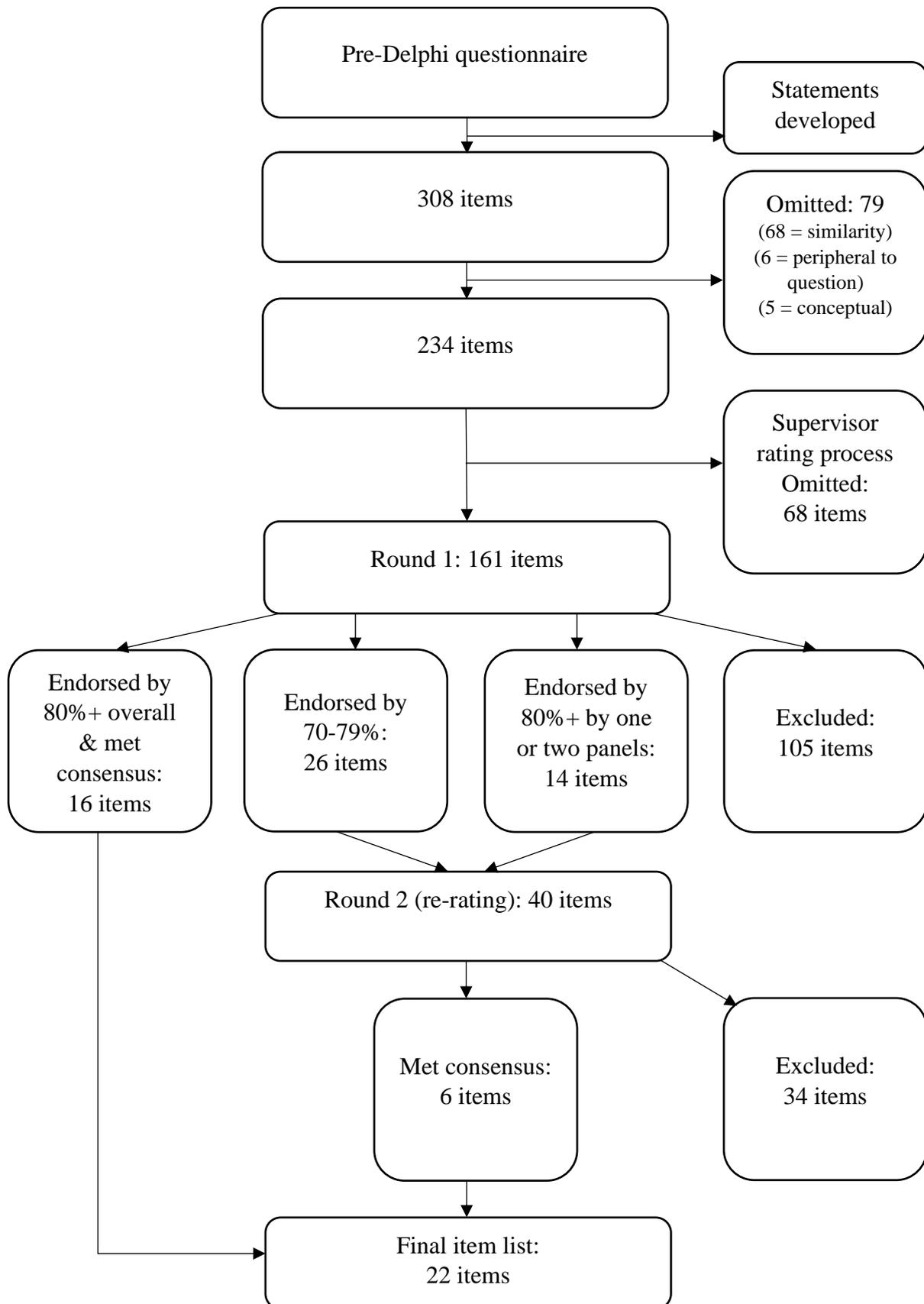
Relationships	12	Individuals with BPD may move between seeking relationships, closeness and care, which they then might reject; a ‘push-pull’ pattern is less likely in autism.	1	80.39%
	13	In relationships, there is more likely to be a general sense of awkwardness in autism, and a feeling of not quite “getting it”.	1	82.35%
	14	Both groups may be vulnerable to coercive or abusive relationships which are difficult to end, and to being exploited by others; autistic people may be “socially naïve” and trust the wrong people, whereas individuals with BPD may struggle to be on their own and stay in unhealthy relationships due to a fear of being abandoned.	1	82.35%
	15	Individuals with BPD are more likely than autistic people to reject others or end friendships for fear of being rejected themselves.	2	93.02%
Social communication	16	Individuals with BPD are less likely to have difficulty with “small talk”, when not experiencing intense emotions or perceiving risk of rejection; autistic individuals are likely to consistently find small talk difficult (although this may not be obvious to an observer due to masking).	2	88.37%
	17	Autistic individuals are more likely to describe not understanding the ‘social rules’ and have less developed social skills than individuals with BPD (although this may be hard to see from an observer perspective due to masking).	1	82.35%

Co-occurring difficulties	18	Autistic individuals may be more likely to have co-occurring neurodevelopmental symptoms, including tic disorders such as Tourette's, compared to those with BPD.	1	80.39%
Childhood indicators	19	Autistic individuals are more likely to report atypical language development including being slower to start communicating with others, than those with BPD.	1	80.39%
	20	Difficulties in socialising with peers is likely to be present at an earlier age in autism (although may not have been picked up on by observers).	1	86.27%
	21	Interpersonal trauma in BPD more often takes the form of neglect or abuse. Autistic children may experience things as traumatising that neurotypical children would not, for example, growing up in environments where they are not understood, or being punished for reasons they do not understand.	2	81.40%
	22	Recalling the following in childhood may indicate autism rather than BPD: - stimming (stimming could be misidentified as self-harm even in childhood, however) - sensory sensitivities - special interests	1	88.24%

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**Figure 1**

*Flow Chart: Development of Items and Items Accepted, Rejected and Re-rated at Each Round*



## **Sensitivity Analysis**

After statements had been re-rated in round two, a sensitivity analysis was performed on these scores. When the threshold for consensus (defined as being rated as useful or extremely useful) was lowered to 70% (69.5%), an additional 21 items met consensus, as displayed in Table 5. Three new categories of statements were identified: special interests; identifying emotions and impact on life.

## **Between-group Comparison**

Odds ratios were calculated for the 16 items which met consensus in the first round, and the 40 items which were re-rated in Round Two. Differences in endorsement ratings from the first round were looked at as a basic measure of disagreement between the three panels. Item number 19 (Table 4), “Autistic individuals are more likely to report atypical language development including being slower to start communicating with others, than those with BPD” was endorsed by significantly more autism experts than experts by experience ( $OR = .1$  (95% CI: .0 - .98),  $p = .048$ ). This was the only item to reach consensus in the first round which was also rated significantly differently by different panels.

Of the 40 items which were re-rated in Round Two, 13 yielded significant differences in endorsement ratings by at least two groups. There were similar levels of disagreement between the groups. Clinical and research experts in autism rated five statements significantly differently than clinical and research experts in BPD. Experts by experience rated six statements significantly differently to both clinical and research experts in BPD and clinical and research experts in autism. Clear trends in differences in ratings across groups are commented on below.

Out of the six significant differences between autism experts and experts by experience, four of these represented items which focused on core (diagnostic) aspects of

autism, such as repetitive behaviours (item 23, Table 5) ( $OR = .1$  (95% CI: .0 - .6),  $p = .02$ ), atypical speech (item 34, Table 5) ( $OR = .1$  (95% CI: .0 - .5),  $p = .01$ ), delayed developmental milestones (item 37, Table 5) ( $OR = .2$  (95% CI: .0 - .9),  $p = .03$ ) and special interests (item 38, Table 5) ( $OR = .1$  (95% CI: .0 - 1.0),  $p = .05$ ). Autism experts rated all four of these items as significantly more useful than the experts by experience.

Out of the five significant differences between autism experts and BPD experts, three of these also represented autism experts rating items related to core aspects of autism as more useful than BPD experts. These items related to autistic individuals having more difficulty in understanding appropriate body language than those with BPD (item 31, Table 5) ( $OR = 10.5$  (95% CI: 1.1 - 98.9),  $p = .04$ ), autistic individuals being more likely to take things literally than those with BPD (item 32, Table 5) ( $OR = 10.5$  (95% CI: 1.1 - 98.9),  $p = .04$ ), and autistic people being more likely to have special interests (item 133, Table 6, Appendix H) ( $OR = .1$  (95% CI: .0 - .5),  $p = .00$ ).

Three out of the six significant differences in endorsement ratings between clinical and research experts in BPD and experts by experience referred to age. BPD experts were less likely to endorse that autistic individuals have difficulties in identifying and communicating emotions earlier than those who develop BPD, compared to experts by experience (item 139, Table 6, Appendix H) ( $OR = .1$  (95% CI: .0 - .5),  $p = .01$ ). BPD experts were also less likely to rate as useful that individuals with BPD, in contrast to autistic individuals, were more likely to move away from behaviours exhibited when struggling to regulate emotions as they got older (item 142, Table 6, Appendix H) ( $OR = .2$  (95% CI: .0 - .9),  $p = .03$ ). Experts by experience were less likely to agree that delayed developmental milestones in childhood were more indicative of autism than BPD, compared to BPD experts (item 37, Table 5) ( $OR = 5.8$  (95% CI: 1.2 - 27.6),  $p = .03$ ).



**Table 5***Sensitivity Analysis: Additional Items Reaching Consensus when the Consensus Threshold is Lowered to 70%*

<b>Category</b>	<b>No.</b>	<b>Item</b>	<b>Endorsement rate</b>
Rules, repetition & routine	23	Repetitive and restricted behaviours and interests are core to autism and are not in BPD.	79.07%
Change	24	Both groups may have difficulties in managing change, but this is likely more marked in autism. In autism, if someone does not know something is happening and cannot control it, this might lead to a meltdown, more so than in BPD.	79.07%
Mentalising	25	Individuals diagnosed with BPD are more likely to misinterpret a situation when mentalising (e.g., “she left the room because she hates me”) whereas autistic people are less likely to mentalise at all (e.g., I have no idea why she left the room”).	74.42%
	26	Autistic individuals may be more likely to be confused by the task of mentalising (partly due to difficulties in reading facial expressions), whereas individuals with BPD may interpret others feeling and thoughts with a negative bias.	69.77%
Relationships	27	After having socialised, autistic individuals are more likely to need to compensate with a period of being alone, compared to those with BPD.	69.77%
	28	Relationship difficulties in autism are more likely to be driven by: rigidity in routines; everything needing to be in its place; sensory difficulties; the other person doing something unexpected, rather	69.77%

than an interaction, as in BPD.

	29	Autistic individuals may have more of an aversion to group interactions than individuals with BPD.	69.77%
	30	Relationships being draining and exhausting, in autism, is likely in part due to masking (hiding autistic traits), whereas this is more likely to do with anxiety related to fear of being abandoned in BPD.	72.09%
Social communication	31	Autistic individuals may have more difficulties understanding appropriate body language than individuals with BPD.	79.07%
	32	Autistic individuals are more likely to take things literally, not ‘get’ sarcasm, and struggle with metaphors and similes, which is unlikely to be a problem for individuals with BPD.	72.09%
	33	Autistic individuals may be more likely to report struggling with using eye contact than those with BPD.	76.74%
	34	Autistic individuals are more likely to have atypical speech than those with BPD, including limited tonal range (which would not be expected in individuals with BPD).	79.07%
Co-occurring difficulties	35	Autistic individuals are more likely to have learning disabilities or learning difficulties than individuals with BPD, including specific learning difficulties such as dyslexia, dyspraxia, and dyscalculia.	69.77%

Childhood indicators	36	Difficulties at school for autistic children may be due to the environment (e.g., too noisy; difficulty following verbal instructions). In a person later diagnosed with BPD, difficulties may be caused by unsupportive parents/carers, anxiety or dissociation.	69.77%
	37	Autistic adults are more likely to report delayed developmental milestones (i.e., walking and talking at expected times) than individuals who go on to be diagnosed with BPD.	76.74%
Special interests	38	Autistic individuals may be more likely to have the ability to focus intensely on special interests, but have markedly lower function in other areas (such as self-care or in other core life skills). Individuals with BPD are less likely to show such differences.	74.42%
	39	Autistic individuals are more likely to have a special interest which they may fixate on, i.e., an ongoing specific and narrow interest in an object, thing, or topic. This may be seen as atypical, i.e., intense interest in trainspotting, or be considered more typical (especially in women), i.e., intense interest in animal welfare, climate change, or centred around work. Special interests would not be expected in individuals with BPD.	76.74%
	40	Relationships may be more focused around hobbies or special interests in autism, compared to individuals with BPD.	76.74%
Identifying emotions	41	Both groups may have difficulty identifying other people's emotions. This may be a consistent difficulty for autistic individuals, whereas those with BPD may be better able to identify and describe others' emotions when not under stress or highly emotional.	76.74%

	42	Both groups may have difficulty identifying their own emotions (this may be described as alexithymia). This may be a consistent difficulty for autistic individuals, whereas those with BPD may be better able to identify and describe their emotions when not under stress or highly emotional.	72.09%
Impact on life	43	The type of problems at work are likely to be different. Someone with autism is likely to have specific requirements for the type of environment they are comfortable working in, e.g., working alone, needing adjustment to uniform policy due to materials, working regular shift pattern for predictability. Someone with BPD may be more likely to struggle to maintain one job due to impulsivity or difficulties working with others.	69.77%

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## Discussion

### Summary of Results

This study aimed to establish expert consensus on factors which help to differentiate autism and BPD. Fifty-one panellists, comprised of 18 experts by experience, 16 clinical or research experts in autism and 17 clinical or research experts in BPD took part in the two-round Delphi study. Consensus (defined by endorsement by  $\geq 80\%$  of panellists) was reached on 22 out of 161 items (13.66%). Fewer items met consensus than is typical in other Delphi studies, including those that used the 80% threshold for consensus (e.g., Langlands et al., 2008; Law & Morrison, 2014; Ross et al., 2014). When the threshold for consensus was lowered to 70% in a sensitivity analysis, an additional 21 items met consensus, bringing the overall number of endorsed items to 43 (26.71%), which is still considerably lower than Delphi studies with a similar consensus threshold (e.g., Crawford et al., 2008; Rosowsky et al., 2019).

According to the panels of experts, a person presenting with BPD could be differentiated from an autistic person by considering the following categories of characteristics: sensory/processing; rules, repetition & routine; impulsivity; change; mentalising; emotion regulation; relationships; social communication; and childhood indicators. If someone is hypersensitive to sensory stimuli to the extent that it is overwhelming, contributes to co-occurring mental health problems or leads to restrictions in activity, this may be indicative of autism rather than BPD (item 1, Table 4). If someone experiences sensory processing difficulties, this may also suggest autism rather than BPD (item 3, Table 4). Panellist ratings suggest that those whose behaviours, including daily routines and eating behaviours, are driven by a preference for sameness may be more likely to be autistic (items 4-6, Table 4). In contrast, exhibiting behaviours which are driven by

impulsivity might suggest that someone has BPD, rather than being autistic (items 7 & 8, Table 4).

The statement regarding change (item 9, Table 4) may be particularly relevant to services; emotions which are difficult to regulate may be caused by another changing plans at the last minute for both autistic people and those with BPD. However, for autistic individuals, strong emotions are likely to be driven by a dislike of change, whereas those with BPD may feel that they have been rejected or abandoned. It could be useful for healthcare professionals to ask questions to understand why an individual finds last-minute change distressing. Similarly, difficulties in emotion regulation may be driven by unexpected change for autistic people and by perceived rejection or invalidation for people with BPD (item 11, Table 4).

Panellists endorsed that autistic individuals have more social communication difficulties than people with BPD (items 16 & 17). Endorsed statements also included that lack of understanding of social rules may influence relationship difficulties for autistic people (item 13, Table 4) whereas fears of being rejected (item 15, Table 4) may influence a ‘push-pull’ pattern in relationships for people with BPD (item 12, Table 4).

Regarding childhood indicators, autistic people were judged as more likely to have difficulties socialising at an earlier age than those who develop BPD (item 20, Table 4) and to report atypical language development in childhood (item 19, Table 4). Whilst both groups may experience interpersonal trauma, panellists endorsed that those who go on to develop BPD may be more likely to experience neglect and abuse in childhood compared to autistic people (item 21, Table 4).

In addition to this core analysis, the sensitivity analysis suggested that the categories of special interests, identifying emotions and impact on life might also be helpful to consider when differentiating autism and BPD. Specifically, the presence of special interests may be

more likely to indicate autism than BPD (items 38-40, Table 5). The endorsed statements suggest that autistic people may consistently struggle to identify both their own and others' emotions, whereas people with BPD will find this particularly difficult when under stress or highly emotional (items 41 & 42, Table 5). The sensitivity analysis also reinforced that the categories identified in round one, namely rules, repetition and routine, change, mentalising, relationships, social communication, co-occurring difficulties and childhood indicators, are useful to consider when differentiating autism and BPD.

### **Comparison to Other Studies**

The items related to rules, repetition & routine are similar to behaviours and characteristics suggested previously, for example, 'preference for predictability', 'repetitive language' (Cox et al., 2019) and repetitive behaviours (Gordon et al., 2020). The aforementioned studies also state mentalising as an area of overlap, and Gordon et al. (2020), - akin to the mentalising item in the current study -, posits that mentalising ability is influenced by level of emotional distress more so in BPD than in autism. The two other publications both refer to relationships being different in BPD and autism and include references to fears around rejection being particularly characteristic of BPD. The current study adds to the area of relationships with statements referring to vulnerability in relationships but for different reasons and to an awkwardness being present in the relationships of autistic people compared to those with BPD. The differentiating categories of emotion regulation and social communication are also referred to in previous publications.

Although both the adult Coventry grid (Cox et al., 2019) and the guidelines developed by Gordon et al. (2020) both refer to sensory difficulties in other items, this study is the first to consider sensory difficulties and processing as a separate category proposed to differentiate autism and BPD. Impulsivity is also included in the current study as a differentiating category, which is different to previous literature. Co-occurring difficulties and childhood

indicators are also suggested as new categories of differentiation in the current study, compared to other guidelines, although considering developmental history has previously been suggested as important in differentiation (Lai & Baron-Cohen, 2015). Although resistance to change is referred to as a cause for affective instability in autism by Cox et al. (2019), the current study is the first to consider specifically the contrasting reasons why change, in the context of interpersonal relationships, is difficult for autistic individuals and those with BPD.

When the sensitivity analysis was performed, three additional categories were identified: special interests; identifying emotions; and impact on life. Although alexithymia (related to identifying emotions) is cited in the guidelines by Gordon et al. (2020), and difficulties understanding others' emotions is referred to in the adapted Coventry grid (Cox et al., 2019), none of the three additional categories identified in the sensitivity analysis are explicitly referred to in previous guidelines.

### **Between-group Comparison**

Clinical and research experts in autism were significantly more likely to endorse statements which referred to core characteristics of autism, such as restricted and repetitive behaviours and social communication difficulties, compared to both clinical and research experts in BPD and experts by experience. Clinical and research experts in BPD were more likely to rate statements significantly differently than experts by experience when they referred to timepoints across the lifespan. Although these differences can be noted, it is not known *why* the panels disagreed. Whilst obtaining qualitative data from panellists regarding why they rated items in the way they did would have helped to clarify reasons behind group differences, it would have increased the burden of participation on panellists. However, future studies could bring all three groups together for discussion regarding which items they

feel are important; being able to hear other groups' reasons for the usefulness rating given to an item may influence consensus across groups.

### **Excluded Items**

It is also enlightening to consider which categories of statements were not endorsed by the panellists, even when the consensus threshold was lowered to 70% (for the full list of items and endorsement ratings, see appendix E). Categories such as suicide and self-harm, and how individuals present in therapy sessions, were not represented in the final list of endorsed statements. This suggests that these are areas of similarity and reinforces the idea that BPD and autism present similarly and are hard to differentiate in clinical settings. Whilst Gordon et al. (2020) posits that there are different triggers for self-harm in BPD and autism, and that improvement in therapy may be more indicative of BPD than autism, such statements were not endorsed in the current study.

### **Application to Services**

This study provides some evidence to distinguish autism and BPD. Expert consensus is considered a low standard of evidence (Jorm, 2015) and the findings from the Delphi study represent an early step towards robust evidence-based practice in this area. Indeed, the items which met consensus as differentiating BPD and autism can be viewed as hypotheses to be tested in future studies.

Nevertheless, the current study is the most systematic research conducted to date on how to differentiate autism and BPD. Referring to the 22 endorsed statements in clinical services likely ensures better care than using no guidelines to inform practice. Furthermore, the final item list is not intended to be used diagnostically. However, the differentiating statements can inform the questions which clinicians ask when assessing clients, particularly where there is uncertainty regarding whether someone meets criteria for autism, BPD, or both

conditions. The list of statements may also help to raise awareness of the potential for misdiagnosis, and the importance of differential diagnosis, in adult mental health teams, which may not always consider autism (Fusar-Poli et al., 2020). The differentiating statements may also help clinicians in mental health services to decide whether or not to make a referral for a formal autism assessment. This could be particularly relevant in complex emotional needs or personality disorder services, where routinely considering a differential diagnosis of autism may help to signpost individuals to autism services sooner, and prevent possibly harmful delays to appropriate care.

The endorsed statements may also help to identify individuals with co-occurring autism and BPD which is particularly important due to initial evidence which suggests that this group may have lower global functioning and be at higher risk of suicide (Dell’Osso et al., 2018; Ryden et al., 2008).

### **Other Co-occurring Conditions**

Although the list of statements is potentially useful in helping to differentiate autism and BPD in mental health services, common co-occurring conditions may make differentiation more complex in practice. For example, attention deficit hyperactivity disorder (ADHD) commonly co-occurs with autism, with 28-44% of autistic individuals also meeting criteria for an ADHD diagnosis (Lai et al., 2014). Impulsivity is a hall-mark feature of ADHD (American Psychiatric Association, 2013). Several of the endorsed items refer to impulsivity, or lack of preference for routine, as indicating BPD rather than autism. However, autistic individuals with co-occurring ADHD may present similarly to individuals with BPD.

Personality disorders can be seen as consanguineous, i.e., the various personality disorders are so closely related that they should be seen as one disorder, rather than separate ones (Tyrrer, 2017). Thus, it is plausible that individuals with a diagnosis of BPD may also have traits of obsessive-compulsive personality disorder (OCPD), for example, which

includes features such as: rigidity; being preoccupied with rules, lists and schedules; and being inflexible about matters of morality, ethics or values (American Psychiatric Association). Therefore, an individual with BPD in addition to traits of OCPD could present very similarly to an autistic individual, or an individual with co-occurring autism and BPD. Thus, other conditions, notably ADHD and criteria for other personality disorders should be considered when thinking about differentiating autism and BPD.

### **Strengths**

This is the first study to use a Delphi method to investigate expert consensus on how to differentiate autism and BPD. A particular strength of the study is the range of expertise amongst panellists; in recruiting clinical and research experts in autism, clinical and research experts in BPD, and experts by experience, a heterogeneous sample was recruited, which meets the requirements of Delphi panellists to have a diversity of experience (Surowiecki, 2004). In particular, the inclusion of experts by experience – both individuals who have been (or believe they have been) misdiagnosed, and those with co-occurring autism and BPD, is a strength of the study and it is the first study researching the differentiation of the conditions to do so. The anonymised nature of the Delphi, which in turn removes power dynamics that typically occur in group decision-making processes, was perhaps particularly beneficial for the expert by experience group, who could have felt more influenced by BPD and autism experts due to the power differential involved in patient-clinician relationships.

The study also used a rigorous process to develop the items for the Delphi. Participants across all three groups were recruited to answer, based on their experiences, what factors they believed differentiated autism from BPD, via open-text answers. The data were reviewed systematically to develop statements (items) whilst ensuring fidelity to the answers given by participants. These statements were then reviewed for relevance and readability, and a systematic process was followed in order to reduce the number of items in order to

minimise participant burden and therefore reduce the risk of attrition. This process of developing items for the Delphi was rigorous and described in more detail than is common in the Delphi literature.

Delphi studies are at high risk of attrition (Trevelyan & Robinson, 2015) as the same participants are required to participate in multiple rounds. Eighty-four percent of the panellists who participated in round one completed the final round. Although there was a slight overrepresentation of experts by experience in the final round, the overall number of participants was satisfactory.

### **Limitations**

It may be that the very process of comparing BPD and autism means that they are falsely dichotomised. For example, in the pursuit of developing statements which differentiate autism and BPD, it is possible that the conditions have become stereotyped and that the statements do not engage with the diversity of presentations. In particular, it is possible that nuances of how autism presents in women have been lost due to trying to refer to autism more broadly. However, some statements did specifically consider how autism presents in women, for example, three statements made specific references to masking, which is particularly relevant to women (Hull et al., 2019). Women having more typical special interests (Grove et al., 2018) was also referred to.

The vast majority of the experts by experience were female (see Table 1 and Table 2). Although having a lower representation of males could be seen as a weakness of the sample, the over-representation of females could indicate that women are more likely to be misdiagnosed with BPD before being diagnosed as autistic or are more likely to be diagnosed with both conditions, compared to males.

Delphi studies typically recruit panellists who are experts on the entirety of the topic referred to in the research question. However, in the current study, panellists – particularly the research and clinical experts – had expertise in either autism or BPD. Although inclusion criteria ensured that research and clinical experts had some experience in the other area, this typically would not be described as expertise. Ideally, panellists would have met the definition of an expert in both BPD and autism. However, as the conditions are conceptually different, and people with these diagnoses would be worked with very differently in services, clinicians are unlikely to identify as experts in both areas. Given this, and some significant differences between the groups in endorsement ratings, it would likely be beneficial to bring experts from all three groups together to share their expertise regarding the research question, in future studies.

### **Low Consensus Rates**

Compared to other Delphis, the current study had a low consensus rate. A lower proportion of items meeting consensus may in part be explained by the heterogenous group of experts who participated as panellists; the more diverse the nature of expertise, the lower the expected agreement rates (Jorm, 2015). Indeed, recruiting panellists internationally increased the heterogeneity of the sample. Although the majority of the participants were from the UK, some panellists resided in Canada, the United States, and the Netherlands. It could be that the varying experiences of panellists in these countries increased the heterogeneity of the sample and thus contributed to the low consensus rate. However, as a general principle, heterogeneous groups likely produce better quality decisions than homogeneous ones (Surowiecki, 2004 in Jorm, 2015). It is also possible that only a small proportion of items were endorsed because it is particularly difficult to differentiate autism and BPD or because there is so little known about how to do so.

It is also possible that the low consensus rates were influenced by the characteristics

of the panel, i.e., that the research and clinical experts had expertise in either autism or in BPD rather than in both conditions. It would have been interesting to have had a fourth panel where participants met the inclusion criteria for being an expert in both conditions, to see whether they rated items differently to the BPD and autism experts. Additionally, it is plausible that, when re-rating the items in round two, other panellists' re-rating of statements might have been particularly influenced by a panel who had expertise in both areas. However, as there was not scope for panellists to state *why* they rated statements as they did – as this would have increased participant burden and increased the risk of attrition – a mixed panel may have had a limited impact on how other panellists re-rated items in round two.

Consensus rates could also have been higher if the study had more explicitly focused on a specific subgroup of autistic individuals. The term autism encapsulates a very broad group of people with a range of skills and difficulties; any one statement referring to an autistic person is unlikely to apply to all autistic individuals. In fact, experts by experience were significantly less likely to endorse statements referencing core diagnostic features of autism compared to research and clinical experts in autism. As the experts by experience were almost all female, it could be hypothesised that this group refuted statements which were less representative of the female phenotype of autism. If a focus on autistic women had been specified, it is possible that the three groups may have rated items more similarly, which may have increased consensus rates.

If the study had focused on autistic women with normal-range IQ – who may be more likely to be diagnosed with BPD - experts who had experience of this specific group could have been recruited. This would have meant less heterogeneity in experience and could have yielded higher consensus rates. However, it is an assumption that differentiating between BPD and autism is more relevant to women; it is not known how relevant this clinical conundrum is to men or those with co-occurring learning disabilities.

## **Diagnostic Frameworks**

The current study used diagnostic categories to define two types of difficulties. Diagnostic categories have utility in that they provide terms which can be used consistently to demarcate a group of people or type of difficulty. However, it is not assumed that a formal diagnosis of either is necessarily desirable. BPD has many negative connotations attached to it, and the harm this does in terms of prejudice and discrimination from healthcare professionals is well-documented (Ring & Lawn, 2016). Nevertheless, some individuals report finding a diagnosis helpful (Bilderbeck, Saunders & Goodwin, 2014). In contrast to BPD, many adults who receive an autism diagnosis describe it, overall, as a positive experience (Punshon, Skirrow & Glynis, 2009). Thus, whilst differentiating between the diagnostic entities of autism and BPD is important, whether or not it is helpful for a diagnosis to be given may depend on which condition is identified.

However, even if a diagnosis is not made, using diagnostic frameworks to conceptualise difficulties may help individuals be signposted or referred to the most appropriate services. Furthermore, a transdiagnostic approach is not deemed to be useful as, although the overt presentation of BPD and autism might look similar, the processes underlying these may well be distinct (e.g., self-harm is a shared feature across the conditions but is hypothesised to be triggered by sensory overload (Duerden et al., 2012) and interpersonal conflict (Gordon et al., 2020) in autism and BPD respectively). Therefore, using robust diagnostic categories to research this question is helpful and likely necessary as a first step to ensure those with BPD and autistic individuals are offered appropriate care.

## **Conclusions**

A Delphi study was conducted to establish expert consensus on what helps to differentiate autism and BPD. As well as being used in health services, the statements which reached expert consensus may act as hypotheses which can be tested by future research. It is

also possible that these statements, if validated by other research, could be developed into a measure which could be used to assess whether someone is likely to be autistic or to meet criteria for BPD.

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### **Part Three: Critical Appraisal**

## **Overview**

This appraisal considers how the idea for the empirical paper developed and reflects on this in the context of the scientist-practitioner model. It then goes on to reflect on both the design and delivery of the study, including strengths and weaknesses.

## **Journey to an Idea**

The idea for this project developed over three years. In the last year of my undergraduate degree, in 2016, one of my final essays was entitled, “Critically evaluate how a recent journal article impacts upon our understanding of autism and highlight any implications for the field”. I critically evaluated an article called, “Looking behind the mask: social coping strategies of girls on the autistic spectrum” (Tierney et al., 2016), which I believe was one of the earlier studies on autism in girls and women and at the beginning of a surge in research in this area. The study used interpretative phenomenological analysis to analyse data from interviews with ten 13-19-year-old autistic females, to investigate whether autistic adolescent females used particular strategies to manage their social environment (Tierney et al., 2016).

I was particularly struck by the finding that the participants purposefully masked their autistic characteristics in order to fit in and that the toll of this was associated with anxiety and depression (Tierney et al., 2016). The study also found that the girls in the study desired social relationships including friendships, which countered the social motivation theory, i.e., that social deficits in autism are explained by a lack of interest in social relationships (Chevallier et al., 2012). Indeed, the girls’ experience stood in stark contrast to this idea, as imitating others was described as a specific attempt to maintain friendships (Tierney et al., 2016). I concluded that the paper should act as a catalyst for future research looking at the female experience of autism and quoted a paper by Dworsynski et al. (2012) which stated that

such research was necessary to ensure that research and clinical practice was not failing autistic girls and women. This article made me reflect on how there must be many autistic girls and women already being seen in healthcare services, including mental health teams, whose autism is not recognised. As discussed within the thesis, that autistic women are missed or misdiagnosed has been corroborated by research (Adamson et al., 2020; Fusar-Poli et al., 2020).

After graduating I joined a Complex Needs Service where I worked with individuals who were diagnosable with a personality disorder; I wondered whether our service saw women who were in fact autistic. In 2017, I delivered a presentation to my team on autism in women, based on the articles studied in my degree and others published since; there were several more publications in the area just one year later (e.g., Bargiela et al., 2016; Gould, 2016; Tint & Weiss, 2017; Kanfischer et al., 2017). As well as speaking about incorrect stereotypes perpetuated by healthcare services, such as autistic individuals not wanting relationships and being unable to give eye contact (Tint & Weiss, 2017), I also referenced other characteristics of autism, some of which seemed particularly relevant to women. These included: feeling anxious and depressed partly due to the toll of camouflaging; suicidal thoughts; finding social interactions difficult and exhausting; difficulty identifying one's own emotions and an increased risk of having been a victim of childhood sexual abuse, compared to neurotypical individuals. This led to a team discussion on how we, as clinicians in a service which primarily worked with individuals who met criteria for borderline personality disorder (BPD), would be able to differentiate an autistic individual from someone with BPD. The team, including myself, were more able to generate similarities across these conditions, than differentiators, and we concluded that it would likely be difficult to identify an autistic individual in our service.

Whilst preparing for interviews for the doctorate in Clinical Psychology later that year (on an East Anglian train somewhere between London and Suffolk), I began thinking that, if I was successful, perhaps I would try to research autism and BPD together. Early on in 2019, in my first year of the clinical doctorate, I suggested this area to my primary supervisor, who supported me to develop a more specific research idea, regarding differentiation, possibly using a Delphi design. I went on to research this area and methodology and, after the project had been accepted, developed the research protocol.

### **Reflections on the Journey to an Idea**

This process demonstrates how I have embodied the scientist-practitioner model. This model proposes that clinical psychologists should be knowledgeable in both research and practice and, crucially, be able to integrate these (Jones & Mehr, 2007); I presented academic journal articles to a clinical team and discussed them in the context of our practice, and subsequently developed research informed by this conversation. This demonstrates both practitioner-initiated research and practice-informed research (Stricker, 2002). Indeed, it is suggested that the more research is informed by practice, the more likely practitioners are to value it and apply it in their work (Stricker, 2002).

Although only an initial step in this area, my hope is that the 22 statements endorsed in the empirical paper will help to shape conversations in relevant services to inform assessments of individuals' difficulties. In order to evaluate the clinical utility of the items, clinicians could report on the usefulness, including advantages and challenges, of trying to apply this list of differentiating factors to individuals in services, as a way of evaluating the clinical utility of the statements. This would continue the research-practice-research-practice cycle.

Although I feel that I have embodied the scientist-practitioner, it was a challenging task; starting clinical training with much more experience as a clinician than a researcher, I

found it difficult to hone my ideas and to set out the details of how the study would be run. It was also challenging to dedicate sufficient time to the research whilst undertaking various clinical placements. The responsibility of being a practitioner, i.e., offering good care to patients within the NHS, often made it feel impossible, and even undesirable or unethical, to prioritise the research in terms of time and headspace. I imagine that finding it difficult to dedicate time to research will continue throughout my career post-qualification.

### **Context: Covid-19**

Of course, the study was run and written up during the Covid-19 pandemic. This affected the research process in three ways. Firstly, it felt harder to appreciate the importance of psychological research, and of embodying the scientist-practitioner model; on placement I was acutely aware of the difficulties occurring in the inpatient Learning Disabilities ward, for example, lack of personal protective equipment and Covid-19 tests, which made the residents and staff vulnerable. However, on reflection, and on a broader level, the pandemic has also highlighted the vital role of research, for example clinical trials of vaccines, in improving people's lives.

Secondly, the pandemic impacted on the delivery of the study; I originally delayed recruitment, with the aim to wait until Covid-19 was no longer dominating day-to-day life, particularly as NHS professionals were being recruited. However, as it became clear that this situation was more permanent, I decided to start recruiting. Unfortunately, this meant that recruitment occurred during the height of the UK's second Covid-19 wave and throughout the third lockdown. This likely made it harder to recruit participants, as many people were concerned about loved ones, home-schooling children, or otherwise struggling. Yet, with this context in mind, the study's ample sample size is a strength of the project.

The third impact of carrying out the project in the Covid-19 pandemic was more

personal. It was challenging to focus on fine-tuning the study, to concentrate, and to stretch myself to learn new skills whilst isolated from friends, family, and colleagues and thus without the support networks I was accustomed to.

### **Designing the Study**

My newness to research also meant that I initially wanted more questions answered by the research than was feasible for a thesis project constrained by the time limit of the course. The focus of my project narrowed throughout the development of the study. My original research questions included, “what factors help to identify co-occurring autism and BPD?” and this question was asked in the pre-Delphi questionnaire. This question felt important as initial research suggested that autistic individuals who also have BPD have lower global functioning (Ryden et al., 2008) and are at higher risk of suicide (Chabrol & Raynal, 2018; Ryden et al., 2008) Answers to this question in the pre-Delphi questionnaire were brief and the suggestions given did not differ from the characteristics suggested as similarities across the conditions. I reflected that this question was likely a step beyond the scope of this study, and that the differentiators needed to be established and clarified before it was feasible to identify characteristics that would suggest someone meets the criteria for both conditions. However, differentiating factors in and of themselves may help to identify if an individual has co-occurring autism and BPD, i.e., if parts of the item pertaining to BPD and autism are both relevant to an individual, this might indicate that co-occurrence should be considered. For example, *“Another person changing plans at the last minute may be difficult for individuals in both groups, and trigger emotions which are difficult to regulate. For individuals with BPD this could be due to perceived rejection or fears of abandonment; for autistic individuals, this may be due to disliking change (but may be misinterpreted by services).* If an individual found last-minute change difficult both because of the change in

and of itself, in addition to feeling rejected, and if this pattern of relating to both conditions occurred further, a hypothesis that the individual was autistic and had BPD might be formed.

I also originally planned to investigate, and indeed asked in the pre-Delphi questionnaire, “what social factors influence whether a BPD or autism diagnosis is given?”. This question was presented with the following text:

*“Although the process of giving a diagnosis is ideally objective, it is inevitably impacted by the clinician’s own beliefs, experiences and biases. What diagnosis is given, whether informally or formally, is likely to be influenced by the characteristics of the service-user, such as their age, gender, class, race, ethnicity, and sexuality.*

*(i) Based on your experience, how might the characteristics of the service-user, such as their age, gender, class, race, ethnicity, and sexuality influence which diagnosis is made or thought to be correct?*

*(ii) Other factors may affect which diagnosis is given or thought to be correct (i.e. profession / experience of the referring or diagnosing clinician; absence or presence of local specialist BPD and autism services; how long someone will have to wait to be seen at a particular service; and whether the clinician is working privately). Based on your experience, what other factors, such as those listed above, may influence which diagnosis is given or thought to be correct?”*

I felt it was important to include such questions in order to recognise that diagnosis is not an objective process or free from bias of the referring or diagnosing clinician. The questions on social factors were also based on research indicating such biases; for example, women are more likely to be diagnosed with BPD despite equal true prevalence across genders (Grant et al., 2008) and men are more likely to be diagnosed as autistic with women more likely to be missed.

Other studies, for example, on race and gender identity, prompted me to want to ask about the impact of social factors on diagnosis. Although a comprehensive review of the social factors which may influence whether a diagnosis of BPD or autism is given is beyond the scope of this critical appraisal, some examples are listed below. Some clinicians may falsely interpret someone being transgender or gender-diverse as identity diffusion (i.e., a disturbed sense of self which manifests by sudden changes, such as in values or religious beliefs (Lind et al., 2019) and therefore a possible indicator of BPD (Goldhammer et al., 2019). Furthermore, lower rates of personality disorder diagnoses in Black individuals have been observed, compared to rates of diagnoses in white individuals, which could suggest that services are not identifying the needs of Black patients (McGilloway et al., 2010). Lower autism identification in minority ethnic groups compared to white groups has also been found (Tromans et al., 2020).

From observations in my practice, I also wondered whether, due to long waiting-lists and NHS systems sometimes being difficult to navigate, it was easier for well-educated middle-class individuals to be assessed for autism, either because they could afford to pay privately or were better equipped to successfully navigate the health system. It felt important to include discussion around social factors to a) recognise that the process of diagnosis is subject to bias and b) so that items which would have met consensus could help alert clinicians to such biases.

However, the decision to discontinue the questions regarding social factors was made because a) the study was delayed partly due to Covid-19; in order to ensure it was finished within the time constraints of the course, the primary research question was focused on and b) several processes had to be developed to reduce the number of items panellists were asked to rate in the first round of the Delphi study from 308 to 161. Including items on social factors, which had been drafted, would have meant asking panellists to rate an additional 37 items.

Thus, in order to decrease participant burden and therefore potential drop-out from the study, the items were not used in the Delphi. This sat uncomfortably with me and I hope it is researched in the future; as 37 items were developed from the pre-Delphi questionnaire, these could be used in future research.

### **Language: the term, BPD**

The current study clearly uses the term, borderline personality disorder. There were arguments for and against using the term, which I will outline below, after contextualising the conundrum.

As outlined in the conceptual introduction, individuals with a diagnosis of BPD are often treated discriminately by healthcare professionals (Veysey, 2014). Many people believe that the term itself contributes to this stigma, including service-users who have campaigned for the name to be changed (Recovery in the Bin, 2019). Indeed, when the study was advertised on social media, several people who had been diagnosed with BPD commented that they did not think research should be using this term. I felt uncomfortable and questioned whether the research I was conducting was moral. I do not disagree with the arguments put forward by those who wish for the name to be changed; it is true that the term causes distress for some service-users.

I reflected that it is also true that individuals get misdiagnosed as having BPD when they are indeed autistic (Takara et al., 2015) and that this can also cause harm, for example, by depriving individuals of understanding their condition, and possibly by offering groups, interventions, or other care that is not appropriate (e.g., Babb et al., 2021). In fact, this was corroborated by several individuals who were part of the expert by experience panel; in the process of signing up to the study, individuals emailed me to say that they had been misdiagnosed with BPD and that it had taken many years to be assessed for autism.

Participants expressed that this had caused confusion, distress, and meant that they had received inappropriate care from services. Others commented that their BPD diagnosis made it harder to access an autism assessment, were prescribed inappropriate medication or offered unhelpful group therapy. Several professionals also got in touch to say that they could recall situations where it was unclear whether someone met criteria for autism or BPD. Other professionals told me that they had worked in services where individuals in personality disorder services had unrecognised autism or perhaps met criteria for both conditions, but it was unclear; this last point felt particularly important given initial research that suggests that those who meet criteria for both conditions are at higher risk of suicide. Thus, whilst it is true that the BPD diagnosis can cause harm, it is also true that misdiagnosis, likely perpetuated by too little research, can also cause harm.

On twitter, one comment referred to the fact that the research might be beneficial for autistic individuals, but because it gave them a route out of the BPD category, that this was beneficial *because* losing the BPD label would mean that they would be treated better by services. Via email, another expert by experience reflected that she was treated more favourably when her needs were thought to be explained by autism, than when BPD was used as an explanatory framework, despite presenting to services in the same way.

Whilst designing the study, I wondered whether I could use a different term, other than BPD, because of the negative connotations attached to it. However, whilst some endorse renaming the difficulties encapsulated as BPD as “complex post-traumatic stress disorder” (Kulkarni et al., 2017), others disagree that these concepts can be merged (Cloitre et al., 2014). Other terms used to describe these difficulties, such as “complex emotional needs” or “complex trauma” are not particularly well-defined and would make drawing on similarities and differences to autism difficult. Thus, I felt that using a different albeit less stigmatising term, would mean that the results of the study would be hard to apply to practice.

On reflection, it would have been useful to have presented this dilemma - of needing to research an important area to reduce the risk of people being harmed by misdiagnosis, without an unsatisfactory term - to experts by experience, and other professionals to see if an alternative term could have been agreed upon.

### **Including Experts by Experience**

Although experts by experience were not consulted in the design process, which is a flaw of the study, experts by experience were included as an expert panel in all three stages of the study. Indeed, experts by experience being involved in the pre-Delphi stage of the study meant that this group made a substantial contribution to the content of the items iterated in the Delphi, and thus did influence the design of the study. Moreover, other Delphi studies have recruited experts by experience but not always as a separate panel and this group have not always been retained throughout the rounds (for example, Mitchell et al., 2020). In this study, experts by experience were the best-represented group in all three stages of the study. Thus, the representation of experts by experience in the participation of the study is a strength.

Although including experts by experience is undoubtedly invaluable, using the term BPD may have meant that some individuals had to engage with a term they disagreed with or thought harmful, in order to participate in the research. This reinforces my reflection that it would have been better to have consulted with experts by experience prior to planning the study, to think about how the dilemma of needing to research a clearly defined concept, but the only clearly defined concept being stigmatising, could have been managed.

## **Reflections on Methodology**

### **Pre-Delphi Questionnaire**

On reflection, the pre-Delphi questionnaire was too long. As there is not much

research on the differences between autism and BPD, I thought it would be helpful to a) scaffold participants in their thinking by first asking about similarities and b) ask about similarities and differences via sub-questions based broadly on areas covered in the literature, such as mentalizing, and standard ways of understanding diagnosis, such as core features. However, this made for a lengthy questionnaire which was likely burdensome for participants; some respondents did not finish the questionnaire, and others repeated content in later questions that they had covered in earlier questions. Indeed, it is recommended to use few well-structured and open-ended questions in the first round, in part to lessen participant burden and to reduce the amount of data which needs to be reviewed for the subsequent round (Trevelyan, 2015). Nonetheless, asking about differentiating factors in relation to specific topics could be partly why so many different items were developed.

However, a long questionnaire, including repetition in the data, also meant that developing these free text answers into statements was burdensome, complex and time-consuming. The pre-Delphi questionnaire generated approximately 50,000 words of data which needed to be synthesized; although I developed processes to do this systematically the toll on me as a researcher, conducting this study largely on my own, was high. On reflection, the pre-Delphi questionnaire could have been developed differently, for example, by developing items based on the current literature. However, at the planning stage of the study there were few papers on the overlap of the conditions, and this method would have meant that the ideas and knowledge of the experts by experience, in addition to clinicians, would not have informed the items. Furthermore, there is very limited guidance on how to develop the pre-Delphi questionnaire. Many published Delphi studies also include only very sparse details of the processes by which the Delphi items were developed. This lack of direction meant that designing the pre-Delphi questionnaire and developing the items was particularly challenging and time-consuming.

## **The Delphi Study**

There is also a lack of clarity and guidance regarding how a Delphi study should be conducted. There is, ironically, a lack of consensus on how many rounds there should be, the size of panels, the threshold used to determine consensus, and the criteria for re-rating items. This meant that, to ensure that the Delphi was rigorous, good practice had to be inferred by reading many journal articles in the Delphi literature.

A strength of the study is the good rate of participant retention throughout the three stages of the study. Enabling new participants to take part in the first round of the Delphi who had not participated in the pre-Delphi questionnaire ensured that the first round was responded to by a satisfactory number of panellists. The second round of the Delphi also retained 84.3% of the panellists from the first round. This is particularly good given that attrition is the biggest threat to Delphi studies (Treveleyan & Robinson, 2015). The current study utilised indicators of good practice documented in the research such as sending regular reminders to panellists (McPherson et al., 2018). Other elements of good practice include encouraging panellists to take ownership of the research process by reminding them that each round has been shaped by their previous answers (Keeney et al. 2006); this was made explicit in the email sent to panellists, which asked them to complete the final round of the Delphi. I also coded Qualtrics to show every panellist their previous answer next to each separate item in round two, which meant that there was a high degree of individualisation for each panellist. This, in addition to the Round Two questionnaire providing access to the statements which reached consensus in the first round, likely positively influenced response rates.

## **Conclusion**

This critical appraisal began by outlining the experiences, both from academia and research and from clinical practice, which influenced my idea for the study. It seems fitting to

reflect on what I will take from the experience of conducting the project itself. Looking back at my pre-training job in a complex needs service, with the knowledge I now have regarding differentiating autism and BPD, several service-users come to mind who may have been autistic, but whose difficulties were perceived through the lens of BPD. I hope to work with people diagnosable with a personality disorder, or who have complex emotional needs, throughout my career. I will endeavour to hold autism at the forefront of my mind and to start conversations in relation to service-users whose autistic traits may have previously gone unnoticed.

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## Appendices

### Appendix A: UCL Letter of Ethical Approval

20<sup>th</sup> March 2020

Dr Will Mandy  
Clinical, Education and Health Psychology  
Division of Psychology and Language Sciences  
UCL

Cc: Kimberley Guest

Dear Dr Mandy

**Notification of Ethics Approval with Provisos**

**Project ID/Title: 17119/001: Autism, borderline personality disorder or both? A Delphi Study to reach expert consensus**

Further to your satisfactory responses to the Committee's comments on your application, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **20<sup>th</sup> March 2021**.

Ethical approval is subject to the following conditions:

**Notification of Amendments to the Research**

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'  
<http://ethics.grad.ucl.ac.uk/responsibilities.php>

**Adverse Event Reporting – Serious and Non-Serious**

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

**Final Report**

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <https://www.ucl.ac.uk/srs/file/579>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



**Professor Michael Heinrich**  
**Joint Chair, UCL Research Ethics Committee**

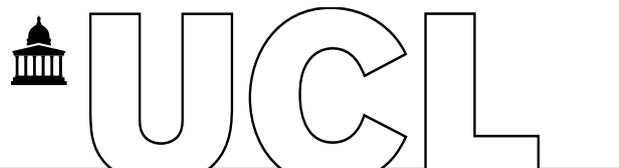
## Appendix B: Participant Information Sheet (Experts by Experience)

UCL Research Department of Clinical,

Educational & Health Psychology

1-19 Torrington Place

University College London



### PARTICIPANT CONSENT FORM: EXPERTS BY EXPERIENCE

**Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.**

**Title of Study: Autism, Borderline Personality Disorder (BPD), or both? A Delphi study to establish expert consensus.**

Please note that BPD is also termed emotionally unstable personality disorder (EUPD) and we will be recruiting those who have a diagnosis of either BPD or EUPD, in addition to those with a diagnosis of autism.

**Department:** Clinical, Education, and Health Psychology, Division of Language Sciences

**Name and Contact Details of the Researcher:** Kim Guest (Kimberley.guest.18@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Will Mandy  
(w.mandy@ucl.ac.uk)

**Name and Contact Details of the UCL Data Protection Officer:** Alex Potts  
(a.potts@ucl.ac.uk)

**This study has been approved by the UCL Research Ethics Committee:**

**Project ID number:** Z6364106/2020/01/153

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

		Tick Box
1.	I confirm that I have read and understood the Information Sheet dated 19/01/2020 for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to	

	ask questions which have been answered to my satisfaction and would like to take part in the study.	
2.	Due to the nature of the study (i.e. data collected in rounds one and two inform what will be asked in two and three), I understand that my data cannot be withdrawn unless requested within two weeks of completing a questionnaire.	
3.	I consent to participate in the study. I understand that my personal information (gender; ethnicity; age at diagnosis and who diagnosis was given by) will be used for the purposes explained to me. I understand that according to data protection legislation, ‘public task’ will be the lawful basis for processing personal data and ‘for research purposes’ is the legal basis for special category data (i.e. ethnicity and gender).	
4.	<p><b>Use of the information for this project only</b></p> <p>I understand that confidentiality will be respected subject to legal constraints and professional guidelines</p> <p>Anonymity is optional for this research. Please select from the following 3 options:</p> <p>(a) I agree for my real name and role/affiliation to be used in connection with any words I have said or information I have passed on.</p> <p>(b) I request that my comments are presented anonymously but give permission to connect my role/affiliation with my comments (but not the title of my position).</p> <p>(c) I request that my comments are presented anonymously with no mention of my role/affiliation.</p>	
5.	<p>I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my legal rights being affected.</p> <p>I understand that if I decide to withdraw, any data I have provided up to that point cannot be deleted as it may have already been shared anonymously with other participants in a summary of responses and used to inform what questions are asked in later rounds. However, I understand that my personal data will not be included in publication or dissemination of the write-up of the study, should I choose to withdraw.</p>	
6.	I understand that there are minimal risks of participating but am aware of the support that will be available to me should I become distressed during the course of the research.	
7.	I understand the direct/indirect benefits of participating.	
8.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	

9.	I understand that I will receive £5 per completed questionnaire (of which there are three) for participation in this study.	
10.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
11.	I am aware of who I should contact if I wish to lodge a complaint.	
12.	I voluntarily agree to take part in this study.	
13.	<p><b>Use of information for this project and beyond</b></p> <p>I would be happy for the data I provide to be anonymously and securely archived at University College London.</p> <p>I understand that other authenticated researchers could have access to my anonymised data.</p>	

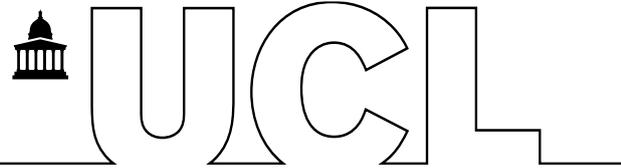
**If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.**

<input type="checkbox"/>	Yes, I would be happy to be contacted in this way	
<input type="checkbox"/>	No, I would not like to be contacted	

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

## Appendix C: Participant Information Sheet (Research & Clinical Experts in Autism)

UCL Research Department of Clinical,  
Educational & Health Psychology  
1-19 Torrington Place  
University College London  
London  
WC1E 7HB



### Participant Information Sheet: Clinical and Research Experts in Autism

**Study Title: Autism, BPD, or both? A Delphi Study to establish expert consensus**

**Project ID number:** Z6364106/2020/01/153

**Researcher:** Kim Guest

**Supervisors:** Will Mandy & Steve Pearce

#### Introduction

We would like to invite you to take part in a research study, which is being undertaken as a thesis under the Doctorate in Clinical Psychology. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take your time to read and consider the information on this sheet. Please get in touch if there is anything that is not clear to you, if you have any questions, or would like more information. Contact details can be found at the end of this document.

#### What is the purpose of the study?

Autism and borderline personality disorder (BPD), otherwise called emotionally unstable personality disorder, share many characteristics. Clinical experience tells us that many people are misdiagnosed, which could lead to distress and/or inappropriate care. There is very little research which looks at the differences and similarities between autism and BPD, and how people present when they co-occur. Therefore, this study seeks to establish expert consensus on what differentiates autism from BPD from their co-occurrence. It also asks what care would be most appropriate for someone with both BPD and autism.

#### What is a Delphi study?

Delphi studies are often used as an initial step to establish expert consensus on an under-researched issue. Expert consensus is gained through a series of semi-structured questionnaires; participants receive an anonymized summary of respondents' answers to the previous round, and thus can consider this information in their responses in the next round. Delphi studies rely on the premise that groups, under specific conditions, make better judgments than individuals.

#### Why have I been invited?

You have been invited to participate because you have worked in autism (with some experience of working with people with BPD) for three or more years, or because you have

conducted research in this area. A group of clinical and research experts in BPD (with some experience of autism) are also being recruited. Experts by experience, who have either been misdiagnosed with BPD or autism, or who have been diagnosed with both, are being recruited too.

**Do I have to take part?**

No. It is completely up to you whether or not you take part. You have the right to withdraw at any point during the study without giving a reason. However, your anonymized contributions until the point of withdrawal will still be used (unless you withdraw within two weeks of submitting your response; in this case, your contributions in the most recent round can be withdrawn).

**What will happen if I take part?**

There are three rounds to the Delphi, spaced approximately several weeks apart. In each round you will be asked to fill in an online questionnaire. In between rounds two and three you will be given an anonymized summary of what the participants as a whole answered; you can then consider this information in the next round. In the questionnaire at the beginning of round one you will also be asked whether you are an expert in BPD or autism, number of years practiced in that area, and number of publications.

**How much time will it take to participate?**

Each round of the Delphi will take around 30 minutes to complete. With all three rounds, participation will take around 1.5 hours, spread over several months.

**What are the possible advantages of taking part?**

Taking part may help to enhance your understanding on this topic, which may support you in clinical practice and/or research work. It is also an opportunity to contribute your expertise in an under-researched but clinically important area, which may have future benefit for those with BPD and/or autism.

**What are the possible disadvantages of taking part?**

There are no apparent disadvantages of taking part.

**What will happen if something goes wrong?**

Please contact Kim Guest (researcher) or Will Mandy (supervisor and principal investigator) if you are unhappy with any aspect of the study. If want to talk to someone independent of the study please contact the UCL ethics committee on 020 7679 8717 or [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk).

**Will my taking part in this study be confidential?**

All information about you will be handled in confidence. Other participants will not be informed who else will be participating in the study. Only the researcher, and supervisors, will have access to this information. Personal information and questionnaire responses will be collated and aggregated anonymously. Your identity and responses will not be traceable back to you.

**How will data be stored?**

Your data will be stored on a secure university of college London (UCL) desktop which is

password-protected. Personal data will not be transferred. From the end of the study, the data will be kept on a UCL password-protected computer for ten years before it is destroyed.

### **What will happen to the results of the research study?**

The results will be published in a peer-reviewed journal article. The results may also be disseminated at conferences. The consent form will ask whether you consent to comments you make being included in publications and disseminations; these will be anonymized. (Not consenting to this will not affect your eligibility to take part in the study).

### **Who is organizing and funding the research?**

This research is being undertaken as a thesis as part of the Doctorate in Clinical Psychology Programme at UCL. The Clinical, Educational, and Health Psychology Department awards a small amount of money to cover costs.

### **Who has reviewed this study?**

The UCL Research Ethics Committee have reviewed and approved the application for this study. The ethics ID number is: 17119/001.

### **Local Data Protection Privacy Notice**

#### **Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, visit: <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies>

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

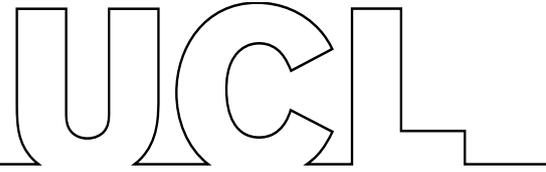
#### **Further information**

Contact details:

Kim Guest ([kimberley.guest.18@ucl.ac.uk](mailto:kimberley.guest.18@ucl.ac.uk)); Will Mandy ([w.mandy@ucl.ac.uk](mailto:w.mandy@ucl.ac.uk))

## Appendix D: Participant Information Sheet (Clinical and Research Experts in BPD)

UCL Research Department of Clinical,  
Educational & Health Psychology  
1-19 Torrington Place  
University College London  
London  
WC1E 7HB



### Participant Information Sheet: Clinical and Research Experts in BPD

**Study Title: Autism, BPD, or both? A Delphi Study to establish expert consensus**

**Project ID number:** Z6364106/2020/01/153

**Researcher:** Kim Guest

**Supervisors:** Will Mandy & Steve Pearce

#### Introduction

We would like to invite you to take part in a research study, which is being undertaken as a thesis under the Doctorate in Clinical Psychology. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take your time to read and consider the information on this sheet. Please get in touch if there is anything that is not clear to you, if you have any questions, or would like more information. Contact details can be found at the end of this document.

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#### Why have I been invited?

You have been invited to participate because you have worked in BPD (with some experience of working with people with autism) for three or more years, or because you have conducted research in this area. A group of clinical and research experts in autism (with some

experience of BPD) are also being recruited. Experts by experience, who have either been misdiagnosed with BPD or autism, or who have been diagnosed with both, are being recruited too.

### **Do I have to take part?**

No. It is completely up to you whether or not you take part. You have the right to withdraw at any point during the study without giving a reason. However, your anonymized contributions until the point of withdrawal will still be used (unless you withdraw within two weeks of submitting your response; in this case, your contributions in the most recent round can be withdrawn).

### **What will happen if I take part?**

There are three rounds to the Delphi, spaced approximately several weeks apart. In each round you will be asked to fill in an online questionnaire. In between rounds two and three you will be given an anonymized summary of what the participants as a whole answered; you can then consider this information in the next round. In the questionnaire at the beginning of round one you will also be asked whether you are an expert in BPD or autism, number of years practiced in that area, and number of publications.

### **How much time will it take to participate?**

Each round of the Delphi will take around 30 minutes to complete. With all three rounds, participation will take around 1.5 hours, spread over several months.

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Taking part may help to enhance your understanding on this topic, which may support you in clinical practice and/or research work. It is also an opportunity to contribute your expertise in an under-researched but clinically important area, which may have future benefit for those with BPD and/or autism.

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The results will be published in a peer-reviewed journal article. The results may also be disseminated at conferences. The consent form will ask whether you consent to comments you make being included in publications and disseminations; these will be anonymized. (Not consenting to this will not affect your eligibility to take part in the study).

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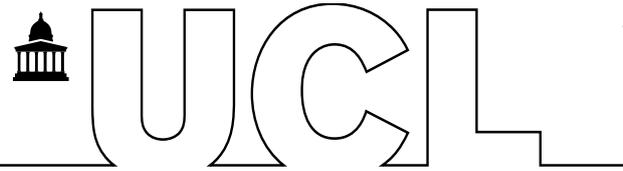
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## Appendix E: Participant Consent Form (Experts by Experience)

UCL Research Department of Clinical,  
Educational & Health Psychology  
1-19 Torrington Place  
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**Department:** Clinical, Education, and Health Psychology, Division of Language Sciences

**Name and Contact Details of the Researcher:** Kim Guest (Kimberley.guest.18@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Will Mandy  
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**Project ID number:** Z6364106/2020/01/153

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

		Tick Box
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14.	I confirm that I have read and understood the Information Sheet dated 19/01/2020 for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in the study.	
15.	Due to the nature of the study (i.e. data collected in rounds one and two inform what will be asked in two and three), I understand that my data cannot be withdrawn unless requested within two weeks of completing a questionnaire.	
16.	I consent to participate in the study. I understand that my personal information (gender; ethnicity; age at diagnosis and who diagnosis was given by) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing personal data and 'for research purposes' is the legal basis for special category data (i.e. ethnicity and gender).	
17.	<p><b>Use of the information for this project only</b></p> <p>I understand that confidentiality will be respected subject to legal constraints and professional guidelines</p> <p>Anonymity is optional for this research. Please select from the following 3 options:</p> <p>(d) I agree for my real name and role/affiliation to be used in connection with any words I have said or information I have passed on.</p> <p>(e) I request that my comments are presented anonymously but give permission to connect my role/affiliation with my comments (but not the title of my position).</p> <p>(f) I request that my comments are presented anonymously with no mention of my role/affiliation.</p>	
18.	<p>I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my legal rights being affected.</p> <p>I understand that if I decide to withdraw, any data I have provided up to that point cannot be deleted as it may have already been shared anonymously with other participants in a summary of responses and used to inform what questions are asked in later rounds. However, I understand that my personal data will not be included in publication or dissemination of the write-up of the study, should I choose to withdraw.</p>	
19.	I understand that there are minimal risks of participating but am aware of the support that will be available to me should I become distressed during the course of the research.	
20.	I understand the direct/indirect benefits of participating.	

21.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
22.	I understand that I will receive £5 per completed questionnaire (of which there are three) for participation in this study.	
23.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
24.	I am aware of who I should contact if I wish to lodge a complaint.	
25.	I voluntarily agree to take part in this study.	
26.	<p><b>Use of information for this project and beyond</b></p> <p>I would be happy for the data I provide to be anonymously and securely archived at University College London.</p> <p>I understand that other authenticated researchers could have access to my anonymised data.</p>	

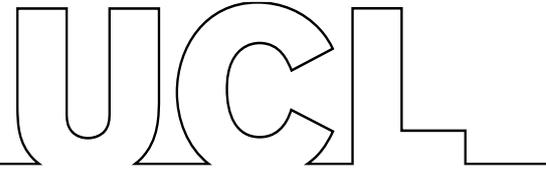
**If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.**

<input type="checkbox"/>	Yes, I would be happy to be contacted in this way	
<input type="checkbox"/>	No, I would not like to be contacted	

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

## Appendix F: Participant Consent Form (Research and Clinical Experts in BPD and Autism)

UCL Research Department of Clinical,  
Educational & Health Psychology  
1-19 Torrington Place  
University College London



### PARTICIPANT CONSENT FORM: CLINICAL AND RESEARCH EXPERTS

**Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.**

**Title of Study: Autism, Borderline Personality Disorder (BPD), or both? A Delphi study to establish expert consensus.**

Please note that BPD is also termed emotionally unstable personality disorder (EUPD) and we will be recruiting those who have a diagnosis of either BPD or EUPD, in addition to those with a diagnosis of autism.

**Department:** Clinical, Education, and Health Psychology, Division of Language Sciences

**Name and Contact Details of the Researcher:** Kim Guest (Kimberley.guest.18@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Will Mandy  
(w.mandy@ucl.ac.uk)

**Name and Contact Details of the UCL Data Protection Officer:** Alex Potts  
(a.potts@ucl.ac.uk)

**This study has been approved by the UCL Research Ethics Committee:**

**Project ID number:** Z6364106/2020/01/153

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

		Tick Box
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1	I confirm that I have read and understood the Information Sheet dated 19/01/2020 for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in the study.	
2	Due to the nature of the study (i.e. data collected in rounds one and two inform what will be asked in two and three), I understand that my data cannot be withdrawn unless requested within two weeks of completing a questionnaire.	
3	I consent to participate in the study. I understand that my personal information (gender; ethnicity; years worked in Autism or BPD and number of publications or diagnosis) will be used for the purposes explained to me. I understand that according to data protection legislation, ‘public task’ will be the lawful basis for processing personal data and ‘for research purposes’ is the legal basis for special category data (i.e. ethnicity and gender).	
4	<p><b>Use of the information for this project only</b></p> <p>I understand that confidentiality will be respected subject to legal constraints and professional guidelines</p> <p>Anonymity is optional for this research. Please select from the following 3 options:</p> <p>(g) I agree for my real name and role/affiliation to be used in connection with any words I have said or information I have passed on.</p> <p>(h) I request that my comments are presented anonymously but give permission to connect my role/affiliation with my comments (but not the title of my position).</p> <p>(i) I request that my comments are presented anonymously with no mention of my role/affiliation.</p>	
5	<p>I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my legal rights being affected.</p> <p>I understand that if I decide to withdraw, any data I have provided up to that point cannot be deleted as it may have already been shared anonymously with other participants in a summary of responses and used to inform what questions are asked in later rounds. However, I understand that my personal data will not be included in publication or dissemination of the write-up of the study, should I choose to withdraw.</p>	
6	I understand that there are minimal risks of participating but am aware of the support that will be available to me should I become distressed during the course of the research.	

7	I understand the direct/indirect benefits of participating.	
8	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
9	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
1 0	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
1 1	I am aware of who I should contact if I wish to lodge a complaint.	
1 2	I voluntarily agree to take part in this study.	
1 3	<b>Use of information for this project and beyond</b> I would be happy for the data I provide to be anonymously and securely archived at University College London. I understand that other authenticated researchers could have access to my anonymised data.	

**If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.**

<input type="checkbox"/>	Yes, I would be happy to be contacted in this way	
<input type="checkbox"/>	No, I would not like to be contacted	

\_\_\_\_\_  
Name of participant                      Date                      Signature

\_\_\_\_\_  
Researcher                      Date                      Signature

## Appendix G: Pre-Delphi Questionnaire

**Thank you for taking the time to contribute to this Delphi study, which seeks to gain a better understanding of how autism and the diagnostic entity of borderline personality disorder (BPD) can be distinguished from each other.**

### A note on terminology

This questionnaire uses the term "borderline personality disorder" ("BPD"). Some people may refer to such difficulties as "emotionally unstable personality disorder" (EUPD). Although these are defined slightly differently, they are often used synonymously in practice.

We acknowledge that many people experience the terms BPD and EUPD as unhelpful. However, for clarity of expression, and to help answer the above research question, which we believe is important, this questionnaire uses the term "borderline personality disorder" (BPD). When we use this term, we are also referring to the experiences and characteristics of those who describe their difficulties as complex emotional needs, EUPD or complex trauma. Person-first language will be used (e.g. "person diagnosed with BPD").

When we use the term, autism, we are describing "autism spectrum disorder", including people diagnosed with "Asperger's syndrome". Identity-first language will be used in relation to autism (e.g. "autistic person")

### *[demographic questions and questions pertaining to the nature of expertise]*

We will now ask you a series of questions about how autism and BPD are similar, and how they differ.

This will cover a number of different areas, for example, how autism and BPD are similar and different in terms of their diagnostic features, associated risks, impact on everyday life and so on.

Please do feel free to email Kim on kimberley.guest.18@ucl.ac.uk if you have any questions about the wording used.

This is an under-researched area, where little is currently known. Please feel free to share any ideas you have on this topic, even if you are not totally sure of them.

## **What factors help to differentiate autism from BPD in adults?**

### **a) Presenting difficulties**

**Presenting difficulties** are the difficulties spoken about when individuals first access mental health services or what they are referred to mental health services for.

- i) *Based on your experience, in terms of presenting difficulties, how are autism and BPD similar?*

- ii) *Based on your experience, in terms of presenting difficulties, how are autism and BPD different?*

### **b) Core features**

**Core features** are the fundamental characteristics of a condition, which are set out in diagnostic criteria presented in the Diagnostic and Statistical Manual and International Classification of Diseases (the manuals used to make diagnoses).

- i) *Based on your experience, in terms of core features, how are autism and BPD similar?*
- ii) *Based on your experience, in terms of core features, how are autism and BPD different?*

### **c) Co-occurring difficulties**

**Co-occurring difficulties** are challenges that may occur at higher than chance rates in autistic individuals and individuals diagnosed with BPD. These include but are not limited to: physical health problems; mental health difficulties including eating behaviours; and substance misuse.

- i) *Based on your experience, in terms of co-occurring difficulties, how are autism and BPD similar?*
- ii) *Based on your experience, in terms of co-occurring difficulties, how are autism and BPD different?*

### **d) Early life experiences**

**Early life experiences** refer to any positive or negative childhood experiences. They can include but are not limited to: traumatic experiences such as abuse or neglect; attachment, for example, the nature of the relationship with primary caregivers; experiences at school including relationships with other children. This could also include information about reaching developmental milestones such as walking and talking.

- i) *Based on your experience, how might early life experiences associated with autism and BPD be similar?*
- ii) *Based on your experience, how might early life experiences of autistic individuals and individuals diagnosed with BPD be different?*

### **e) Associated risks**

**Associated risks** are specific risky behaviours associated with either BPD or autism. These

include behaviours that are risky to the person who does them (e.g., self-harm, suicide attempts, self-neglect, using alcohol and drugs, and so on).

- i) *In your experience, how are autism and BPD **similar** in terms of their associated risks?*
- ii) *In your experience, how are autism and BPD **different** in terms of their associated risks?*

#### **f) Relationships with others**

**Relationships with others** refers to friendships, family relationships, romantic relationships, relationships at work and relationships with professionals. This could include whether relationships are easy or difficult to initiate and maintain. It also refers to the nature of relationships, i.e., whether relationships are stable, turbulent, intense, balanced, etc. The emotional impact of interacting with others is also relevant here, i.e., whether it is draining, anxiety-provoking. This question refers to relationships as adults.

- i) *Based on your experience, how are the relationships that individuals have with others **similar**, for autistic individuals and individuals diagnosed with BPD?*
- ii) *Based on your experience, how are the relationships that individuals have with others **different**, for autistic individuals and individuals diagnosed with BPD?*

#### **g) Ability to mentalise and empathise**

**Ability to mentalise and empathise** refers to individuals' ability to understand what others may be feeling or thinking and why, including what others' intentions may be. It may include whether this is learnt or intuitive, and whether this ability changes depending on mood or who the other person is.

- i) *Based on your experience, in terms of ability to mentalise/empathise, how are autism and BPD **similar**?*
- ii) *Based on your experience, in terms of ability to mentalise/empathise, how are autism and BPD **different**?*

#### **i) Impact on everyday life**

**Impact on everyday life** refers to the day-to-day difficulties experienced because of autism and/or BPD, for example impact on mental health, relationships, work, etc.

- i) *Based on your experience, how is the impact of difficulties associated with BPD and autism **similar**?*
- ii) *Based on your experience, how is the impact of difficulties associated with BPD and autism **different**?*

**(iii) Based on your experience, what other factors might help to distinguish autism from BPD?** (Please list as many as you can think of, and do not hesitate to include ideas that you are not fully sure of).





**Appendix H: Delphi Items: Endorsement Ratings for all 161 Items**

**Table 6**

*Delphi Items: Endorsement Ratings for all 161 items*

Item no.	Item	Endorsement percentage			
		Across panels	Expert by experience	Autism expert panel	BPD expert panel
1*	Individuals with BPD are more likely than autistic people to reject others or end friendships for fear of being rejected themselves.	93.02%	100%	100%	76.92%
2*	Autistic individuals are more likely to have processing difficulties, for example, may be slower to process and comprehend information, and struggle with verbal instructions. This is not characteristic of BPD.	88.37%	82.35%	100%	84.62%
3*	Individuals with BPD are less likely to have difficulty with “small talk”, when not experiencing intense emotions or perceiving risk of rejection; autistic individuals are likely to consistently find small talk difficult (although this may not be obvious to an observer due to masking).	88.37%	88.24%	100%	76.9%

4	Autistic individuals are more likely to experience sensory difficulties (i.e., hypersensitive to sound, light, touch, smells, visual cues) to the extent that it is overwhelming, contributes to co-occurring mental health problems and leads to restrictions in activity, compared to BPD.	86.27%	88.89%	87.50%	82.35%
5	Difficulties in socialising with peers is likely to be present at an earlier age in autism (although may not have been picked up on by observers).	86.27%	83.33%	87.50%	88.24%
6	Recalling the following in childhood may indicate autism rather than BPD: - stimming (stimming could be misidentified as self-harm even in childhood, however) - sensory sensitivities - special interests	88.24%	88.89%	87.50%	88.24%
7	In autism, eating behaviours may be driven more by rules, rituals and routines, such as wanting to eat the same thing every day, fear of trying new food, or only eating from a particular plate, than in BPD.	88.24%	72.22%	100.00%	94.12%
8*	In BPD, emotion regulation difficulties are likely to be triggered by an interaction involving perceived rejection or invalidation. In autism, emotion regulation difficulties are more likely due to other factors, like sensory overload, social exhaustion or unexpected changes.	86.05%	94.12%	84.62%	76.92%
9*	Individuals with BPD are much more likely to be impulsive than autistic individuals, including in regards to behaviours that may be self-damaging, i.e., overspending, unsafe sex,	86.05%	94.12%	92.31%	69.23%

	substance misuse, reckless driving, binge eating. Impulsive actions that do occur in autism may be due to having struggled to process information or plan.				
10	Another person changing plans at the last minute may be difficult for individuals in both groups, and trigger emotions which are difficult to regulate. For individuals with BPD this could be due to perceived rejection or fears of abandonment; for autistic individuals, this may be due to disliking change (but may be misinterpreted by services).	84.31%	94.44%	81.25%	76.47%
11	For individuals with BPD, mentalising skills may be lost when highly emotional or when feeling vulnerable. For autistic individuals, difficulty mentalising is more consistent across time and situations (although, feeling distressed, tired, anxious or overwhelmed may exacerbate mentalising difficulties for autistic individuals).	84.31%	88.89%	81.25%	82.35%
12	Autistic individuals are more likely to describe not understanding the ‘social rules’ and have less developed social skills than individuals with BPD (although this may be hard to see from an observer perspective due to masking).	82.35%	88.89%	87.50%	70.59%
13	Autistic individuals show insistence on sameness, inflexible adherence to routines, and a preference for structure to a greater extent than individuals with BPD, whereas someone with BPD may change their habits more often.	82.35%	72.22%	93.75%	82.35%
14	In relationships, there is more likely to be a general sense of awkwardness in autism, and a feeling of not quite “getting it”.	82.35%	83.33%	87.50%	76.47%

15	Autistic individuals are more likely to adhere strictly to rules than those with BPD.	82.35%	72.22%	100%	76.47%
16	Autistic people often have stimming habits such as repetitive hand movements, humming or pacing. Individuals with BPD are much less likely to show this.	82.35%	83.33%	81.25%	82.35%
17	Both groups may be vulnerable to coercive or abusive relationships which are difficult to end, and to being exploited by others; autistic people may be “socially naïve” and trust the wrong people, whereas individuals with BPD may struggle to be on their own and stay in unhealthy relationships due to a fear of being abandoned.	82.35%	83.33%	87.50%	76.47%
18*	Interpersonal trauma in BPD more often takes the form of neglect or abuse. Autistic children may experience things as traumatising that neurotypical children would not, for example, growing up in environments where they are not understood, or being punished for reasons they do not understand.	81.40%	88.24%	69.23%	84.62%
19	Autistic individuals are more likely to report atypical language development including being slower to start communicating with others, than those with BPD.	80.39%	61.11%	93.75%	88.24%
20	Individuals with BPD may be more likely to engage in other risky behaviours in an impulsive way (i.e., sexually risky behaviour; gambling; overspending) compared to autistic individuals.	80.39%	77.78%	87.50%	76.47%

21	Individuals with BPD may move between seeking relationships, closeness and care, which they then might reject; a ‘push-pull’ pattern is less likely in autism.	80.39%	66.67%	93.75%	82.35%
22	Autistic individuals may be more likely to have co-occurring neurodevelopmental symptoms, including tic disorders such as Tourette’s, compared to those with BPD.	80.39%	72.22%	87.50%	82.35%
23*	Repetitive and restricted behaviours and interests are core to autism and are not in BPD.	79.07%	70.59%	92.31	76.92
24*	Autistic individuals are more likely to have atypical speech than those with BPD, including limited tonal range (which would not be expected in individuals with BPD).	79.07%	64.71%	100%	76.92%
25*	Autistic individuals may have more difficulties understanding appropriate body language than individuals with BPD.	79.07%	76.47%	100%	61.54%
26*	Both groups may have difficulties in managing change, but this is likely more marked in autism. In autism, if someone does not know something is happening and cannot control it, this might lead to a meltdown, more so than in BPD.	79.07%	88.24%	69.23%	76.92%
27*	Autistic adults are more likely to report delayed developmental milestones (i.e., walking and talking at expected times) than individuals who go	76.74%	64.71%	92.31%	76.92%

	on to be diagnosed with BPD.				
28*	Autistic individuals are more likely to have a special interest which they may fixate on, i.e., an ongoing specific and narrow interest in an object, thing, or topic. This may be seen as atypical, i.e., intense interest in trainspotting, or be considered more typical (especially in women), i.e., intense interest in animal welfare, climate change, or centred around work. Special interests would not be expected in individuals with BPD.	76.74%	70.59%	92.31%	69.23%
29*	Both groups may have difficulty identifying other people's emotions. This may be a consistent difficulty for autistic individuals, whereas those with BPD may be better able to identify and describe others' emotions when not under stress or highly emotional.	76.74%	58.82%	92.31%	84.62%
30*	Relationships may be more focused around hobbies or special interests in autism, compared to individuals with BPD.	76.74%	64.71%	84.62%	84.62%
31*	Autistic individuals may be more likely to report struggling with using eye contact than those with BPD.	76.74%	70.59%	76.92%	84.62%
32*	Individuals diagnosed with BPD are more likely to misinterpret a situation when mentalising (e.g., "she left the room because she hates me") whereas autistic people are less likely to mentalise at all (e.g., I have no idea why she left the room").	74.42%	70.59%	69.23%	84.62%
33*	Autistic individuals may be more likely to have the ability to focus intensely on special interests, but have markedly lower function in other areas (such as self-care or in other core	74.42%	58.82%	84.62%	84.62%

	life skills). Individuals with BPD are less likely to show such differences.				
34*	Autistic individuals are more likely to take things literally, not ‘get’ sarcasm, and struggle with metaphors and similes, which is unlikely to be a problem for individuals with BPD.	72.09%	70.59%	92.31%	53.85%
35*	Both groups may have difficulty identifying their own emotions (this may be described as alexithymia). This may be a consistent difficulty for autistic individuals, whereas those with BPD may be better able to identify and describe their emotions when not under stress or highly emotional.	72.09%	58.82%	100%	61.54%
36*	Relationships being draining and exhausting, in autism, is likely in part due to masking (hiding autistic traits), whereas this is more likely to do with anxiety-related to fear of being abandoned in BPD.	72.09%	82.35%	61.54%	69.23%
37*	After having socialised, autistic individuals are more likely to need to compensate with a period of being alone, compared to those with BPD.	69.77%	76.47%	61.54%	69.23%
38*	Autistic individuals are more likely to have learning disabilities or learning difficulties than individuals with BPD, including specific learning difficulties such as dyslexia, dyspraxia, and dyscalculia.	69.77%	52.94%	100%	61.54%
39*	Autistic individuals may have more of an aversion to group interactions than individuals with BPD.	69.77%	70.59%	76.92%	61.54%

40*	Difficulties at school for autistic children may be due to the environment (e.g., too noisy; difficulty following verbal instructions). In a person later diagnosed with BPD, difficulties may be caused by unsupportive parents/carers, anxiety or dissociation.	69.77%	76.47%	61.54%	69.23%
41*	Relationship difficulties in autism are more likely to be driven by: rigidity in routines; everything needing to be in its place; sensory difficulties; the other person doing something unexpected, rather than an interaction, as in BPD.	69.77%	88.24%	53.85%	61.54%
42*	The type of problems at work are likely to be different. Someone with autism is likely to have specific requirements for the type of environment they are comfortable working in, e.g., working alone, needing adjustment to uniform policy due to materials, working regular shift pattern for predictability. Someone with BPD may be more likely to struggle to maintain one job due to impulsivity or difficulties working with others.	69.77%	76.47%	53.85%	76.92%
43*	Autistic individuals may be more likely to be confused by the task of mentalising (partly due to difficulties in reading facial expressions), whereas individuals with BPD may interpret others feeling and thoughts with a negative bias.	69.77%	76.47%	61.54%	69.23%
44	Autistic individuals may find it more difficult to learn mentalising skills, for example, in therapy, than those with BPD.	68.63%	61.11%	75.00%	70.59%
45	Relationships tend to be more turbulent in BPD, which may be exhilarating but also intensely painful. Autistic individuals are more likely to be emotionally detached from relationships	68.63%	72.22%	62.50%	70.59%

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and not experience such highs and lows. (However, if autism is undiagnosed, relationships may be turbulent as others' may not understand particular aspects of the autistic person or their interactions).

46	Autistic individuals are more likely to have exceptional ability in a specific area, for example, excellent memory of facts and dates, compared to people with BPD.	66.67%	61.11%	75.00%	64.71%
47	In BPD, eating behaviours are more likely to be used as a way to control difficult emotions than in autism.	66.67%	55.56%	75.00%	70.59%
48	Mentalising is more intuitive for individuals diagnosed with BPD; autistic individuals may report having to learn this, either by observing others or learning rules about how it "works" (and may struggle when others' emotions don't follow the rules they have learnt)	66.67%	66.67%	75.00%	58.82%
49	Autism is often more of a stable presentation than BPD.	66.67%	55.56%	75.00%	70.59%
50	Friendships of autistic individuals are more likely to be stable, balanced and long-lasting, especially if there are no external changes to the relationship. As relationships develop in BPD, it is more likely they become all-consuming and/or turbulent	66.67%	72.22%	56.25%	70.59%
51	Distress in autism is likely to be caused by too much input from one of the five senses; in BPD, distress is likely to be caused by interactions with others (what appears to be sensory sensitivity in BPD is more likely to related to traumatic experiences).	66.67%	77.78%	62.50%	58.82%

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52*	Autistic individuals are much less likely to have a fear of abandonment than individuals with BPD typically experience; therefore, behaviours to avoid abandonment are characteristic to BPD and not autism.	65.12%	64.71%	84.62%	46.15%
53	Individuals with BPD, more so than autistic individuals, are likely to struggle to maintain a sense of self in a relationship, which may result in enmeshment (where boundaries between people are unclear) or subjugation (being controlled by another).	64.71%	72.22%	62.50%	58.82%
54	In relationships, individuals with BPD are much more likely to describe or show a fear of being abandoned, which might lead to attempts to prevent it; this is not characteristic of autism.	64.71%	50.00%	75.00%	70.59%
55	Autistic individuals, unlike those diagnosed with BPD, may struggle to empathise as they may value facts, information and practical solutions which could help someone, over expression, talking, comforting and physical affection.	64.71%	61.11%	62.50%	70.59%
56	Individuals with BPD are more likely to move from idealising others (seeing them as all good) to devaluing others (seeing them as all bad), compared to autistic individuals, who may see their loved one in a more stable, consistent way.	64.71%	50.00%	75.00%	70.59%
57	For individuals with BPD, an interest may be interpersonally focused, e.g., a new interest might be developed as a way of entry to a particular group, rather than an end in itself.	64.71%	50.00%	68.75%	76.47%

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	Autistic individuals’ main relationships may be more hobby-centred, but the focus remains on the hobby, rather than the relationship.				
58	Individuals in both groups may report “being different” and having a sense of not fitting in, although this may start earlier for autistic individuals, and start later for those later diagnosed with BPD.	64.71%	77.78%	50.00%	64.71%
59	Therapy is more likely to involve ruptures in the therapeutic relationship, as well as mistrust, in BPD than in autism.	62.80%	61.11	62.50	64.71%
60*	Autistic individuals may find it hard to express how they are feeling; individuals with BPD are less likely to struggle with this, and may do so involuntarily, even if trying to suppress it (such as in the workplace).	62.79%	70.59%	69.23%	46.2%
61	Children with autism are more likely to have been ostracised or bullied at school, citing reasons such as always being different, not fitting in, not wearing the right clothes or liking the right things. Individuals diagnosed with BPD may report being bullied at school for being different due to the impact of neglect, abuse or trauma.	62.75%	72.22%	68.75%	47.06%
62	Autistic individuals may have more difficulty in initiating friendships (partly due to difficulties with small talk, other subtle social behaviours, and ‘reading’ others’ emotions) than those with BPD. Individuals with BPD may have more difficulties in maintaining friendships, rather than initiating/making them).	62.75%	61.11%	68.75%	58.82%

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63	Autistic individuals may cite that they were more vulnerable to abuse or damaging relationships due to a lack of understanding about relationships, trouble spotting danger, social naivety, and understanding what is ‘normal’, in addition to being isolated from peers, compared to individuals diagnosed with BPD.	62.75%	77.78%	62.50%	47.06%
64	Individuals in both groups may struggle with touch which might make intimate relationships difficult; in autism, this may relate to a sensory difficulty whereas in BPD this could relate to past experiences of trauma.	62.75%	66.67%	50.00%	70.59%
65	Difficulties with cognitive empathy (understanding what someone might be feeling and thinking) may be more pronounced in autistic people than in people diagnosed with BPD.	62.75%	55.56%	68.75%	64.71%
66	Those diagnosed with BPD may be more likely than autistic individuals to recall a chaotic or unstable home life including parents having their own physical or mental health problems, financial or relationship difficulties.	62.75%	44.44%	68.75%	76.47%
67	The difficulties of autistic individuals may align with transitions, i.e., between schools or moving; for those who may get a BPD diagnosis, difficulties may get worse over time but not necessarily correlate with school stage transitions.	62.75%	66.67%	56.25%	64.71%
68	Avoidant Restrictive Food Intake Disorder (ARFID) is more common in autistic individuals than those with BPD (i.e., involves restricting food but this is not due to distress around body shape, size, or fears of fatness).	60.78%	55.56%	62.50%	64.71%
69	Adapting the environment might lead to significant improvement in difficulties, in autism. This is not the case for individuals with BPD.	60.78%	61.11%	68.75%	52.94%

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70	Autistic individuals may experience difficulties in mentalising regardless of the emotion expressed and may not pick up on anger or disinterest, whereas individuals with BPD may misread neutral communication as anger or disinterest.	60.78%	61.11%	43.75%	76.47%
71	Both groups may experience financial difficulties. For individuals with BPD this is more likely to be associated with impulsive behaviour leading to debt; for autistic individuals this may be due to difficulties such as paying bills due to executive function difficulties.	60.78%	55.56%	75.00%	52.94%
72	Self-neglect in autism is due to not understanding what is expected or appropriate, or due to lack of development of executive skills (e.g., starting tasks, planning, organizing). In BPD, self-neglect is more likely associated with emotions such as depression impacting motivation, or low self-esteem.	60.78%	61.11%	56.25%	64.71%
73*	“Black and white thinking” in BPD may be specific to other people (who may be seen as all good or all bad at different times). Black and white thinking may be more global in autism, including with regard to non-emotional topics.	60.47%	58.82%	69.23%	53.8%
74	Eating disorders that involve impulsive behaviours, such as binge eating disorder, are more likely to be experienced in individuals diagnosed with BPD than in autistic individuals (although there may be a sensory element to bingeing and purging in autism which is not present in BPD).	58.82%	61.11%	56.25%	58.82%
75	Autistic individuals may find it challenging or confusing to initiate romantic relationships; this is not characteristic of BPD. However, once started, the relationship may be more stable and long-lasting as opposed to turbulent, intense and more likely short-lived in BPD.	58.82%	55.56%	62.50%	58.82%

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76	Autistic individuals are less likely than individuals with BPD, to use gestures, facial expression and coordinated eye contact to communicate effectively with others.	58.82%	50.00%	62.50%	64.71%
77	Individuals with BPD may be more likely to use substances impulsively than autistic adults.	58.82%	77.78%	62.50%	35.29%
78	Individuals with BPD may be more likely to say that they don't know who they are, what their interests are, what their opinion is on things, or what they value, which is at odds with autism where individuals may have fixed and rigid interests, opinions and values.	58.82%	61.11%	37.50%	76.47%
79	Individuals with BPD may be more likely to use substances to numb intense emotions than autistic individuals.	58.82%	77.78%	43.75%	52.94%
80	Autistic individuals are more likely to have no or little interest in romantic relationships than individuals with BPD, or no history of romantic relationships, and might prefer to be on their own; individuals with BPD are more likely to have histories of moving from one relationship to another and fearing being on their own.	58.82%	44.44%	68.75%	64.71%
81	Therapeutic relationships, i.e., the relationship between a clinician and a patient, may feel more turbulent for both parties in BPD, and more predictable in autism.	58.82%	38.89%	75.00%	64.71%
82	Both groups may experience social anxiety but this may be more prominent in autistic individuals.	58.82%	72.22%	56.25%	47.06%

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83*	In autism, eating behaviours may be driven by sensory-seeking or sensory-avoidance, or discomfort with being full. This is not characteristic of BPD.	58.14%	52.94%	61.54%	61.54%
84*	Individuals with BPD may have increased capacity to reflect when no longer experiencing intense emotions, compared to autistic individuals. For example, individuals with BPD, when emotionally regulated, can, with time, work through some of their triggers and identify what might have led to difficult feelings and thoughts; autistic individuals may more consistently struggle to articulate the cause of their distress.	58.14%	64.71%	46.15%	61.54%
85*	For autistic individuals, tasks involving adaptive function (such as: getting from place to place, managing the home, maintaining self-care and hygiene: solving problems, planning, and organising) may be more difficult than those with BPD.	58.14%	47.06%	84.62%	46.15%
86*	Whilst both groups are more likely to have medically unexplained symptoms such as Chronic Fatigue Syndrome, and Fibromyalgia, autistic individuals may be more likely to have other co-occurring physical health problems, including complex medical conditions, than those with BPD, including: seizures; epilepsy; hypermobility; allergies; Ehlers Danlos Syndrome; Postural Tachycardia Syndrome (POTS); rare genetic conditions; eye sight or hearing problems; skin problems (N.B. it is possible that pain may be dismissed as ‘somatising’ or fibromyalgia in those with undiagnosed autism, when it could relate to one of the above conditions).	58.14%	58.82%	76.92%	38.46%
87	Autistic adults are more likely to find it difficult to balance time given to relationships with time spent on interests, or activities, compared to those with BPD.	56.86%	61.11%	68.75%	41.18%

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88	Individuals with BPD may be more likely to use risky behaviours as a way to ‘thrill-seek’ compared to autistic adults.	56.86%	61.11%	56.25%	52.94%
89	Autistic individuals may be more likely to report always having felt different, or odd, and may be more likely to say, “I just feel different; I want to understand why my brain works so differently to other people’s” than individuals with BPD.	56.86%	61.11%	62.50%	47.06%
90	Individuals with BPD are more likely to self-harm or show suicidal intent in the context of fear of abandonment, compared to autistic individuals.	56.86%	50.00%	75.00%	47.06%
91	Friendship difficulties at school may be due to not understanding others in autistic individuals, and due to difficulties self-regulating in children who are later diagnosed with BPD as adults.	56.86%	66.67%	56.25%	47.06%
92	Autistic individuals are more likely to have difficulties in all areas of their life, and these difficulties can be present regardless of an individual’s current mental health. Difficulties may get worse and better at times due to stress but they are almost always present, whereas people with BPD may go through periods of having relatively little difficulty.	56.86%	66.67%	75.00%	29.41%
93*	Individuals with BPD may be more likely than those with autism, to be ‘in tune’ with others’ emotions, i.e., can easily read between the lines when someone says something but means	55.81%	58.82%	53.85%	53.80%

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	something else, or feels differently to the way they are saying they do; individuals with autism would likely struggle with this.				
94	Autistic individuals are more likely to be expressionless or show restricted emotion in therapy, than individuals with BPD.	54.90%	44.44%	62.50%	58.82%
95	Autistic individuals may feel physically exhausted and drained following day-to-day social interaction, to a greater extent than individuals with BPD.	54.90%	66.67%	68.75%	29.41%
96	People with BPD may be more focused on the emotional aspects of a relationship while autistic people may be more focused on the functional aspects of a relationship.	54.90%	50.00%	50.00%	64.71%
97	Autistic individuals may struggle to accurately identify which emotion another is experiencing in the absence of physical cues such as crying, whereas someone with BPD would be expected to be able to identify such emotions.	54.90%	61.11%	62.50%	41.18%
98	Individuals with BPD may describe vigilance for others' mental states due to needing to either care for and/or be wary of attachment figures in childhood. This is not characteristic of autism.	54.90%	38.89%	62.50%	64.71%
99	Transference and countertransference are more dominant when working with people with BPD, compared to autistic individuals, i.e., the interaction may leave the therapist or clinicians feeling strong emotions, as if they have been passed on.	54.90%	27.78%	75.00%	64.71%

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100	Self-harm in autistic adults, as opposed to BPD, may be ‘stimming’, i.e., a repetitive motor behaviour used to engage the senses in a way that the person finds soothing, particularly as a form of release from tension caused by sensory overload. This is not the case in BPD.	54.90%	55.56%	43.75%	64.71%
101	In autism, co-occurring difficulties are more likely to be associated with executive function difficulties (such as avoidance, concentration, maintaining hygiene, and work and education) which may lead to harmful behaviours; the co-occurring difficulties in BPD focus on coping mechanisms, which may be impulsive and extreme.	54.90%	50.00%	56.25%	58.82%
102*	Both autistic individuals and individuals diagnosed with BPD may present with symptoms of obsessive-compulsive disorder (OCD), but this is more common in autistic adults.	53.49%	70.59%	38.46%	46.15%
103	Suicide attempts are more frequent in those with BPD than in autistic individuals.	52.98%	44.44%	50.00%	58.82%
104	An autistic individual may avoid or withdraw from friendships due to not feeling understood by others, feeling overwhelmed or needing their own space, whereas someone with BPD may withdraw or avoid friendships to avoid being rejected.	52.94%	66.67%	37.50%	52.94%
105	Autistic individuals may be less likely to seek out friendships and other relationships than those with BPD.	52.94%	44.44%	50.00%	64.71%

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106	Autistic individuals may be more likely to use substances to manage social situations, including to ‘mask’ their autism, including for reasons such as: to overcome social anxiety; to fit in; to reduce discomfort, to connect with peers, or to ‘feel normal’	52.94%	55.56%	75.00%	29.41%
107	Individuals diagnosed with BPD are more likely to show dissociative symptoms (feeling disconnected from themselves and the world around them).	52.94%	38.89%	68.75%	52.94%
108	Dissociation (feeling disconnected from oneself and the world around them) tends to be discussed more in sessions with BPD clients who are worried about “losing time” in their day under stress. Autistic patients are more likely to remember sessions with great clarity.	52.94%	55.56%	50.00%	52.94%
109	Autistic adults are more likely to self-harm when the environment is not adapted to their individual needs or if they are in an unfamiliar situation or unstable environment. This is not the case in BPD.	52.94%	50.00%	56.25%	52.94%
110	Individuals with BPD may be more likely to “over-empathise” compared to autistic individuals; empathy may feel more intense and physical in BPD.	52.94%	55.56%	31.25%	70.59%
111	For an autistic individual, there may be more anxiety and distress in starting a relationship; for individuals with BPD, there may be more anxiety and distress once the relationship has already started.	52.94%	72.22%	37.50%	47.06%

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112	A long-term pattern of suicidality and recurrent psychiatric inpatient admissions is more characteristic of BPD than autism.	52.94%	44.44%	50.00%	64.71%
113	Autistic individuals may cite that abuse, if it occurred, was due to observable differences, not being “normal”, and because their parents did not understand autism, compared to those with BPD.	50.98%	77.78%	37.50%	35.29%
114	Individuals with BPD, in contrast to autistic individuals, would not be expected to struggle with reciprocity (i.e., turn-taking and back-and-forth conversation) when talking to others.	50.98%	55.56%	62.50%	35.29%
115	Both groups may often feel and appear to be angry or frustrated, which may be perceived as disproportionate by observers. In autism, this may be due to sensory overload whilst in BPD this may be more likely due to an interaction with another person.	50.98%	50.00%	37.50%	64.71%
116	Autistic individuals are likely to respond less well to group therapy due to the large social aspect and unstructured nature.	50.98%	66.67%	37.50%	47.06%
117	Autistic individuals are be more likely to have synaesthesia (where senses are blended, for example, being able to hear music as colours, or taste shapes) compared to those with BPD.	50.98%	61.11%	50.00%	41.18%
118	Overall, autistic individuals may start having sexual relationships at a later age than individuals with BPD.	50.98%	55.56%	50.00%	47.06%

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119	In those with BPD, self-harm is more likely to be associated with interpersonal conflict compared to autistic adults.	50.98%	55.56%	50.00%	47.06%
120	Although both groups may be at an elevated risk of developing addiction to alcohol or non-prescription drugs, compared to the general population, this risk may be greater in those with BPD.	49.02%	66.67%	62.50%	17.65%
121	Self-harm is more likely to be impulsive in adults with BPD than in autistic adults. Self-harm is more likely to be planned, ritualistic and use the same method in autistic adults.	49.02%	72.22%	37.50%	35.29%
122	Autistic adults may be more likely to engage in repetitive, sometimes compulsive, self-injurious behaviours (such as headbanging, picking, scratching, pulling hair, punching self) whereas those with BPD may be more likely to cut.	49.02%	27.78%	68.75%	52.94%
123	Individuals with BPD may use behaviours to communicate a need for care from others; autistic individuals may be less likely to do this.	49.02%	44.44%	43.75%	58.82%
124	Individuals with BPD may be more likely to access support after a major life event, such as a suicide attempt; having autistic traits may be a much slower realization, feeling that something isn't right over time.	49.02%	55.56%	50.00%	41.18%

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125	Although both groups may be at an elevated risk compared to the general population, individuals diagnosed with BPD may be more likely to use substances than autistic adults.	49.02%	55.56%	56.25%	35.29%
126*	For those with BPD, self-harm may be used to communicate distress, or communicate to others in some way. Autistic adults are less likely to think about impact of self-harming on others.	48.84%	58.82%	61.54%	23.08%
127	Individuals with BPD are more likely to experience feelings of emptiness than autistic adults.	47.06%	44.44%	37.50%	58.82%
128	In autism, having an unstable sense of self may be particularly acute for those with undiagnosed autism, and can resolve as a result of an autism diagnosis. Unstable sense of self is unlikely to improve for those with BPD merely as a result of receiving a BPD diagnosis.	47.06%	61.11%	37.50%	41.18%
129	Autistic individuals may report retreating into their 'inner world' following trauma, whereas a child who grows up to get a BPD diagnosis may be described as "acting out".	47.06%	61.11%	50.00%	29.41%
130	Autistic individuals may require more direction and confirmation from the therapist than those with BPD.	47.06%	55.56%	56.25%	29.41%
131	Autistic people tend to be confused by people and situations whereas individuals with BPD may be aggravated by them.	47.06%	55.56%	37.50%	47.06%

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132	The process of seeking support may be more difficult for autistic individuals than those with BPD, as they may believe they should be able to manage independently, may not recognise that they need support, or find it harder to access, i.e., may find it hard to use the telephone.	47.06%	55.56%	50.00%	35.29%
133*	Autistic individuals are more likely to retain the same interest or hobby for a sustained period of time; individuals with BPD are more likely to start various hobbies but not continue with them, or switch between them.	46.51%	58.82%	15.38%	61.54%
134	Individuals with BPD may be more likely to self-harm than autistic adults.	45.18%	33.33%	50.00%	41.18%
135	Social relationships in general may feel less important to autistic individuals than those with BPD.	45.10%	38.89%	31.25%	64.71%
136	Feelings of shame and anger may be more prominent in individuals with BPD than in autistic individuals.	45.10%	44.44%	31.25%	58.82%
137	Adults with BPD may be more likely to attempt suicide than autistic adults (although those with undiagnosed autism may be more likely to attempt suicide than those with diagnosed autism).	45.10%	50.00%	37.50%	47.06%
138	The aim of suicide attempts may be different; for autistic adults, the aim might be to be dead; for individuals with BPD, the aim might be to escape a situation or feeling.	45.10%	44.44%	37.50%	52.94%

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139*	Autistic individuals are likely to recall difficulties in identifying and communicating emotions starting earlier in life, whereas individuals with BPD may refer to these difficulties emerging in adolescence or early adulthood.	44.19%	64.71%	38.46%	23.08%
140	Autistic adults who self-harm may be less able to weigh up the risks involved, or lack awareness of consequences; individuals with BPD may understand the risk but this is over-ridden by distress.	43.14%	55.56%	37.50%	35.29%
141	Autistic individuals are unlikely to seek intimacy when stressed, in contrast to those with BPD.	43.14%	38.89%	50.00%	41.18%
142*	With age, people with BPD can move away from some of the behaviours exhibited when struggling to regulate emotions; although they still experience difficulties, these may not be expressed so overtly. Autistic people struggle with "meltdowns" and this does not lessen with time although autistic people may learn to avoid triggers if that is possible.	41.86%	70.59%	7.69%	38.46%
143	Autistic people may find it harder to ask for help than those with BPD.	41.18%	44.44%	50.00%	29.41%
144	The relationships of people with BPD are more likely to end suddenly than relationships of autistic people.	41.18%	44.44%	31.25%	47.06%

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145	Due to impulsivity, individuals with BPD may be more likely to have contact with the criminal justice system than autistic individuals (although the risk for individuals with autism is higher than in the general population).	41.18%	61.11%	31.25%	29.41%
146	In those with BPD, self-harm may be more likely associated with difficulty regulating emotions/managing emotions.	39.22%	55.56%	18.75%	41.18%
147	For individuals with BPD, risky behaviours (self-harm, substance misuse) may be used as a form of self-punishment more so than in autism.	39.22%	38.89%	43.75%	35.29%
148	Autistic individuals often have a 'list' in their head of what they need to say and come back to this list of things in their head throughout the session, which is less characteristic of BPD.	39.22%	55.56%	31.25%	29.41%
149	Autistic individuals are more likely to have a clear and internally coherent sense of self, compared to individuals with BPD.	37.25%	44.44%	25.00%	41.18%
150	In BPD the overall drive is to move away from or go to another place where things are better; in autism, usually the drive is to go back to the way things were (not better or worse but as they were).	35.29%	50.00%	25.00%	29.41%
151	Individuals diagnosed with BPD are more likely to have experienced childhood adversity than autistic individuals.	35.29%	33.33%	37.50%	35.29%

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152	Autistic individuals may be more likely to develop gaming addictions than those diagnosed with BPD.	33.33%	33.33%	31.25%	35.29%
153	Autistic individuals may struggle to separate their own inner world from that of others (“she left the room because I am bored”).	33.33%	44.44%	12.50%	41.18%
154	Autistic individuals may not experience the same sense of intense loss as individuals with BPD, when a relationship ends.	33.33%	38.89%	25.00%	35.29%
155	Individuals with BPD are more likely to have long-term problems with self-harm and suicide attempts which are not easily managed or helped with usual therapies; for autistic individuals with associated depression and anxiety, self-harm is more likely to reduce after treatment such as antidepressants or cognitive behavioural therapy (CBT).	31.37%	44.44%	25.00%	23.53%
156	Autistic individuals are more likely to appear avoidant of their emotions than individuals with BPD.	29.41%	27.78%	25.00%	35.29%
157	Autistic individuals may find it more difficult to empathise with strangers more so than friends/family, whereas individuals diagnosed with BPD may find empathizing more difficult with those they are attached to.	29.41%	33.33%	37.50%	17.65%

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158	Autistic individuals may be more likely to self-harm due to isolation and subsequent low mood, compared to individuals with BPD.	25.49%	55.56%	12.50%	5.88%
159	Autistic people can often come across as seeming young for their age. This is usually not the case for individuals with BPD.	23.53%	22.22%	18.75%	29.41%
160	Autistic individuals are more likely to have online relationships than individuals with BPD.	23.53%	27.78%	31.25%	11.76%
161	Unlike BPD, self-harm in autistic adults may be a form of mimicry where they have heard or observed others doing similarly when distressed.	15.69%	22.22%	12.50%	11.76%

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*Note.* Items shaded in light blue were endorsed by 80% or more of panellists and were included in the final item list. Items shaded in darker blue were endorsed by 70-79% of panellists and met consensus when the threshold was lowered by 10% in the sensitivity analysis. Asterix (\*) highlight items which were re-rated. The endorsement ratings for re-rated items are from the second round.

**Appendix I: Between-group Differences in Endorsement Ratings: Odds Ratios**

**Table 7**

*Between-group Differences in Endorsement Ratings: Odds Ratios*

Category	Item	Round one (95% CI)		
		Autism experts x BPD experts BPD experts = comparison group	BPD Experts x Experts by Experience Experts by experience = comparison group	Experts by Experience x Autism experts Autism experts = comparison group
Met consensus	Autistic individuals are more likely to adhere strictly to rules than those with BPD.	OR = 11.0 (.5–223.0) p = .12	OR = 1.3 (.3–5.7) p = .77	OR = .1 (.0–1.5) p = .09

in first round	Autistic individuals show insistence on sameness, inflexible adherence to routines, and a preference for structure to a greater extent than individuals with BPD, whereas someone with BPD may change their habits more often.	<i>OR</i> = 3.2 (.3–34.6) <i>p</i> = .34	<i>OR</i> = 1.8 (.4–9.1) <i>p</i> = .48	<i>OR</i> = .2 (.0–1.7) <i>p</i> = .13
	Another person changing plans at the last minute may be difficult for individuals in both groups, and trigger emotions which are difficult to regulate. For individuals with BPD this could be due to perceived rejection or fears of abandonment; for autistic individuals, this may be due to disliking change (but may be misinterpreted by services).	<i>OR</i> = 1.3 (.3–7.1) <i>p</i> = .74	<i>OR</i> = .2 (.0–1.9) <i>p</i> = .16	<i>OR</i> = 3.9 (.4– 42.2) <i>p</i> = .26
	Autistic individuals are more likely to describe not understanding the ‘social rules’ and have less developed social skills than individuals with BPD (although this may be hard to see from an observer perspective due to masking).	<i>OR</i> = 2.9 (.5–17.9) <i>p</i> = .25	<i>OR</i> = .3 (.1–1.8) <i>p</i> = .19	<i>OR</i> = 1.1 (.1–9.2) <i>p</i> = .90
	Autistic individuals are more likely to experience sensory difficulties (i.e., hypersensitive to sound, light, touch, smells, visual cues) to the extent that it is overwhelming, contributes to co-occurring mental health problems and leads to restrictions in activity, compared to BPD.	<i>OR</i> = 1.5 (.2–10.4) <i>p</i> = .68	<i>OR</i> = .6 (.1–4.0) <i>p</i> = .58	<i>OR</i> = 1.1 (.1–9.2) <i>p</i> = .90
	Autistic people often have stimming habits such as repetitive hand movements, humming or pacing. Individuals with BPD are much less likely to show this.	<i>OR</i> = .9 (.2–5.5) <i>p</i> = .93	<i>OR</i> = .93 (.2–5.4) <i>p</i> = .94	<i>OR</i> = 1.2 (.2–6.7) <i>p</i> = .87
	For individuals with BPD, mentalising skills may be lost when highly emotional or when feeling vulnerable. For autistic individuals, difficulty mentalising is more consistent across time and situations (although, feeling distressed, tired, anxious or overwhelmed may exacerbate mentalising difficulties for autistic individuals).	<i>OR</i> = .9 (.2–5.5) <i>p</i> = .93	<i>OR</i> = .6 (.1– 4.0) <i>p</i> = .58	<i>OR</i> = 1.9 (.3–12.8) <i>p</i> = .53

Individuals with BPD may move between seeking relationships, closeness and care, which they then might reject; a ‘push-pull’ pattern is less likely in autism.	<i>OR</i> = 3.2 (.3–34.6) <i>p</i> = .34	<i>OR</i> = 2.3 (.5–11.4) <i>p</i> = .30	<i>OR</i> = .1 (.0–1.3) <i>p</i> = .08
In relationships, there is more likely to be a general sense of awkwardness in autism, and a feeling of not quite “getting it”.	<i>OR</i> = 2.2 (.3–13.8) <i>p</i> = .42	<i>OR</i> = .7 (.1–3.5) <i>p</i> = .61	<i>OR</i> = 1.5 (.3–8.2) <i>p</i> = .61
Both groups may be vulnerable to coercive or abusive relationships which are difficult to end, and to being exploited by others; autistic people may be “socially naïve” and trust the wrong people, whereas individuals with BPD may struggle to be on their own and stay in unhealthy relationships due to a fear of being abandoned.	<i>OR</i> = 2.2 (.3–13.8) <i>p</i> = .42	<i>OR</i> = .7 (.12–46.0) <i>p</i> = .61	<i>OR</i> = .7 (.2–4.9) <i>p</i> = .73
Individuals with BPD may be more likely to engage in other risky behaviours in an impulsive way (i.e., sexually risky behaviour; gambling; overspending) compared to autistic individuals.	<i>OR</i> = 2.2 (.3–13.8) <i>p</i> = .42	<i>OR</i> = .9 (.20–4.5) <i>p</i> = .93	<i>OR</i> = .5 (.1–3.0) <i>p</i> = .46
In autism, eating behaviours may be driven more by rules, rituals and routines, such as wanting to eat the same thing every day, fear of trying new food, or only eating from a particular plate, than in BPD.	<i>OR</i> = 3.0 (.1–79.1) <i>p</i> = .51	<i>OR</i> = 6.2 (.6–59.5) <i>p</i> = .17	<i>OR</i> = .1 (.0–1.5) <i>p</i> = .09
Autistic individuals may be more likely to have co-occurring neurodevelopmental symptoms, including tic disorders such as Tourette’s, compared to those with BPD.	<i>OR</i> = 1.5 (.2–10.4) <i>p</i> = .68	<i>OR</i> = 1.8 (.4–9.1) <i>p</i> = .48	<i>OR</i> = .4 (.1–2.3) <i>p</i> = .28

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	Difficulties in socialising with peers is likely to be present at an earlier age in autism (although may not have been picked up on by observers).	<i>OR</i> = .9 (.1–7.6) <i>p</i> = .95	<i>OR</i> = 1.5 (.2–10.3) <i>p</i> = .68	<i>OR</i> = .7 (.1–4.9) <i>p</i> = .73
	Autistic individuals are more likely to report atypical language development including being slower to start communicating with others, than those with BPD.	<i>OR</i> = 2.0 (.2–24.5) <i>p</i> = .59	<i>OR</i> = 4.8 (.8–27.6) <i>p</i> = .08	<b><i>OR</i> = 9.5 (1.0–89.2) <i>p</i> = .05</b>
	Recalling the following in childhood may indicate autism rather than BPD: - stimming (stimming could be misidentified as self-harm even in childhood, however) - sensory sensitivities - special interests	<i>OR</i> = .9 (.1–7.6) <i>p</i> = .95	<i>OR</i> = .9 (.1–7.5) <i>p</i> = .95	<i>OR</i> = 1.1 (.1–9.2) <i>p</i> = .90
Re-rated in second round (endorsed by 70%-80% of panellists overall)	In BPD, emotion regulation difficulties are likely to be triggered by an interaction involving perceived rejection or invalidation. In autism, emotion regulation difficulties are more likely due to other factors, like sensory overload, social exhaustion or unexpected changes.	<i>OR</i> = 2.4 (.5–11.7) <i>p</i> = .29	<i>OR</i> = .4 (.1–1.80) <i>p</i> = .22	<i>OR</i> = 1.2 (.2–6.7) <i>p</i> = .87
	Both groups may have difficulty identifying their own emotions (this may be described as alexithymia). This may be a consistent difficulty for autistic individuals, whereas those with BPD may be better able to identify and describe their emotions when not under stress or highly emotional.	<i>OR</i> = 1.5 (.2–10.4) <i>p</i> = .68	<i>OR</i> = 3.7 (.8–17.7) <i>p</i> = .10	<i>OR</i> = .2 (.0–1.0) <i>p</i> = .05
	Individuals with BPD may be more likely than those with autism, to be ‘in tune’ with others’ emotions, i.e., can easily read between the lines when someone says something but	<i>OR</i> = .3 (.1–1.8) <i>p</i> = .19	<i>OR</i> = 4.8 (.8–27.6) <i>p</i> = .08	<i>OR</i> = .7 (.2–3.0) <i>p</i> = .64

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means something else, or feels differently to the way they are saying they do; individuals with autism would likely struggle with this.

Autistic individuals may find it hard to express how they are feeling; individuals with BPD are less likely to struggle with this, and may do so involuntarily, even if trying to suppress it (such as in the workplace).	<i>OR</i> = 3.8 (.6–22.8) <i>p</i> = .14	<i>OR</i> = 1.2 (.3–4.6) <i>p</i> = .83	<i>OR</i> = .2 (.0–1.3) <i>p</i> = .10
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“Black and white thinking” in BPD may be specific to other people (who may be seen as all good or all bad at different times). Black and white thinking may be more global in autism, including with regard to non-emotional topics.	<i>OR</i> = 3.8 (.6–22.8) <i>p</i> = .14	<i>OR</i> = 1.2 (.3–4.6) <i>p</i> = .83	<i>OR</i> = .2 (.0–1.3) <i>p</i> = .10
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Individuals with BPD are much more likely to be impulsive than autistic individuals, including in regards to behaviours that may be self-damaging, i.e., overspending, unsafe sex, substance misuse, reckless driving, binge eating. Impulsive actions that do occur in autism may be due to having struggled to process information or plan.	<i>OR</i> = 2.9 (.5–17.9) <i>p</i> = .25	<i>OR</i> = .9 (.2–4.0) <i>p</i> = .91	<i>OR</i> = .4 (.1–2.3) <i>p</i> = .28
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Both groups may have difficulties in managing change, but this is likely more marked in autism. In autism, if someone does not know something is happening and cannot control it, this might lead to a meltdown, more so than in BPD.	<i>OR</i> = 2.4 (.5–11.7) <i>p</i> = .29	<i>OR</i> = .4 (.1–1.8) <i>p</i> = .22	<i>OR</i> = 1.2 (.2–6.7) <i>p</i> = .87
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Autistic individuals may have more difficulties understanding appropriate body language than individuals with BPD.	<b><i>OR</i> = 10.5</b> <b>(1.1–98.9)</b> <b><i>p</i> = .04</b>	<i>OR</i> = .4 (.1–1.8) <i>p</i> = .23	<i>OR</i> = .2 (.0–2.4) <i>p</i> = .22
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Autistic individuals are more likely to take things literally, not ‘get’ sarcasm, and struggle with metaphors and similes, which is unlikely to be a problem for individuals with BPD.	<b><i>OR</i> = 10.5</b> <b>(1.1–98.9)</b> <b><i>p</i> = .04</b>	<i>OR</i> = .4 (.1–1.8) <i>p</i> = .23	<i>OR</i> = .2 (.0–2.4) <i>p</i> = .22
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Autistic individuals may be more likely to report struggling with using eye contact than those with BPD.	<i>OR</i> = 1.3 (.3–5.8) <i>p</i> = .78	<i>OR</i> = .9 (.2–4.0) <i>p</i> = .91	<i>OR</i> = .9 (.2–4.0) <i>p</i> = .85
Autistic individuals are more likely to have atypical speech than those with BPD, including limited tonal range (which would not be expected in individuals with BPD).	<i>OR</i> = 2.0 (.2–24.5) <i>p</i> = .59	<b><i>OR</i> = 9.4</b> <b>(1.6 – 53.6)</b> <b><i>p</i> = .01</b>	<b><i>OR</i> = .1</b> <b>(.0-.5)</b> <b><i>p</i> = .01</b>
Individuals with BPD are less likely to have difficulty with “small talk”, when not experiencing intense emotions or perceiving risk of rejection; autistic individuals are likely to consistently find small talk difficult (although this may not be obvious to an observer due to masking).	<i>OR</i> = 14.5 (.7–287.9) <i>p</i> = .08	<i>OR</i> = 1.2 (.3 – 5.0) <i>p</i> = .80	<i>OR</i> = .06 (.0 – 1.1) <i>p</i> = .06
Autistic individuals are more likely to have a special interest which they may fixate on, i.e., an ongoing specific and narrow interest in an object, thing, or topic. This may be seen as atypical, i.e., intense interest in trainspotting, or be considered more typical (especially in women), i.e., intense interest in animal welfare, climate change, or centred around work. Special interests would not be expected in individuals with BPD.	<i>OR</i> = 3.8 (.6–22.8) <i>p</i> = .14	<i>OR</i> = 1.2 (.3–4.6) <i>p</i> = .83	<i>OR</i> = .2 (.0–1.31) <i>p</i> = .10
Autistic individuals are more likely to have processing difficulties, for example, may be slower to process and comprehend information, and struggle with verbal instructions. This is not characteristic of BPD.	<i>OR</i> = 2.9 (.5–17.8) <i>p</i> = .25	<i>OR</i> = .7 (.2–3.2) <i>p</i> = .63	<i>OR</i> = .5 (.01–3.2) <i>p</i> = .46

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Repetitive and restricted behaviours and interests are core to autism and are not in BPD.	<i>OR</i> = 4.6 (.5–46.7) <i>p</i> = .20	<i>OR</i> = 3.3 (.8–13.9) <i>p</i> = .11	<b><i>OR</i> = .1</b> <b>(.0-.6)</b> <b><i>p</i> = .02</b>
Individuals diagnosed with BPD are more likely to misinterpret a situation when mentalising (e.g., “she left the room because she hates me”) whereas autistic people are less likely to mentalise at all (e.g., I have no idea why she left the room”).	<i>OR</i> = .4 (.1–2.6) <i>p</i> = .33	<i>OR</i> = 4.8 (.8– 27.6) <i>p</i> = .08	<i>OR</i> = .5 (.1–2.3) <i>p</i> = .39
Relationships may be more focused around hobbies or special interests in autism, compared to individuals with BPD.	<i>OR</i> = 1.8 (.4–9.2) <i>p</i> = .48	<i>OR</i> = 1.5 (.4–6.3) <i>p</i> = .56	<i>OR</i> = .36 (.1–1.8) <i>p</i> = .21
Individuals with BPD are more likely than autistic people to reject others or end friendships for fear of being rejected themselves.	<i>OR</i> = 1.3 (.3–7.2) <i>p</i> = .74	<i>OR</i> = 1.3 (.3–5.7) <i>p</i> = .77	<i>OR</i> = .6 (.12–3.1) <i>p</i> = .54
After having socialised, autistic individuals are more likely to need to compensate with a period of being alone, compared to those with BPD.	<i>OR</i> = 3.0 (.6–14.8) <i>p</i> = .17	<i>OR</i> = .6 (.1–2.3) <i>p</i> = .41	<i>OR</i> = .6 (.1– 3.1) <i>p</i> = .54
Relationship difficulties in autism are more likely to be driven by: rigidity in routines; everything needing to be in its place; sensory difficulties; the other person doing something unexpected, rather than an interaction, as in BPD.	<i>OR</i> = .7 (.2–3.0) <i>p</i> = .62	<i>OR</i> = .3 (.1–1.8) <i>p</i> = .19	<i>OR</i> = 4.8 (.8–28.6) <i>p</i> = .09
Autistic individuals may have more of an aversion to group interactions than individuals with BPD.	<i>OR</i> = 3.0 (.6–14.8)	<i>OR</i> = .4 (.1–1.8) <i>p</i> = .23	<i>OR</i> = .8 (.2–4.3) <i>p</i> = .80

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	<i>p</i> = .17		
Autistic individuals are more likely to have learning disabilities or learning difficulties than individuals with BPD, including specific learning difficulties such as dyslexia, dyspraxia, and dyscalculia.	<i>OR</i> = 1.3 (.3–7.2) <i>p</i> = .74	<i>OR</i> = 2.1 (.5–9.0) <i>p</i> = .33	<i>OR</i> = .36 (.1–1.8) <i>p</i> = .21
Autistic individuals may be more likely to have the ability to focus intensely on special interests, but have markedly lower function in other areas (such as self-care or in other core life skills). Individuals with BPD are less likely to show such differences.	<i>OR</i> = 6.3 (.7–61.0) <i>p</i> = .11	<i>OR</i> = 1.5 (.4–6.3) <i>p</i> = .56	<b><i>OR</i> = .1</b> <b>(.0–1.0)</b> <b><i>p</i> = .05</b>
Interpersonal trauma in BPD more often takes the form of neglect or abuse. Autistic children may experience things as traumatising that neurotypical children would not, for example, growing up in environments where they are not understood, or being punished for reasons they do not understand.	<i>OR</i> = 1.2 (.23–5.1) <i>p</i> = .81	<i>OR</i> = .5 (.2–2.3) <i>p</i> = .40	<i>OR</i> = 1.6 .3–7.4 <i>p</i> = .55
Difficulties at school for autistic children may be due to the environment (e.g., too noisy; difficulty following verbal instructions). In a person later diagnosed with BPD, difficulties may be caused by unsupportive parents/carers, anxiety or dissociation.	<i>OR</i> = .9 (.2–4.1) <i>p</i> = .91	<i>OR</i> = .7 (.2–3.2) <i>p</i> = .63	<i>OR</i> = 1.6 (.3–7.4) <i>p</i> = .55
The type of problems at work are likely to be different. Someone with autism is likely to have specific requirements for the type of environment they are comfortable working in, e.g., working alone, needing adjustment to uniform policy due to materials, working regular shift pattern for predictability. Someone with BPD may be more likely to struggle to maintain one job due to impulsivity or difficulties working with others.	<i>OR</i> = .3 (.1–1.4) <i>p</i> = .11	<i>OR</i> = 1.3 (.3–7.1) <i>p</i> = .74	<i>OR</i> = 2.7 (.6–12.0) <i>p</i> = .12

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Re-rated in second round (endorsed by 80% or more of expert by experience panel)	Autistic individuals are likely to recall difficulties in identifying and communicating emotions starting earlier in life, whereas individuals with BPD may refer to these difficulties emerging in adolescence or early adulthood.	<i>OR</i> = 3.1 (.7–12.6) <i>p</i> = .12	<b><i>OR</i> = .1</b> <b>(.0-.5)</b> <b><i>p</i> = .01</b>	<i>OR</i> = 3.0 (.6–14.9) <i>p</i> = .18
	Relationships being draining and exhausting, in autism, is likely in part due to masking (hiding autistic traits), whereas this is more likely to do with anxiety-related to fear of being abandoned in BPD.	<i>OR</i> = 4.3 (1.0–19.0) <i>p</i> = .06	<b><i>OR</i> = .1</b> <b>(.0-.7)</b> <b><i>p</i> = .01</b>	<i>OR</i> = 1.2 (.2–6.7) <i>p</i> = .87
	Both autistic individuals and individuals diagnosed with BPD may present with symptoms of obsessive-compulsive disorder (OCD), but this is more common in autistic adults.	<i>OR</i> = .7 (.2–2.9) <i>p</i> = .62	<i>OR</i> = .4 (.1–1.8) <i>p</i> = .22	<i>OR</i> = 3.9 (.8–19.0) <i>p</i> = .09
	With age, people with BPD can move away from some of the behaviours exhibited when struggling to regulate emotions; although they still experience difficulties, these may not be expressed so overtly. Autistic people struggle with "meltdowns" and this does not lessen with time although autistic people may learn to avoid triggers if that is possible.	<i>OR</i> = .4 (.1–1.67) <i>p</i> = .19	<b><i>OR</i> = .2</b> <b>(.0-.9)</b> <b><i>p</i> = .03</b>	<b><i>OR</i> = 15.0</b> <b>(2.8–80.3)</b> <b><i>p</i> = .00</b>
Re-rated in second round (endorsed by 80% or more of autism)	Autistic individuals are much less likely to have a fear of abandonment than individuals with BPD typically experience; therefore, behaviours to avoid abandonment are characteristic to BPD and not autism.	<i>OR</i> = 2.4 (.5–11.7) <i>p</i> = .29	<i>OR</i> = 1.5 (.4–5.7) <i>p</i> = .58	<i>OR</i> = .3 (.1–1.4) <i>p</i> = .12
	For those with BPD, self-harm may be used to communicate distress, or communicate to others in some way. Autistic adults are less likely to think about impact of self-harming on others.	<i>OR</i> = 4.9 (.8–28.7) <i>p</i> = .08	<i>OR</i> = 1.8 (.5–6.8) <i>p</i> = .40	<b><i>OR</i> = .1</b> <b>(.0-.7)</b> <b><i>p</i> = .02</b>

expert panel)	In autism, eating behaviours may be driven by sensory-seeking or sensory-avoidance, or discomfort with being full. This is not characteristic of BPD.	<i>OR</i> = 4.9 (.8–28.7) <i>p</i> = .08	<i>OR</i> = 1.1 (.3–4.4) <i>p</i> = .85	<i>OR</i> = .2 (.0–1.0) <i>p</i> = .05
	Whilst both groups are more likely to have medically unexplained symptoms such as Chronic Fatigue Syndrome, and Fibromyalgia, autistic individuals may be more likely to have other co-occurring physical health problems, including complex medical conditions, than those with BPD, including: seizures; epilepsy; hypermobility; allergies; Ehlers Danlos Syndrome; Postural Tachycardia Syndrome (POTS); rare genetic conditions; eye sight or hearing problems; skin problems (N.B. it is possible that pain may be dismissed as ‘somatising’ or fibromyalgia in those with undiagnosed autism, when it could relate to one of the above conditions).	<b><i>OR</i> = 6.2</b> <b>(1.3– 30.2)</b> <b><i>p</i> = .02</b>	<i>OR</i> = .4 (.1–1.4) <i>p</i> = .13	<i>OR</i> = .5 (.1–2.3) <i>p</i> = .34
	Autistic adults are more likely to report delayed developmental milestones (i.e., walking and talking at expected times) than individuals who go on to be diagnosed with BPD.	<i>OR</i> = .9 (.2–5.5) <i>p</i> = .93	<b><i>OR</i> = 5.8</b> <b>(1.2–27.6)</b> <b><i>p</i> = .03</b>	<b><i>OR</i> = .2</b> <b>(.0-.9)</b> <b><i>p</i> = .03</b>
	For autistic individuals, tasks involving adaptive function (such as: getting from place to place, managing the home, maintaining self-care and hygiene, solving problems, planning, and organising) may be more difficult than those with BPD.	<i>OR</i> = 4.9 (.8–28.7) <i>p</i> = .08	<i>OR</i> = .9 (.2–3.5) <i>p</i> = .89	<i>OR</i> = .2 (.0–1.3) <i>p</i> = .10
Re-rated in second round (endorsed)	Both groups may have difficulty identifying other people’s emotions. This may be a consistent difficulty for autistic individuals, whereas those with BPD may be better able to identify and describe others’ emotions when not under stress or highly emotional.	<i>OR</i> = .6 (.1– 3.5) <i>p</i> = .61	<i>OR</i> = 4.7 (1.0–22.0) <i>p</i> = .05	<i>OR</i> = .3 (.1–1.4) <i>p</i> = .14

by 80% or more of BPD expert panel)	Individuals with BPD may have increased capacity to reflect when no longer experiencing intense emotions, compared to autistic individuals. For example, individuals with BPD, when emotionally regulated, can, with time, work through some of their triggers and identify what might have led to difficult feelings and thoughts; autistic individuals may more consistently struggle to articulate the cause of their distress.	<b>OR = .1</b> <b>(.0-.8)</b> <b>p = .03</b>	<b>OR = 6.0</b> <b>(1.1–34.3)</b> <b>p = .04</b>	OR = 1.3 (.3-4.8) p = .75
	Autistic individuals are more likely to retain the same interest or hobby for a sustained period of time; individuals with BPD are more likely to start various hobbies but not continue with them, or switch between them.	<b>OR = .1</b> <b>(.0-.5)</b> <b>p = .00</b>	OR = 3.7 (.8–17.7) p = .10	OR = 2.8 (.7– 11.2) p = .16
	Autistic individuals may be more likely to be confused by the task of mentalising (partly due to difficulties in reading facial expressions), whereas individuals with BPD may interpret others feeling and thoughts with a negative bias.	OR = .2 (.0–1.01) p = .06	OR = 1.8 (.4–9.1) p = .48	OR = 2.6 (.6–10.8) p = .19

*Note.* Emboldened figures represent significantly significant results.