The Experience of the Welfare System for Autistic Benefit Applicants

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Table of Contents

List of Tables

Table of Figures

Abstract

Aims: The impact of Welfare Reform in the UK has been clearly described through recent literature. Much of this research has focused on the experiences of benefit claimants with physical and/or mental health conditions. This study aimed to explore the experiences of autistic women who have applied for Personal Independence Payments (PIP) since 2019. This study also explored the impact of applying for PIP on psychological well-being and identity.

Method: Eight semi-structured interviews were conducted with autistic women who had applied for PIP within the previous three years. Interview data was analysed via Interpretative Phenomenological Analysis.

Findings: Five group experiential themes and ten sub-themes were constructed from the data. The themes highlighted the adverse impact of threat and uncertainty on women's psychological wellbeing. Moreover, the themes outlined the negative impact of misunderstandings between assessors and autistic women due to mutual communication issues and assessor's misconceptions about autism. The themes also described women's experiences of isolation, alongside struggles to define their identity and resistance towards a deficit-focused benefits system.

Discussion: The findings of this study were discussed in relation to the wider literature relating to autism and the benefits system. Clinical implications were also outlined.

Introduction

Chapter Overview

This study used Interpretative Phenomenological Analysis to explore autistic women's experiences of applying for Personal Independence Payments (PIP). In this chapter, I will introduce the reader to the research, my position and epistemological stance, and give an overview of literature related to disability as identity, welfare reform and disability benefits. I integrate autism throughout, highlighting the relevance to autistic people and autism-specific theory where appropriate.

Language Considerations

Autism as an abstract concept is described in diagnostic terms, as autism spectrum disorder (ASD): a persistent impairment in social interaction and communication, alongside restricted or repetitive patterns of behaviour. ASD traits must cause "clinically significant impairment" in functioning to reach the diagnostic threshold (American Psychiatric Association [APA], 2022; World Health Organization [WHO], 2019). This constructs autism through a lens of impairment compared to a non-autistic norm. Nevertheless, there is considerable heterogeneity within the autistic population. This complexity can be understood through the metaphor of autism as a constellation of features within idiosyncratic patterns of strengths, needs, and variations in skills across context and time (Hearst, 2015; Fletcher-Watson & Happé, 2019).

Autism diagnosis rates have rapidly increased in the last 30 years owing to the development of diagnostic criteria and increased awareness of the variety of presentations (e.g. autistic girls/women) (Russell et al., 2022; Silberman, 2015). Increased numbers of adults are diagnosed in adulthood due to being previously overlooked due to others

normalising autistic traits or misattributing them to mental health or behavioural issues (Bargiela et al., 2016; Leedham et al., 2020; Lupindo et al., 2023).

Within this research, I will align with the preferences of the autistic community by using 'autism' when talking about autism as a diagnostic construct, and 'autistic' to describe people who have an autism diagnosis and 'non-autistic' or 'neurotypical' to discuss people without one (Keating et al., 2023; Kenny et al., 2016). I revert to the language used within relevant source materials as required (e.g. ASD used as an official administrative category).

Positioning the Researcher

Interest in the Research Topic

My interest in the topic of neurodiversity and social justice comes from my personal and professional experiences of witnessing the impact that stigma, misunderstanding and a lack of reasonable adjustments have on autistic people. Growing up with a neurodivergent sibling formed a key part of my initial interest in clinical psychology and issues of social justice. I later worked as an assistant psychologist in an adult autism assessment team, where my colleagues and I often discussed the struggles that autistic people face within the disability benefits system. In my second year of training, I read Jessica Saffer's thesis exploring the impact of changes to disability benefits and wondered whether this had been explored through the lens of neurodivergence.

I have found myself in a unique position as a researcher, where I am both an insider and an outsider (Dwyer & Buckle, 2009). While I have access to insider knowledge about autism, being a neurotypical person, I cannot fully understand the experience of being autistic in a neurotypically dominant world. As an outsider, I have an obligation to avoid re-creating dehumanising narratives about autistic people and avoid imposing my interpretations onto their narratives (Botha, 2021). This required me to continually reflect on

my positionality and question my assumptions throughout this research (examples can be found in Appendix A).

Epistemological Stance

This study adopts a critical realist approach (Bhaskar, 2013), which suggests that external reality exists and operates independently of human awareness or knowledge (ontological realism), however, knowledge is relative to our context (epistemological relativism). While there is only one reality, there are numerous interpretations of it (Bhaskar, 2013), including the interpretation offered via this research. Furthermore, although collecting data can bring us closer to reality, it requires further interpretation as knowledge is dependent upon social-cultural context, language and meaning-making (Fletcher, 2017; Maxwell, 2012; McEvoy & Richards, 2003). Critical realism suggests that, as researchers, we cannot directly reach the 'reality' of being autistic, but we can access individual meaning-making about this experience (Rosqvist et al., 2022). This epistemological positioning informed my thinking throughout this thesis and guided research design decisions outlined in Chapter 2.

Understanding Disability

This section gives an overview of disability, including definitions and relevant theories related to identity. This is a complex field; therefore, this thesis cannot cover the breadth of disability literature. This section includes points most pertinent to the current study.

Defining Disability

To be disabled can be described as impaired or limited by a physical, mental, cognitive, or developmental condition (Merriam-Webster, n.d.). Whether a person is disabled under the Equality Act (2010) is determined by the degree and length of any effect

that an impairment has on that person's ability to carry out typical day-to-day activities. An impairment becomes a disability when it has a substantial and long-term impact on daily activities. Specifically, a 'substantial' impairment is more than minor, and 'long-term' is 12 months or more. This definition includes physical health needs (e.g. cancer), mental health and developmental conditions (i.e. autism) (Government Equalities Office, 2011).

Given this definition, and the diagnostic criteria requirement for significant impairment in functioning (APA, 2022; WHO, 2019), autism can be understood as a disability. This can be a contentious point; some autistic people reject the term "disabled" given its associations with being defective or abnormal (Bury et al., 2020; Seers & Hogg, 2021), whilst others have reclaimed it to fight for recognition of their needs for support and reasonable adjustments (Keating et al., 2023; Kenny et al., 2016).

Understanding Disabled Identity

The groups of people contained within the concept of 'disability' have been fluid and changed over time (Roulstone, 2015). These narratives, known as disability models, guide our thinking about body and brain differences and have powerful consequences for how non-disabled and disabled people interact within society (Bogart et al., 2022; Smart, 2004).

Disability has long been considered within a medicalised framework, whereby disability is positioned as an unwanted deviance intrinsic to the person (Smart, 2006). Impairment is equated with disability; someone is disabled by their impairment (Johnston, 1994). Therefore, change is focused on 'curing' the individual rather than making environmental accommodations. This model has been critiqued as regarding disability as a 'personal tragedy' for the disabled person, which individualises disability and implicitly absolves society of responsibility to reflect on its role in creating disabling conditions (Carlson, 2010; Smart, 2006a). This approach of equating disability with defectiveness and

suffering is argued to be ableist (Reynolds, 2017; Smart, 2006b). Within autism research, analysis of research papers suggests that an author's use of a medical model of disability predicts their use of ableist statements (e.g. using dehumanising or stigmatising narratives) (Botha & Cage, 2022).

In contrast, the social model of disability distinguishes between *impairments (i.e.* features of the brain or body that can be positive, neutral or negative regardless of environmental context) and *disability* (i.e. a state of inability perpetuated by social factors) (Goering, 2015). Whilst acknowledging the impact of impairments, this model maintains that disability is a social construct (Oliver, 2013). Disability is seen as a failure of the environment to account for variation, rather than a personal flaw (Andrews, 2017). When barriers and inequalities in society disable people, the solutions are changing public attitudes, laws and policies (Smart, 2006). This has led many in the disabled community to understand themselves as a distinct identity group that can unite to fight for disabled rights, leading to the model being known as the 'minority model' (Hahn, 1985).

Although the majority of autism research has been conducted via a biomedical model focused on aetiology and prevention (Botha & Cage, 2022), the autistic community increasingly views autism as a form of neurodiversity and core to personal identity (Botha et al., 2020, 2021; Bury et al., 2020). Furthermore, Kapp et al. (2013) noted that those who endorsed the concept of neurodiversity tended to view autism itself more positively.

Neurodiversity describes the concept of natural variation in brain structure and functioning (e.g. autism) as part of human diversity, whereby people who conform more to normative societal assumptions are 'neurotypical' than 'neurodivergent' people (Singer, 2017). The paradigm recognises individual impairments and support needs whilst also celebrating the strengths of being neurodivergent (e.g. autistic), as strengths and difficulties

related to cognitive profiles will be adaptive in some environments but may appear disabling in others (Baron-Cohen, 2017). This positions autism as a combination of identity, difference and disability dependant on interactions between individual needs and the environment (den Houting, 2019; Singer, 2017; Kapp, 2020).

Identity Processes

Our identities define us through our traits, roles and ties to social groups – past, present and anticipated (Oyserman, Elmore, & Smith, 2012). Social Identity Theory (SIT; Tajfel & Turner, 1979) proposes that personal and social identities constitute self-identity. Personal identity includes characteristics that define us from others, contributing to our uniqueness. Autism is viewed as a core part of the self when it is integrated into personal identity (e.g. Keating et al., 2023). Social identity represents characteristics that are shared with a group (e.g. disabled, autistic). SIT suggests that humans tend to form groups and define themselves by group memberships, with group members developing self-esteem as they feel more affiliated with the group and proud of being a member.

Dunn and Burcaw (2013) define disability identity as a "sense of self that includes one's disability and feelings of connection to, or solidarity with, the disability community" (p. 148). This has been described as a developmental process, moving from an acceptance of disability to forming relationships with other people within the group, adopting group values and becoming engaged within the disabled community (Forber-Pratt & Zape, 2017). This integration may be complicated given that disability is stigmatised within society, leading to stereotyping and discrimination (Green et al., 2005).

Goffman (1963) defined stigma as an attribute that holds the power to "spoil" the identified person's identity, reducing them "from a whole and usual person to a tainted, discounted one" (p. 3). Goffman proposed that a stigmatised person may internalise the

imposed stigma as self-beliefs. Minority Stress Theory (Meyer, 2003) expanded Goffman's work by suggesting that experiencing stigma, discrimination, prejudice and internalised stigma leads to high-stress levels and contributes to adverse health outcomes for minoritised individuals. For autistic people, poorer mental health has been associated with increased experiences of discrimination, internalised stigma and attempts to conceal their autistic identity from others (Botha & Frost, 2020).

Autistic people face several challenges in constructing an autism identity following diagnosis, including dealing with stereotypes, discrimination and stigma (Botha et al., 2020). Autistic people diagnosed in adulthood describe a "painful" period of identity adjustment post-diagnosis (Leedham et al., 2020, p.145), however their satisfaction with autistic identity increases with time (Corden et al., 2021). Milton and Sims (2016) identified shifts in participant's narratives; moving from internalised dislike of "their autism", to identifying as a "person with autism", before integrating autism into personal identity (i.e. identifying as an "autistic person"). If individuals choose to self-identify as part of the Autistic community, autism becomes a social identity (Cooper et al., 2021).

Affirming disability identity is associated with psychological well-being. For example, autistic people who affiliate with the autistic community have improved mental health (Cooper et al., 2017). Furthermore, autistic adults who emphasised autistic people's strengths had more positive collective self-esteem and felt more connected with autistic people. Pride in being autistic is associated with higher self-esteem (Corden et al., 2021), and accepting autistic identity and feelings accepted by society is negatively associated with depression scores (Cage et al., 2018). Overall, a positive autistic identity appears to be associated with lower anxiety, stress and depression and higher levels of self-esteem and well-being (Davies et al., 2024).

UK Welfare Reform

The 2008 financial crisis led to the UK government borrowing £178 billion to prevent the collapse of the banking sector and implementing a series of austerity economic policies. Employment Support Allowance (ESA), replaced previous out of work disability benefit with tightened eligibility (Shefer et al., 2016). The Welfare Reform Act (2012) outlined significant reforms to benefits for working-age adults, including stricter conditionality and more stringent criteria which were reportedly designed to restrict benefit entitlement, thereby creating £2.8 billion worth of savings by removing entitlement for over 600,000 people (Office of Budget Responsibility, 2019).

The Welfare Reform Act (2012) also provided legislation to reform disability benefits. The government announced plans to replace the previous benefit, Disability Living Allowance (DLA), with Personal Independence Payments (PIP) following concerns about pressure and financial costs placed on the disability benefits system amidst increasing numbers of people claiming DLA (DWP, 2012) The 2010 Budget (HM Treasury, 2010) described these changes as aiming to decrease spending by ensuring that support was provided only to those with the most critical medical requirements as measured through "objective medical assessments" (p.33). It was expected that the introduction of refined criteria and obligatory medial assessments would lead to a 20% reduction in eligible claimants. The government expressed concerns that the DLA assessment relied heavily on written information and was subjective, leading to inaccurate and inconsistent judgements (DWP, 2010). Additionally, lifelong awards were granted without reassessments. The government introduced regular reviews, a standardised points-based system, and face-to-face assessments to assess applicants' functional impairment. They believed that this would create more consistent outcomes and greater transparency by emphasizing objectivity and

gathering more evidence (DWP, 2010). However, it can be argued that relying on the

evidence of 'independent' outsourced assessors marginalised the evidence provided by

claimants (Porter et al., 2021). See Table 1 for an overview of ESA and PIP. See Appendix B

for PIP pathway.

Table 1

Summary of Disability Benefits

Benefit	Summary
Similarities	Two main benefits that are specifically aimed at people with long-term health conditions and disability: Employment and Support Allowance (ESA) and Personal Independence Payments (PIP). Both benefits require claimants to complete a handwritten assessment form before attending an in-person assessment with a disability benefits assessor. Assessors are healthcare professionals (i.e. nurses, paramedics, physiotherapists) employed by private companies (e.g. Capita are contracted to provide PIP assessments).
ESA	Designed to provide out-of-work payments (Citizens Advice, n.d-a). Claimants are assessed through a Work Capability Assessment (WCA) with a clinical assessor who determines their ability to complete a range of daily tasks (both physical and mental). Claimants who are deemed to have either 'limited capacity for work' or 'limited capacity for work-related activity' are not expected to seek work and are awarded ESA. All other claimants are placed in a 'work-related activities group' and are expected to work with job centre staff to seek work or face sanctions on their benefit payments. ESA has now been subsumed under Universal Credit.
PIP	PIP is designed to cover the extra costs of disability (Citizens Advice, n.d-b). Claimants are assessed through assessments with clinical assessors who determine the level of support that the claimant needs to complete tasks within two main areas: 1. Daily living activities (i.e. prepare and cook food, eat and drink, manage any treatments, wash, manage toileting needs, dress and undress, communicate with other people, read and understand written information, mix with other people, make financial decisions). 2. Mobility (i.e. plan and follow a journey and moving around). Claimants are graded against a list of statements (descriptors) for each activity and allocated points accordingly. The total number of points determines whether PIP is awarded and the level of award (standard rate or enhanced rate).

Supporters of the changes state that this increases the reliability and fairness of assessments, however, claimants have raised concerns that assessments fail to provide a realistic insight into their condition (Porter et al., 2021). Moreover, independent reviews of PIP have recommended improvements to increase the fairness and consistency of assessments (Gray, 2014; 2017). Whereas the UN Committee on the Rights of Persons with Disabilities (2017) determined that welfare reforms had disproportionately impacted disabled people, and cited changes to PIP criteria as part of the "grave [and] systematic violations" (p. 18) of disabled people's rights.

Whilst the impact of welfare changes on benefit claimants is well documented, the challenges facing professionals working within the pressures and constraints of the benefits system are less recognised. To the best of the author's knowledge, there is currently no research addressing disability benefit assessor's experiences of work and any impact upon their well-being, however, concerns have been raised about the ongoing psychological impact of service demands placed upon healthcare professionals within assessor roles. One recent article reported the experience of three former benefit assessors who described feeling unable to accurately complete assessments due to pressure to assess up to six people per day, leaving them feeling unable to demonstrate empathy to the people who they assessed and o continue in their role due to the negative impact on their own wellbeing (Mcrea, 2023). Unfortunately, the pressures facing the disability benefit system appear unlikely to relent as the number of disability benefit claims have doubled following the COVID-19 pandemic and is predicted to increase (Ray-Chaudhuri & Waters, 2024).

Critically, reassessment for PIP has led to the removal or reduction of disability benefits for 41% of people due to 'failing' the eligibility assessment (DWP, 2021). It is estimated that disabled claimants have lost an average of £1,200 in benefits payments each

year due to these reforms, with those on the lowest incomes or managing multiple disabilities most affected (Disability Benefit Consortium, 2019). People with learning disabilities, social interaction difficulties and mental health conditions appeared to be most impacted by these changes.

Specific concerns have been highlighted for claimants with invisible conditions. Firstly, the court of appeal ruled that ESA decision-making disadvantaged people with mental health problems, learning disabilities and autism (Mind, 2013). The high court subsequently ruled that PIP decisions were discriminatory against people who experience psychological distress which impacts mobility (i.e. people with mental health problems or autism), leading to the reassessment of 1.6 million claims (Butler, 2018). Secondly, research suggests that claimants with 'invisible' or fluctuating conditions (e.g. chronic pain) face particular difficulties navigating the disability benefit system. Studies describe people facing problems in collecting evidence and filling in application forms to adequately convey their experience of disability, leading some researchers to describe the claims process as inaccessible and the assessment framework as disadvantaging claimants with non-visible conditions (Clarke et al., 2019; Price et al., 2020; Saffer et al., 2018; Shefer et al., 2016). Ultimately these challenges may lead to claims being rejected, leaving claimants facing reductions or removal of benefits, financial hardship, increased anxiety and social isolation.

Demographic Data

Official statistics suggest that 7.3 million people have applied for PIP since its introduction and 1.9 million Work Capability Assessment (WCA) decisions have been made since 2019 (DWP, 2023b). As of March 2023, almost a third of people receiving Universal Credit had a health condition or disability that limited their ability to work. The most

common reason for being placed within the Work-Related Activity Group were difficulties in social interactions and adapting to change.

The majority of PIP applications categorise the claimant's main condition as 'psychiatric disorder', which accounts for 39% of all claims (DWP, 2023a). This category compromises various mental health and developmental conditions, mostly commonly: anxiety and depressive disorders, autistic spectrum disorders, mood disorders, psychotic disorders and learning disability.

According to the Department for Work and Pensions (DWP) and Homer (2021), 82% of PIP-related appeals at tribunals are revised in favour of the claimant. Similarly, the DWP (2023a) has reported that 61% of Work Capability Assessment (WCA) decisions going to Mandatory Reconsideration (MR) were revised on appeal, highlighting potential issues with the current assessment system.

Neurodiversity and the Disability Benefits System

Welfare changes appear to have a disproportionate impact on claimants with invisible conditions. A large-scale analysis of over 300,000 claims found that claimants with a mental health condition or ADHD were respectively 2.4 and 3.4 times more likely to lose their entitlement when moving from DLA to PIP, compared to claimants with a physical health condition (Pybus et al., 2019). Approximately 3.9% of all PIP recipients list autism spectrum disorder[1] as their main health condition (Parkin et al., 2020). A total of 44,652 autistic people were re-assessed during the transition from DLA to PIP, however, 23% of autistic people were not re-awarded PIP. Fifty-two per cent of first-time applicants did not receive PIP (DWP, 2021).

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[1] Language reflective of source.

When PIP was introduced, the NAS (NAS, 2011) raised concerns that the new system would overlook the needs of autistic adults due to the 'hidden' nature of the impact of autism. The proposed 'objective' face-to-face assessments were criticised for being an ineffective way to measure autistic people's needs, given an individual's ability to manage day-to-day life may not be immediately apparent (as discussed below). This appears to mirror wider difficulties that 'high functioning' autistic adults face in accessing support, which may be exacerbated by healthcare professionals lacking adequate knowledge to assess autistic people's needs (National Audit Office, 2009). UK newspapers have since reported cases of autistic adults encountering difficulties during the PIP assessment process, leading to additional stress, financial strain and deteriorating mental health (Andersson, 2022; Hunt, 2018; A. Thomas, 2023).

The need for financial support. Autistic adults may apply for benefits for several reasons. Firstly, autistic adults face inequalities that predispose them towards needing financial support. According to the Office of National Statistics (ONS), autistic people are the second least likely group to be employed compared to all disabled groups[2] and have the largest pay gap compared to non-disabled workers (ONS, 2022a; 2022b). The employment rate of autistic people in the UK during 2021-2022 was only 29%, in contrast to the 80% employment rate of non-disabled adults (ONS, 2022a). Autistic people are also more likely to experience poverty than non-autistic people (Cai, Hall, et al., 2023), in addition to being at a higher risk of developing mental health problems (Hollocks et al., 2019) and premature death (Hirvikoski et al., 2016).

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[2] Employment rates for people who list "severe or specific learning difficulties" (as a main or secondary health condition) are reported as 26.2%, compared to 29.0% for autistic people.

These discrepancies may be explained by unmet needs. Research has established that autistic adults face significant gaps in accessing services, such as inadequate levels of post-diagnostic support (Crane et al., 2018). Less than 35% of autistic adults received post-diagnostic care in line with guidelines and recommendations regarding services for autistic adults (Scattoni et al., 2021). Access to mental health services, adequate housing, accessible transport and employment support remain key concerns for autistic adults (Brede et al., 2022; Tint & Weiss, 2018) alongside support accessing reasonable adjustments within the workplace and healthcare services (Brice et al., 2021; Davies et al., 2022).

Secondly, autistic adults often have unique needs that can affect their day-to-day activities. However, many needs are 'invisible'. For example, difficulties with executive functioning, such as specific difficulties with cognitive flexibility and working memory and requiring more time to plan and make decisions (St. John et al., 2022). Difficulties may impact planning and completing daily tasks (e.g. meal preparation, housework) and managing multiple demands, leading to feelings of overwhelm and anxiety (Grove et al., 2023; Wallace et al., 2016). Likewise, sensory sensitivities can be overwhelming for autistic adults and contribute to poor mental and physical health (e.g. sound sensitivity increasing stress and interrupting sleep) (MacLennan et al., 2022). Moreover, difficulties within social situations may be hidden as autistic people use camouflaging strategies[3] to avoid discrimination and stigma (Perry et al., 2021).

The National Autistic Society ([NAS], 2011) noted that people used DLA payments to cover expenses related to accommodating these needs. Such as paying for support to manage paperwork and bills due to executive functioning difficulties, and costs associated

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[3] Unconscious/conscious strategies which mask autistic behaviour, such as suppressing repetitive movements, forcing eye contact and preparing social scripts (Hull et al., 2017). Research suggests that camouflaging may prevent autistic women from having their needs recognised (Hull et al., 2020; Seers & Hogg, 2021).

with being unable to use public transport due to issues with sensory overload, anxiety, or managing unexpected changes. Financial support may also enable autistic adults to buy specialist equipment, such as noise-cancelling headphones or specialist clothing, to manage sensory sensitivities (Beresford et al., 2020; NAS, 2011).

The Importance of Psychologists' Input

> By themselves, neither psychological nor political explanations suffice in accounting for the sources of suffering and human welfare. By the same token, neither political nor psychological interventions alone can improve human welfare. It is only when we achieve an integrated political and psychological understanding of power, wellness, and oppression that we can effectively change the world around us.
>
> (Prilleltensky, 2008, p.129)

Clinical psychologists are aware of the importance of social context on mental health. Poverty, inequality and stress have adverse impacts on developing mental health problems (Felitti et al., 1998; Thomson et al., 2022). There are concerns that austerity measures and restrictive welfare policies are associated with poorer mental health and increased health inequalities (Marmot, 2020; Simpson et al., 2021). People with disabilities are more likely to be living in financial hardship and have less social support, which increases the risk of becoming unwell (Honey et al., 2011).

As social inequality has a significant impact on healthcare outcomes, social justice cannot be divorced from clinical psychology. Psychologists often experience the benefits system indirectly through the experiences of their clients (Cantrell et al., 2021). Mcgrath and colleagues (2016) argue that, due to having extensive contact with people who experience distress due to socio-political inequalities and the professional power associated with the profession, clinical psychologists have an ethical responsibility to speak out about the

impact of austerity. This overlaps with our ethical and professional responsibility to enable our clients to stay well and attain adequate living standards (Hutton & Mudie, 2023).

The impact of changes to welfare policy has already been felt within clinical practice, highlighting the limitations of individual interventions. NHS psychologists have acknowledged the negative effect that the benefits system can have on their clients' psychological well-being and therapeutic progress (Cantrell et al., 2021). Claiming benefits has been described as an additional burden for clients, which leads to increased demands for psychological interventions. However, the benefits system also posed obstacles that hindered clients from engaging in therapy, leaving psychologists grappling with ethical issues of how to address welfare-related distress, without pathologizing clients, whilst fulfilling their duty of care (Cantrell et al., 2021). This appears to confirm that our efforts may be better placed directly addressing systemic factors contributing to mental health rather than continuing to focus on individual therapy (Rahim & Cooke, 2019).

Attending to social inequities is a fundamental part of a psychologist's role. BPS Practice guidelines (2017) suggest that psychologists have a responsibility to highlight the links between mental health problems and societal factors. This extends to making policymakers, clients and the public aware of policies and practices that perpetuate harm and oppression. Psychologists' skills in understanding and communicating the complex interplay of mental, physical and cognitive needs are highly relevant to communicating the impact of the benefits system, both in written evidence for our clients and at a policy level (Hutton & Mudie, 2023).

Research into the benefits system is one method towards this aim. Highlighting the lived experiences of claimants can provide valuable insights into the psychological consequences of social policy. This could help policymakers make evidence-based decisions to improve the lives of claimants. Psychologists are also well placed to contribute to systemic solutions,

given our knowledge allows us to critique harmful policies and to offer psychologically

informed alternatives (Rahim & Cooke, 2019). Understanding the psychological impact of the

benefits system may also help us to support clients in managing the emotional impact and

help assessors understand claimants' responses (Hutton & Mudie, 2023).

The Psychological Impact of Welfare Changes

Mental Health

Concerns about the impact of welfare reform on claimant mental health were

initially identified by several professional groups, including the British Psychological Society

[BPS] (Baumberg Geiger, 2015; BPS, n.d.) and the Royal College of Psychiatrists (2019).

Further research has suggested that reassessing people on disability benefits using the Work

Capability Assessment was associated with increased mental health issues, antidepressant

prescriptions and people dying by suicide (Barr et al., 2015). Furthermore, greater cuts to

disability benefits have been associated with an increase in fatal opioid overdoses (Koltai et

al., 2021).

Benefit changes also appeared to exacerbate anxiety and depression for claimants

with pre-existing mental health problems (Stuart et al., 2020), with one survey of

psychiatrists noting that attending the WCA led to increasing medication use, self-harm and

more frequent psychiatric appointments amongst some patients (Mental Welfare

Commission for Scotland, 2014). Foster and Elntib (2020) highlighted the systemic impact on

claimant support networks, as more frequent exposure to benefit assessments predicted

lower carer well-being and greater stress levels.

Qualitative studies have explored the lived experience of navigating welfare reforms. A growing body of literature characterises the WCA and PIP assessment processes as intimidating (Shefer et al., 2016), depersonalising (Garthwaite, 2014), dehumanising (Patrick, 2016) and degrading (Clarke et al., 2019; Morris, 2013). The opaqueness and unpredictability of the system have been widely reported to lead to uncertainty, distrust of the system, worry and a fear that benefits would be removed completely (Clarke et al., 2019; Garthwaite, 2014; Morris, 2013; Patrick, 2016; Saffer et al., 2018; Saffer & O'Riordan, 2022a; Wright, 2016). The effects of this uncertainty and fear have been highlighted in a survey by the Disability Benefits Consortium (2017), whereby 80% of respondents agreed that stress and anxiety related to PIP assessment affected their health and 68% felt that their health condition was not understood by assessors. Clarke et al. (2019) described the process of claiming benefits as exhausting, which can lead to feelings of despair and "mental crisis" (p.224) among claimants. Garthwaite (2014) noted that some claimants may feel powerless and worthless due to the lack of choice over the process. Consequently, claimants may have thoughts of suicide (Clarke et al., 2019; Garthwaite, 2014; Morris, 2013).

Concerns about the psychological impact of health assessments have been highlighted in recent findings of the House of Commons Work and Pensions Committee (2023). The report outlined the impact of stress and anxiety on claimants, leading to recommendations for DWP staff to receive suicide prevention and safeguarding training and calls for the DWP to collect and publish data annually outlining the number of deaths associated with health assessments.

Identity

Claiming disability benefits appears to not only be distressing for financial reasons, but also for contesting people's experiences of living with a disability. Some researchers suggest that changes to eligibility criteria reconstruct the boundary of disability as an administrative category, which can be reclassified to restrict benefit access to the newly defined 'truly disabled' (Grover & Soldatic, 2012 in Garthwaite, 2014) based on political needs rather than impairment or disability (Porter et al., 2022).

Research suggests that claimants also face complex changes to their sense of self through the stigma associated with claiming benefits, such as societal 'scrounger' narratives, combined with the stigma of being 'disabled' (Garthwaite, 2015a; Saffer et al., 2018; Saffer & O'Riordan, 2022a). Such stigma may be internalised and trigger existing beliefs of being disbelieved, unworthy of care or not good enough (Hutton & Mudie, 2023). Patrick (2016) described the process of claiming as stigmatising, as claimants' completing forms were forced to confront feelings of dependency on the system. This appeared to deepen the claimant's own internalised feelings of shame and stigma, which added to the emotional strain they had to manage whilst having to demonstrate their eligibility for disability benefits.

Many researchers and claimants have highlighted the impact of political discourse in creating a division between deserving and undeserving benefit claimants, leading to increased suspicion and stigmatisation of disabled people (Saffer & O'Riordan, 2022a). In addition, media narratives of "benefit porn" (Saffer & O'Riordan, 2022; p.30) have been felt to have exacerbated the situation, casting aspersions on the credibility of all benefits

claimants, which leads to scrutiny and policing from the wider public (Garthwaite, 2014; Saffer & O'Riordan, 2022a).

Saffer and colleagues (2018) noted how claimants with physical disabilities (who had their benefits changed) described their identity as being challenged by stigmatising narratives from society. This stigma, compounded by public scrutiny of their disabled status, became internalised as shame and self-judgement. Together with the deficits-focused assessment process, it was reported that this led to claimants 'losing sense of self' characterised by a sense of worthlessness, and a loss of hope and validation as an equal citizen.

Similarly, Day and Shaw (2020) researched shifts in identity for claimants with long-term illnesses facing re-assessment for the WCA. Whilst living with illness altered participants' identity, developing individual sense-making, and understanding of their condition appeared to increase their confidence. This sense-making was undermined by the WCA process focus on 'capability', which participants described as ignoring the qualitative dimensions of their conditions and dehumanising them. Garthwaite (2015a) used the term 'adopting a disabled role' to describe the perceived pressure on Disability Living Allowance claimants to present themselves "on their worst days and portray themselves as being as ill as possible" (p.9) during assessments. Whilst claimants recognised the importance of taking on this role, some also rejected the label of being 'disabled' and struggled to maintain a positive sense of identity.

However, claimants make various attempts to resist and contest these identity conclusions, such as galvanising online support through forums, finding a positive identity through the support of loved ones or forming an activist identity by taking political action as a collective (Garthwaite, 2015a; Saffer & O'Riordan, 2022a). Others attempt to distance themselves from negative judgements by projecting these onto other claimants, viewing

them as the 'true' 'scroungers' (Garthwaite, 2014; Patrick, 2016; Saffer et al., 2018; Saffer & O'Riordan, 2022a), highlighting narratives of past hard work and contributions to society (Moffatt & Noble, 2015), or hiding their claimant identity (Garthwaite, 2015b; Patrick, 2016).

Conclusion

In this chapter, I have outlined my relationship to the research and insider-outsider positioning. I have described the critical-realist position that informed my thinking throughout this thesis. The presented literature has highlighted the negative impact of changes to the disability benefits system, with a significant impact on claimants' mental health and identity. The next chapter systematically examines the literature relating to claimants experiencing mental health problems.

Systematic Review of Relevant Literature

Chapter Overview

In this chapter I will outline the process taken to complete the systematic literature review (SLR), including details of databases searched and inclusion and exclusion criteria applied. I will then present the findings of the SLR. Finally, I will outline the need for the current research and research question.

The current study focused on the experiences of autistic people applying for Personal Independence Payments. Given the lack of research within this area, I initially aimed to focus this SLR on the experience of applicants with neurodevelopmental conditions within the disability benefits system. However, after completing several scoping reviews, I did not identify any relevant peer-reviewed studies. Therefore, the research team and I agreed to broaden the SLR research question.

Previous searches of the literature highlighted a body of peer-reviewed research regarding the experiences of applicants with mental health problems (MH). As a research

team, we considered the relative merits of reviewing this evidence base, including the prevalence of comorbidity between MH and neurodevelopmental conditions (Hollocks et al., 2019; Lai et al., 2019). A search of the PROSPERO database did not find any existing SLR on this topic. Given this comorbidity and lack of previous SLRs within this area, a systematic review of peer-reviewed empirical literature was undertaken to synthesise and critically appraise the current research literature. The research question was:

What is the lived experience of claimants with a history of mental health difficulties applying for disability benefits (following welfare reform in the UK)?

Search Strategy

Searches were conducted in PsycINFO, PsychArticles, Medline and Scopus. These databases were selected for their combined coverage of published research (Bramer et al., 2017; Singh et al., 2021) and applicability to the research question topic area. Titles and key terms from articles and systematic reviews on related topics (e.g. Saffer et al., 2018) were examined for key search terms (see Table 2 for final search terms). Pilot searches informed the search strategy, refined key terms, and ensured that relevant papers were captured. A search was also preformed via Google Scholar using the search term 'experiences of welfare reform disability benefit mental health'. Reference lists of identified papers were searched to identify additional relevant papers, and a main journal for published papers (Disability & Society) was hand searched from 2010 onwards. Final searches across chosen databases and Google Scholar were completed in May 2023.

Table 2

Search Terms Used in the Systematic Review

SPIDER criteria	Search terms
Sample	People living with mental health difficulties. Terms captured in Evaluation section below.
Phenomenon of Interest	Applying for/claiming disability benefits in the UK: ("disability living allowance" OR "personal independence payment" OR "sickness benefit*" OR "Incapacity Benefit*" OR "disability benefit*" OR "welfare reform" OR "welfare claim" OR "disab* benefit*") AND (UK OR England OR Scotland OR Wales)
Design	("questionnaire*" OR "survey*" OR "interview*" OR "focus group*" OR "case stud*" OR "observ*")
Evaluation	Terms related to psychological outcome/experience: ("mental health" OR "wellbeing" OR wellbeing OR psychol* OR psychiat* OR "mental disorder*" OR stigma* OR stress* OR sham* OR distress* OR self esteem OR "self-esteem" OR self worth OR "self-worth" OR identity OR anxiety OR depress* OR affect) AND ("view*" OR "experienc*" OR "opinion*" OR "attitude*" OR "perce*" OR "belie*" OR "feel*" OR "know*" OR "understand*")
Research method	"qualitative" OR "mixed method*"

Inclusion and exclusion criteria (see Table 3) were developed following pilot searches of related literature. Many papers were identified on work programme conditionality; these were excluded to focus on disability-specific benefits. Given the idiosyncratic nature of the UK welfare system and recent significant welfare reforms, articles were limited to research conducted within the UK following the introduction of welfare reform (October 2008). Consequently, all included papers were published in English. Papers that presented claimants' first-hand perspectives on their experiences of the disability benefits system were

included; however, papers were excluded if participants with mental health difficulties could

not be distinguished within the findings.

Table 3

Overview of Eligibility Criteria

Inclusion criteria:	Exclusion criteria:
Studies focusing on UK disability benefits (DLA, PIP, ESA or UC/WCA). Studies including adults with pre-existing mental health difficulties (self-reported).	Studies focusing on conditionality of work employment programmes. Studies where accounts from participants with mental health difficulties cannot be separated or distinguished.
Studies focusing on personal accounts related to claiming or attempting to claim benefits.	Studies focusing on non-UK samples, or where data from UK participants cannot be separated or distinguished.
Accounts were provided by people who were claiming or had attempted to claim benefits.	Conceptual, theory or letters to the editor.
Any article published since welfare changes (i.e., October 2008).	Articles published before the 2008 welfare reform.
Reporting original peer-reviewed research.	Non-peer-reviewed research literature.

The following procedure was used to conduct the systematic review:

☑ Search results imported into CADIMA note management software from

bibliographic databases

☑ Titles and abstracts were screened

☑ Duplicates were removed

☑ Titles and abstracts screened against inclusion/exclusion criteria in table 2

☑ Full-text articles obtained for remaining references and screened against

inclusion criteria. Papers that did not meet inclusion criteria were removed.

Results

A total of 232 articles remained after duplicates were removed. After screening titles and abstracts against inclusion criteria, 194 articles were excluded and 38 remained for full-text screening. Of the 38 articles, 12 met the inclusion for this review. At this point, the reference lists of the remaining papers were searched to identify any potential missed articles. One article was identified from reference searches. As shown in Figure 2, a total of 13 articles were included in the current review. A summary of included papers can be found in Appendix C.

Figure 2

PRISMA Flow Diagram of Systematic Literature Search

Identification

Records identified through database searching (n= 292)

SCORPUS (n = 190)
APA PsycArticles® and APA PsycInfo® (n = 61)

Additional records identified via other methods (n = 41)

Disability & Society hand search (n = 15)
Google Scholar (n = 26)

Screening

Records screened (title) (n = 292)

Records after duplicates removed (n = 232)

Records title and abstract screened (n = 232)

Records excluded due to not being relevant or non-primary research (n = 194)

Eligibility

Full text articles assessed for eligibility (n = 38)

Records excluded:

Not specific to disability benefits (n = 3)
Focused on conditionality (n = 2)
Unable to distinguish participants with mental health problems (n = 11)
Focused solely upon applicants with physical health problems (n = 10)

Included

Papers included in review (n = 12)

Additional papers identified from citation searching (n = 1)

Total studies included in review (n = 13)

Quality Assessment

Given the nature of the research question, all included studies were qualitative in nature and evaluated using the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist (CASP, 2018). The CASP tool was chosen for this review as it is endorsed by the Cochrane Qualitative and Implementation Methods Group and the World Health Organisation for use in qualitative synthesis and is recommended for novice researchers (Long et al., 2020). Appendix D summarises each paper against the CASP criteria.

All papers identified a clear research question or aim and contextualised this within wider literature and recent welfare reforms. Appropriate methodology was used across the included papers; however, many studies did not clearly justify their study design (Clifton et al., 2013; Dwyer et al., 2020; Greener & Moth, 2020; Hansford et al., 2019; Lowe & DeVerteuil, 2020; Mattheys et al., 2018; Pybus et al., 2019; Roberts et al., 2022; Shefer et al., 2016).

Most papers used some form of purposive non-random sampling commonly used within qualitative research (Gill, 2020). Whilst all papers employed sampling strategies appropriate to their aims; despite the risk of selection-bias, only two papers sought to maximise heterogeneity within their sample by recruiting across the country (Dwyer et al., 2020) or employing stratified sampling across age, gender and ethnicity (Shefer et al., 2016). Moreover, a minority of papers (Machin & McCormack, 2021; Ploetner et al., 2020; Scullion & Curchin, 2022) reflected upon the potential impact of sampling strategy, including risks of self-selecting bias and who may have been excluded or underrepresented. For example, Ploetner et al. (2020) discussed that by recruiting from peer-run support groups, insights from claimants who did not attend such groups were missed and highlighted a need for further research to reach this population.

All studies employed suitable data collection methods, with the majority using semi-structured interviews and three studies using focus groups (Clifton et al., 2013; Greener & Moth, 2020; Hansford et al., 2019). A lack of detail was a predominant theme across many papers; with missing information regarding the setting, procedure and topics covered during data collection (Clifton et al., 2013; Greener & Moth, 2020; Hansford et al., 2019; Lowe & DeVerteuil, 2020; Machin & McCormack, 2021; Roberts et al., 2022). For example, Greener and Moth (2020) used a mix of interviews and focus groups to collect data, however provided no discussion about how this design was determined and any impact on the data.

Many studies did not consider the relationship between the researcher and participants, or did not provide sufficient detail on this domain (Clifton et al., 2013; Dwyer et al., 2020; Greener & Moth, 2020; Hansford et al., 2019; Lowe & DeVerteuil, 2020; Machin & McCormack, 2021; Mattheys et al., 2018; Porter et al., 2021; Roberts et al., 2022; Scullion & Curchin, 2022; Shefer et al., 2016). A notable exception to this was Ploetner et al. (2020) who discussed the impact of conducting participatory research; including reflections on researcher and peer-researcher coding disagreements and recruiting via peer networks.

The majority of papers referred to ethical approval, except for three studies (Dwyer et al., 2020; Greener & Moth, 2020; Lowe & DeVerteuil, 2020). Nevertheless, some papers lacked further discussion of ethical issues (e.g. gaining informed consent) (Clifton et al., 2013; Hansford et al., 2019; Porter et al., 2021; Shefer et al., 2016). Overall, there was a lack of discussion around managing the effects of the study on participants. However, some papers showed consideration of participant wellbeing by ensuring that participants had an established support network such as a support group (Ploetner et al.,2020), conducting interviews in line with trauma-informed care (Roberts et al., 2022) and pausing interviews when needed (Machin & McCormack, 2021).

Many studies provided insufficient detail to evaluate the robustness of their analysis (Clifton et al., 2013; Dwyer et al., 2020; Greener & Moth, 2020; Lowe & DeVerteuil, 2020; Mattheys et al., 2018; Roberts et al., 2022; Scullion & Curchin, 2022). Although papers often referred to their analytical method (e.g. thematic analysis), there was limited detail on the stages of analysis, limiting transparency and trustworthiness of results. All papers provided sufficient participant quotes to support the credibility of their findings; however, the theme structure of two papers appeared less developed, compared to other papers (Dwyer et al., 2020; Lowe & DeVerteuil, 2020).

All papers stated their findings in relation to their research question and linked this to wider literature. A minority of papers discussed measures taken to increase credibility within the study, such as using multiple data analysts, internal audits and triangulation (Greener & Moth, 2020; Hansford et al., 2019; Machin & McCormack, 2021; Porter et al., 2021; Roberts et al., 2022). Overall, whilst there were some limitations in the quality of studies, these were judged as reporting practice issues rather than major methodological flaws. All papers were considered of sufficient quality to include in the thematic analysis.

Synthesis of Findings

The review uses thematic synthesis (Thomas & Harden, 2008) to synthesise findings from thirteen papers. This process involved: reviewing and familiarisation with each paper, coding each results section line-by-line, developing descriptive themes to capture core concepts across the group, and finally generating analytical themes to generate new insights and interpretations. Six main themes are discussed, as per Table 4.

Table 4

Summary of Systematic Review Themes

Thematic Synthesis Themes
Inescapable Threat: Uncertainty and Anxiety
Invalidation vs Ticking the Boxes
Assessor Apathy and Active Harm
Picking At a Scab: Hindered Healing
Facing the Stigmatised Self
An Unequal Playing Field

Inescapable Threat: Uncertainty and Anxiety. Endemic uncertainty was a recurring theme across the papers and within the application process, which resulted in participants feeling fearful and anxious. Specifically, fears related to being told to return to work despite feeling unable to do so (Dwyer et al., 2020; Ploetner et al., 2020; Pybus et al., 2021) and the potential financial implications of having benefits cut or denied (Clifton et al., 2013; Dwyer et al., 2020; Machin & McCormack, 2021; Ploetner et al., 2020; Pybus et al., 2021; Shefer et al., 2016).

A lack of readily available information about the application process increased uncertainty for claimants, with some finding the process impenetrably complex (Porter et al., 2021). Several papers discussed a general lack of information and opaque communication from DWP concerning what to expect from the medical assessment (Machin & McCormack, 2021), not explaining when and why benefits are stopped (Ploetner et al., 2020), or why medical assessments were cancelled at short notice (Machin & McCormack, 2021). Numerous papers reported that a lack of clear guidance left claimants confused about the

information required to demonstrate their eligibility for benefits (Clifton et al., 2013; Machin & McCormack, 2021; Porter et al., 2021; Roberts et al., 2022; Shefer et al., 2016). Porter et al. (2021) discussed how this negatively impacted participants' application, as they were unaware of how best to present their lived experience to assessors.

Some participants tried to gain information from unofficial sources, such as online forums, which provided reassurance and community but also increased anxiety and exposed people to false information (Machin & McCormack, 2021). Equally, some participants were confused by conflicting information from different sources (Ploetner et al., 2020).

Fear of an official brown envelope (communicating an outcome or need for reassessment) was a metaphor for the uncertainty and fear of rejection whilst awaiting an outcome (Machin & McCormack, 2021; Mattheys et al., 2018; Roberts et al., 2022; Shefer et al., 2016). For many participants, the post became associated with fear and dread, with participants describing avoiding the post (Mattheys et al., 2018; Shefer et al., 2016), and becoming hypervigilant to its arrival (Roberts et al., 2022).

Several papers captured how claimants felt trapped by the application process (Clifton et al., 2013; Ploetner et al., 2020; Roberts et al., 2022), as the uncertainty and resulting anxiety engulfed participants' daily lives. Participants described a sense of immobility and being unable to move forward in life (Ploetner et al., 2020) or think about the future (Roberts et al., 2022) whilst trapped within the benefits application process.

Eight papers discussed participants' experiencing the welfare system as an inescapable revolving door of assessment, rejections, appeals and reassessments with little time in-between receiving an award and being invited for re-assessment (Clifton et al., 2013; Lowe & DeVerteuil, 2020; Machin & McCormack, 2021; Mattheys et al., 2018; Ploetner et al., 2020; Pybus et al., 2021; Roberts et al., 2022; Shefer et al., 2016). The unpredictability of

this timing left participants fearful that they could be reassessed at any point and without warning (Machin & McCormack, 2021; Ploetner et al., 2020). Claimants of DLA and PIP questioned the need for repeated assessments and time-limited awards for long-standing mental health conditions, given previous medical assessments and life-long DLA awards (Lowe & DeVerteuil, 2020; Machin & McCormack, 2021). Pybus and colleagues (2021) described participants feeling stuck within a cycle of ESA rejection, claiming JSA and becoming unwell enough to re-apply for ESA. This stuckness was related to wider cuts to employment services designed to support people with mental health problems, leaving them with fewer exits to the benefits system (Clifton et al., 2013).

Invalidation vs Ticking the Boxes. The benefits system continually questioned the legitimacy of participants, leaving them frustrated as they struggled to demonstrate the invisible impact of mental health on their daily lives (Dwyer et al., 2020; Greener & Moth, 2020; Jordan, 2022; Lowe & DeVerteuil, 2020; Machin & McCormack, 2021; Ploetner et al., 2020; Porter et al., 2021; Pybus et al., 2021; Roberts et al., 2022; Shefer et al., 2016) . Participants reported feeling under scrutiny and suspicion from DWP workers (Clifton et al., 2013; Machin & McCormack, 2021; Porter et al., 2021; Pybus et al., 2021; Roberts et al., 2022) and having their personal accounts ignored (Dwyer et al., 2020). One participant referred to the pressure of scrutiny as feeling "under the microscope" (Robert et al., 2022, p.9).

Participants felt pressure to prove their innocence, conveying this through the metaphor of being on trial (Machin & McCormack, 2021; Porter et al., 2021; Roberts et al., 2022). Participants described being "cross-examined" and "interrogated and accused" by assessors (Roberts et al., 2022, p.10) as well as feeling intimidated by attending tribunals (Machin & McCormack, 2021; Shefer et al., 2016).

Many participants suggested that the emphasis on proof were better suited to assessing observable disabilities than to assessing mental health (Dwyer et al., 2020; Greener & Moth, 2020; Hansford et al., 2019; Lowe & DeVerteuil, 2020; Pybus et al., 2021; Roberts et al., 2022; Shefer et al., 2016). As a participant in Greener and Moth (2022, p.158) explained: "You can't see them [mental health problems], so I'd have to walk round with a placard on saying these are my illnesses." As a result, participants felt particularly vulnerable to being disbelieved and having their claim disqualified (Pybus et al., 2021).

Participants also questioned the assessors' mental health knowledge and expertise (Hansford et al., 2019; Machin & McCormack, 2021; Ploetner et al., 2020). Assessors were described by participants as having limited knowledge of mental health conditions, making judgements based on stereotyped behaviours (e.g. expecting applicants with anxiety to rock during assessment), and questioning applicants' genuineness when they did not conform (Hansford et al., 2019).

The fluctuating nature of mental health appeared to complicate application process. Participants felt that the format of the PIP application form created tick-box responses, which did not record the complexities and fluctuating nature of mental health (Porter et al., 2021). Several papers described the implications of relying on a one-time assessment to evidence disability, which discounts fluctuations in mental health presentation by assuming that applicants' presentation is stable (Dwyer et al., 2020; Hansford et al., 2019; Lowe & DeVerteuil, 2020; Porter et al., 2021). Claimants who presented as clean and articulate were at a disadvantage because: " [on a 'good medication day] they don't really see the effects the depression can have on you or the bipolar. They just think they're seeing a normal, well-adjusted, healthy person." (Dwyer et al., 2020, p.317).

Participants were aware that they were being assessed on their physical appearance (e.g. cleanliness), overshadowing emotional distress and the role of family members and support in the getting-ready process (Hansford et al., 2019; Ploetner et al., 2020; Pybus et al., 2019). Many participants felt trapped in a catch-22: allowing their mental health symptoms to stop them from attending or contributing to the assessment and risk their claim, or making a concerted effort to attend the assessment and comply with social norms (i.e. being well presented, making eye contact) but having their needs underestimated (Hansford et al., 2019). However, observably unwell participants were also excluded from welfare support, as not complying with the system (e.g. not opening correspondence during an episode of severe depression and missing an assessment) could result in benefits being terminated (Pybus et al., 2019).

Several papers described participants feeling pressured to present as if on their worst day and appear more like stereotypes of someone with mental illness to convince assessors that their mental health needs were genuine (Greener & Moth, 2020; Hansford et al., 2019; Lowe & DeVerteuil, 2020; Porter et al., 2021; Shefer et al., 2016). Participants described not washing and wearing dirty clothes to the assessment (Greener & Moth, 2020), avoiding eye contact, providing minimal responses and bringing advocates to assessments to demonstrate the extent of their needs to assessors (Lowe & DeVerteuil, 2020). One participant even felt compelled to discontinue her antidepressant medication several days before to her WCA to reduce the numbing effect on her depression symptoms (Hansford et al., 2019). Complying to these stereotypes left applicants feeling guilty, embarrassed (Porter et al., 2021), frustrated (Shefer et al., 2016), and humiliated (Lowe & DeVerteuil, 2020). Nevertheless, claimants felt compelled to perform their mental illness to avoid their distress and needs being invalidated (Greener & Moth, 2020).

Several papers described the invalidating impact of having a claim denied. Participants who had received welfare support before welfare changes expressed frustration with the lack of consistency in awards (Lowe & DeVerteuil, 2020), while some applicants described feeling "like I wasn't disabled anymore" (Machin & McCormack, 2021, p.13). Other applicants described feeling offended, rejected, and belittled by the messages implied in the rejection of their claim: assessors doubted their lived experiences and they were lying to get benefits (Roberts et al., 2022; Shefer et al., 2016). This appeared to be especially distressing for applicants who had previously been accused of lying or had their needs dismissed by others (Shefer et al., 2016).

Assessor Apathy and Active Harm. The negative influence of the assessor was a consistent theme across papers. Whilst some participants felt that their assessor was attentive and appeared empathetic to how they were feeling (Machin & McCormack, 2021; Pybus et al., 2021; Roberts et al., 2022), many studies suggested that medical assessments were distressing for applicants (Hansford et al., 2019; Machin & McCormack, 2021; Ploetner et al., 2020; Porter et al., 2021; Pybus et al., 2021; Roberts et al., 2022; Scullion & Curchin, 2022; Shefer et al., 2016). Participants described PIP and ESA assessments as humiliating and belittling (Hansford et al., 2019), and an assault on their dignity (Roberts et al., 2022). Assessments were described as impersonal 'tick-box' exercises that felt scripted and prevented participants from providing a full account of how their mental health condition affected them (Clifton et al., 2013; Machin & McCormack, 2021; Pybus et al., 2021; Roberts et al., 2022). Several papers (Ploetner et al., 2020; Roberts et al., 2022; Shefer et al., 2016) discussed how participants felt rushed, unheard and like "just another person...a number" (Shefer et al., 2016, p.839) and forced into categories that did not fit their experiences rather than an individual (Clifton et al., 2013).

Several papers described assessors as lacking empathy towards participants' distress, appearing detached, "robotic" (Roberts et al., 2022, p. 8) and "like zombies" (Shefer et al., 2016; p.838). This sense was compounded as assessors appeared to be focused on their computers, rather than looking at participants (Machin & McCormack, 2021; Porter et al., 2021; Roberts et al., 2022; Shefer et al., 2016). Some participants described feeling equally uncomfortable as their assessor appeared irritated and stern (Roberts et al., 2022).

Having to share personal information about mental health and difficult life events to provide proof of illness was described as humiliating and intrusive (Hansford et al., 2019; Jordan, 2022; Pybus et al., 2021; Roberts et al., 2022). Participants attending both WCA (Hansford et al., 2019; Jordan, 2022) and PIP assessments (Pybus et al., 2019; Roberts et al., 2022) described a dilemma: to either expose the full extent of how mental health disabled their daily lives to protect their benefits, but worsen their mental state, or protect their privacy and self-esteem but jeopardise their entitlement. However, assessors forced this decision by reminding claimants that not answering questions may result in their money being stopped, leaving participants feeling powerless (Pybus et al., 2021).

People with a history of traumatic experiences appeared to be re-traumatised by the questions posed during the assessment and a lack of choice whether to disclose highly sensitive information (e.g. previous suicide attempts) to a stranger in a non-therapeutic setting (Hansford et al., 2019; Pybus et al., 2021; Roberts et al., 2022). One participant described the re-traumatising impact of intrusive questioning, about her experiences of sexual assault, by a male assessor: "I felt like I had been stripped [of my] dignity, because this was a male asking me these questions…It's like he was taking bit by bit off me" (Hansford et al., 2019, p.361).

Some assessors appeared to disregard participants' distress by 'ploughing on' to complete the assessment regardless of the distress it may cause (Roberts et al., 2022; Scullion & Curchin, 2022) or omitting any mention of participants' emotional reactions in their assessment report (Roberts et al., 2022).

Picking at a Scab: Hindered Healing. A decline in participants' well-being was reflected across papers (Clifton et al., 2013; Dwyer et al., 2020; Machin & McCormack, 2021; Mattheys et al., 2018; Ploetner et al., 2020; Pybus et al., 2021; Roberts et al., 2022; Scullion & Curchin, 2022; Shefer et al., 2016). Lowe and DeVerteuil (2020) described participants' sense of being "precariously balanced at all times between 'wellness' and 'illness'"(p.19) which was threatened by the system meant to support them.

 The impact of the assessment system was described as actively sabotaging applicants' attempts to improve their mental health (Clifton et al., 2013; Machin & McCormack, 2021; Roberts et al., 2022; Shefer et al., 2016), and providing a recurrent reminder to question their progress towards recovery (Clifton et al., 2013). This impact was described by one participant as "picking at a scab", whereby the demands and stress of application undoes any previous progress towards recovery:

> They'll pick and say you've gotta come to this or you've got to come to that, you've got to be here or we're stopping your money [...] I just go in my kitchen and sit on the floor and sob. You might have took 5 baby steps but it throw you 10 back. (Shefer et al., 2016, p.838).

The application experience appeared to be re-traumatising for some applicants. A lack of control over the assessment process (i.e. interview location or gender of the interviewer) forced participants to leave their homes, be alone with males and interact with strangers, exacerbating anxiety connected to traumatic experiences (Pybus et al., 2019;

Roberts et al., 2022; Scullion & Curchin, 2022). One participant described how the application system's inflexibility created a catch-22 that caused distress:

> […] they said to me, 'No, but you've got to come in for an assessment. You've got to provide evidence that you've got PTSD'. […] my anxiety levels were so high I tried popping a couple of diazepam and that wouldn't work. I took a serrated knife to my arm […] (Scullion & Curchin, 2022, p.102).

Several papers described the inescapable distress of the application system leading to thoughts of suicide (Dwyer et al., 2020; Hansford et al., 2019; Ploetner et al., 2020; Pybus et al., 2021; Roberts et al., 2022). Ploetner and colleagues (2020) highlighted that many participants appeared distressed when describing how low they felt throughout the application process, illustrating how fears of the future and a sense of hopelessness exacerbated this:

> If I was told to go back to work, I would overdose. I would kill myself, because I've went through too much to get myself to where I am this now, and it was a lot of hard work and a lot of heartache… I couldn't go back. (Ploetner et al., 2020, p.680).

Two papers reported that suicidal ideation became action for some participants after having their application declined (Hansford et al., 2019; Roberts et al., 2022).

Facing the Stigmatised Self. Several papers highlighted participants' conflicting feelings about acknowledging the extent of their difficulties during the application process. Lowe and DeVerteuil (2020) noted that participants found being reminded of their worst days (and most disabled selves) painful, as some wished "to show them how well I was. When you actually feel good, you feel that you want to shout about it." (p.15). Presenting their needs in this way required claimants to sacrifice protective measures of denial and admit the full extent of their disability rather than present an ideal self (Hansford et al., 2019). This

appeared to stigmatise applicants and threaten their preferred self-perceptions (Porter et al.,2021).

Concerns about benefits stigma and a desire to avoid a stigmatised identity featured prominently across multiple studies (Greener & Moth, 2020; Ploetner et al., 2020; Roberts et al., 2022; Shefer et al., 2016). Greener and Moth (2022) contextualised this concern within a context of 'deservingness' discourses, as mental health problems lack observable signs (i.e. visible and biological markers) to legitimise participants' needs to others. Participants described worrying about neighbours and the public judging their eligibility for benefits due to this. Other participants felt that they had lost social status due to stigma from others and being unable to afford to socialise (Ploetner et al., 2020). Participants described feeling isolated and rejected by working people and loved ones due to claiming benefits, leading them to feel that "if you aren't looking for a job and you are on benefits you are some kind, some kind of less of a person" (Ploetner et al., 2020, p.683). Participants linked stigmatising discourses to media influence, such as television programmes featuring 'benefit scammers' (Ploetner et al., 2020; Roberts et al., 2022), and politicians condemning people with mental health issues for claiming disability benefits (Ploetner et al., 2020).

However, several papers noted that participants rejected their stigmatised identity by condemning 'the poor' and emphasising their eligibility in contrast to perceptions of other 'undeserving' claimants (Greener & Moth, 2020; Ploetner et al., 2020; Porter et al., 2021; Roberts et al., 2022; Shefer et al., 2016). Participants who were unable to work attempted to distance themselves from stereotypes of laziness by emphasising their desire to work and that they did not choose to become unwell (Porter et al., 2021; Shefer et al., 2016), and their contributions to society through voluntary work (Ploetner et al., 2020).

This stigma was internalised by some participants who felt "not worth anything" (Hansford et al., 2019, p.360), "guilty for being disabled" and like a "benefit scrounger" (Shefer et al., 2016, p.839). Participants who had previously received disability benefits began to question their entitlement, wondering whether they had cheated the system (Machin & McCormack, 2021) or comparing themselves to visibly disabled people who were denied disability benefits (Pybus et al., 2021).

An Unequal Playing Field. The necessity yet inaccessibility of support was echoed across papers. Several papers outlined professionals intervening to support claimants to understand and navigate the application process, from assisting completion of forms (Hansford et al., 2019; Machin & McCormack, 2021; Pybus et al., 2021), attending assessments and tribunals (Hansford et al., 2019; Ploetner et al., 2020), through to advocating for applicants that were unable to attend the typical face-to-face assessment due to their mental health (Machin & McCormack, 2021; Pybus et al., 2021). Some participants said they would have abandoned their applications without external support (Machin & McCormack, 2021; Shefer et al., 2016), and some papers noted that those who accessed support appeared more likely to receive an award (Machin & McCormack, 2021; Pybus et al., 2021).

Medical evidence from mental health professionals was described as particularly helpful to participants (Porter et al., 2021; Pybus et al., 2021; Roberts et al., 2022). However, the value given to professionals' medical evidence was disempowering for some claimants and highlighted their diminished status as evidence-givers: "It's the fact that I've got to get my psychologist to give proof, it's quite crap – like I've got to get evidence from a higher-up person." (Roberts et al., 2022, p.11).

The pursuit of objectivity at the cost of personal evidence appeared to create a double disadvantage for claimants who did not have access to professional support systems (e.g. mental health services). Although information regarding access to mental health services was not routinely recorded within papers, Pybus et al. (2021) noted that few participants in their sample had access to specialist mental health services to provide medical evidence. Those who could access private healthcare professionals were able to provide personalised, and more effective, supporting evidence that addressed both diagnosis and impact (Porter et al., 2021). Whereas participants reliant on their GP voiced disappointment at the lack of evidence and advocacy available (Porter et al., 2021; Pybus et al., 2021). Furthermore, the process of finding community welfare support services was described as time-consuming and difficult within the context of service cutbacks (Ploetner et al., 2020).

Even with professional support, papers noted that outcomes valued assessor judgement over medical professional testimony, giving participants the impression that the process "is completely skewed against you and real evidence" (Porter et al., 2021, p.288). Other examples of unfairness were described including: assessors reinterpreting medical evidence to disallow claims and directly contradicting mental health professionals' recommendations that the person was too unwell to be 'fit for work' (Greener & Moth, 2020; Hansford et al., 2019; Scullion & Curchin, 2022).

Conclusion

To conclude, six main themes were constructed in this systematic review. The first theme - 'Inescapable Threat: Uncertainty and Anxiety' - described an atmosphere of uncertainty and fear during the application process, which left participants feeling trapped and powerless. The second theme, 'Invalidation vs Ticking the Boxes', outlines the challenges

and dilemmas that claimants faced in proving their needs to a system that relied upon visible evidence and fitting assessors' assumptions about mental illness. Thirdly, 'Assessor Apathy and Active Harm' related to the role of the assessor in creating a distressing and potentially re-traumatising for assessment experience. In the fourth theme, 'Picking at a Scab: Hindered Healing', the detrimental impact of the assessment process on claimants' mental health was described, with a specific focus on stalled recovery and healing. The fifth theme was 'Facing the Stigmatised Self', which detailed the psychological impact of several layers of stigma associated with applying for disability benefits and claimants' attempts to re-negotiate their identities and self-esteem. The final theme, 'An Unequal Playing Field', highlighted the need for professional support through the application process, inequalities in accessing this, and imbalances in the significance given to medical evidence compared to assessor reports.

Rational for the Current Research The introduction and systematic review highlight important gaps in the literature. As established, people with mental health conditions are less likely to be re-awarded disability benefits (Pybus et al., 2019). The systematic review outlined how claimants with mental health problems face specific dilemmas in how to demonstrate their needs whilst navigating a lack of understanding, invalidation, deteriorating mental health and stigma. Whilst some studies in the review highlighted comorbidity between mental and physical health conditions, none discussed the potential overlaps with other invisible conditions, such as neurodevelopmental conditions. Autism appears particularly relevant, given the high levels of comorbidity with mental health problems within both community and inpatient mental health services (Lai et al., 2019; Nyrenius et al., 2022; Tromans et al., 2018).

Mirroring the findings of the systematic review, autistic adults face barriers to accessing services due to staff lacking the skills and knowledge to recognise their needs (National Audit Office, 2009). As a 'hidden disability' the impact of ASD on an individual's ability to manage with day-to-day life may not be apparent in disability benefit assessments. However, it remains unclear how autistic people experience the benefit application process and any further barriers they may face.

Additionally, whilst the impact of benefits-related stigma and renegotiation of identity was a theme across the systematic review, there are additional identity factors to consider for autistic people. Autistic people already face multiple challenges in constructing their identity following diagnosis; including navigating the effects of stereotypes, discrimination, and stigma (Botha et al., 2020). Many autistic adults identify autism as part of their identity rather than a deficit (Botha et al., 2020; R. Cooper et al., 2021). It is unknown how this sense-making interacts within the stigmatisation and shame described by the systematic review.

Finally, the psychological impact of the welfare system has been highlighted throughout this chapter. The theme of 'picking at a scab: hindered healing' described in the systematic review, suggests that people with pre-existing mental health problems may be particularly impacted by benefits-related stress. Given autistic people's poorer mental health and heightened risk of dying by suicide (Hirvikoski et al., 2016; Lai et al.,2019), it is important to understand their experiences of applying for disability benefits and the impact on psychological well-being.

Methodology

Chapter Overview

This chapter will describe the research question and methodology used within this research. This includes: the rationale for the study design, the role of consultation in the study design, consideration of ethics, recruitment of participants and an overview of data collection and analysis methods.

Research Aims and Questions

The research initially aimed to answer the following questions:

1. How do autistic people experience the process of applying for Personal Independence Payments?

2. How do autistic people experience the impact of PIP applications on their mental well-being and sense of identity?

However, this was later refined to specifically focus upon the experiences of late-diagnosed autistic women. See Appendix E for a summary of the evolution of the research question and further discussion in the Participants section.

Design

This study aims to examine the experience of late-diagnosed autistic women's experiences of applying for Personal Independence Payments and their perception of the impact on well-being and identity. A qualitative approach using semi-structured interviews was chosen as the optimal fit for this aim, given the focus on capturing rich and detailed accounts of participants' experiences and meaning-making (Pietkiewicz & Smith, 2014). This approach also aligned with this research's critical-realist epistemological stance which recognises the role of researcher interpretation in developing knowledge (Fletcher, 2017).

Interpretative Phenomenological Analysis (IPA)

Given the research question, this research takes an interpretative phenomenological approach, placing emphasis on the subjective meaning-making of participants rather than determining absolutes about the world (Harper, 2011). This is consistent with IPA's foundations in the philosophical principles of phenomenology, hermeneutics, and idiography (Smith et al., 2022). Firstly, its phenomenological approach aims to produce an account of lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions. IPA posits that people are situated within a pre-existing world of objects, language, and culture (Smith, et al., 2022). Therefore, human meaning-making is always perspectival and subject to individual interpretation which cannot be detached from its social and historical contexts (Larkin et al., 2019; Smith, et al., 2022). The foregrounding of participants' interpretations allows an opportunity to gain insight into the lived experience of autistic individuals, whose 'insider interpretations' have historically been overlooked within research literature (L. Pellicano et al., 2013). This contextualised perspective is particularly relevant to the current research, given that the autistic community and disability benefits claimants are often defined through their social-historical context.

Secondly, IPA takes a hermeneutic approach, which recognises that making sense of participants' accounts requires the researcher to engage in close interpretation. This process relies upon the researcher engaging in a 'hermeneutic cycle'; an iterative and dynamic process of moving back and forth between the part and the whole on multiple levels when interpreting the text (Smith et al., 2022; pp. 22-23). There is also recognition that each party brings their subjectivities to the interpretation process. This is described as the 'double-hermeneutic', whereby the participant offers their interpretation of experience within their account, which the researcher in turn interprets within their analysis (Smith et al., 2022;

p.29). This acknowledges the joint meaning-making between participants' words and drawing upon the researcher's experience and knowledge, as well as the importance of 'bracketing' the researcher's own biases to remain 'experience close' (Smith et al., 2022).

Hermeneutics provides an avenue to address the double empathy problem; whereby non-autistic researchers may struggle to understand autistic participants and vice versa (Milton, 2012). As such, the double hermeneutic explicitly acknowledges this difference in interpretation and critiques the ways in which it may limit my interpretations of participants' meaning-making (MacLeod, 2019). This focus on the interdependence of participant and researcher meaning-making arguably makes IPA particularly suitable as a method of bridging misunderstandings between myself (a neurotypical researcher) and autistic participants (Howard et al., 2019). The reflexive interpretation also allowed this research to remain respectfully grounded in participants' meaning-making and centred them as experts in their own experiences (Howard et al., 2019; MacLeod, 2019).

Finally, IPA shows an idiographic commitment to detail: placing emphasis on individual meaning-making in context, above generalised knowledge claims (Smith, et al., 2022). Small sample sizes are used to focus on individual experiences before building to a group-level analysis of similarities and differences, creating detailed and nuanced patterns of meaning across shared experiences. Arguably, IPA methodology may be best placed to illuminate under-researched perspectives, such as autistic women's experiences of the benefits system. Understanding these lesser-heard perspectives require an in-depth exploration at an individual level, which can provide new insights and identify flaws in previous taken-for-granted assumptions within existing theory and research (Smith et al., 2009).

Limitations of IPA. A common critique of IPA is the reliance upon language to convey the complexities of participant experiences (Willig, 2019). This was pertinent to this research given the potential social-communication difficulties inherent in receiving an autism diagnosis, information processing delays and the potential impact of expressive communication limitations or overly-formal language limiting the depth and detail of interview data (Dewinter et al., 2017). However, this ableist presumption suggests that only the most eloquent participants are permitted to describe their experiences (Tuffour, 2017). Although many participants, autistic and non-autistic, may struggle to articulate their inner-world this does not negate the need for researchers to develop ways of working with participants to capture their experiences in creative and personalised ways (Howard et al., 2019). This was considered carefully in the interview schedule design.

Another limitation of IPA was the potential of re-describing, instead of producing 'comprehensive, systematic, and persuasive accounts' of participant experiences (Smith et al., 2022). I was particularly concerned with achieving a balance between descriptive and interpretative analysis whilst remaining aware of the double empathy problem. Although this added to a tentative approach to interpretation at times, I was also aware that the quality of interpretations varies according to the researcher's engagement with their own reflexive processes. Whilst my personal and clinical experiences with autistic adults provided me with skills that aided this research, it also presented preconceptions that required bracketing. I drew upon my experiences of reflective practice within clinical psychology training (British Psychological Society, 2017), used a reflective journal and supervision throughout data collection and analysis to support me to return to reflexivity throughout this research.

Consideration of Alternative Approaches

Whilst many qualitative methodologies explore lived experience, an idiographic focus is unique to IPA. Given the potential diversity within the autistic community and the challenges in reaching this population, IPA's focus on examining a particular experience within a specific context (Smith, et al., 2022) is most helpful to answer the research question when compared to approaches such as Narrative Analysis, Reflexive Thematic Analysis, and Discourse Analysis which lack this focus.

Grounded Theory (GT; Charmaz, 2014) was considered as an alternative methodology, as a well-established approach with various versions directing research in different directions. GT shares IPA's aim to capture something of participants' views of the world and the nature of the phenomenon under research through analysing data using cycles of inductive analysis. However, whilst IPA focuses on gaining a detailed and nuanced insight into participants' psychological world, GT aims to produce a more conceptual account of contextualised social processes that account for a phenomenon (Willig, 2019). Thus, IPA offered a more helpful framework to answer the current research question.

Consultation

Researchers within the field of autism have advocated for more ethical research practices, such as centring the priorities of the autistic community in research, to offset the longstanding context of neurotypical researchers being positioned as experts on autistic experience, despite epistemological and ethical questions regarding such claims (Milton, 2014). For this research, a team of three consultant Experts by Experience were recruited through professional contacts within the field. One of the consultants expressed interest in participating in the study and was later recruited as a participant.

Each consultant had lived experience of navigating the welfare system as an autistic person and was able to advise the researcher at several key stages in the design of this study:

1. Consultants reviewed the initial proposal for the study and commented upon the importance and perceived relevance of the research question for autistic people and professionals who work alongside them.

2. Consultants then reviewed participant materials (participant information sheet, consent form and pre-interview survey) and the interview schedule, commenting upon the clarity and wording of materials.. This lead to additional prompts and changes to the phrasing of the interview schedule (e.g. offering examples of potential thoughts and emotions).

3. Consultants reviewed aspects of the study design and suggested changes to the recruitment process. For example, consultants suggested that requesting a scan of a diagnostic report to screen eligibility would be preferable to the potential stress related to answering multiple questions within a screening questionnaire.

In addition, all participants were asked about their experience of the interview during the post-interview debriefing, however no changes were suggested.

Participants

Given the need for detailed accounts of individual experiences, IPA studies benefit from smaller and homogeneous participant samples to allow for detailed examination of convergence and divergence within the data (Smith, et al., 2022). For the purposes of this research, it was sufficient for the sample to be homogeneous regarding being autistic

women with experience of applying for PIP within the three years prior to this research. No restrictions were made in terms of specific diagnostic terms, due to recent changes in diagnostic terms (APA, 2013). Purposive sampling was used to recruit eight autistic people, in line with the suggested sample sizes (six to ten participants) to provide a rich data set sufficient for a professional doctorate (Smith, et al., 2022).

Inclusion Criteria

Firstly, participants were required to be an autistic adult with a formal diagnosis of ASD (APA, 2013), irrespective of whether they lived with any comorbid physical or mental health conditions. Given the limited remit of this study, it was not possible to substantially validate self-identified ASD, and therefore only adults with formal diagnoses were included.

Secondly, participants had to have lived experience of applying for PIP between December 2019 and December 2022. There were no conditions on the outcome of benefit applications or the number of applications made within this time frame. This time frame captured the three years prior to data collection in December 2022. A timeframe of 2019 to 2022 was decided to ensure that participants had experienced similar COVID-19 adaptations, as applications made in December 2019 would have progressed to the assessment interview stage several months later (coinciding with COVID restrictions).

Finally, all potential participants were required to be aged between 18-68 years old, reflecting the application criteria for PIP (with 2-3 additional years to allow for time since making the application).

Exclusion Criteria

There is concern that the needs of autistic adults without intellectual disabilities (ID) are overlooked in comparison to individuals with ID and autism. Terms used to differentiate

autistic adults without an ID, such as 'high-functioning autism', reflect assumptions that autistic adults function 'well' and without difficulties in daily life and overshadow the less visible difficulties in multiple areas. This can lead to society disabling autistic adults further by creating a false impression that additional support is not needed (Kenny et al., 2016). Furthermore, whilst little is known regarding autistic adults' experiences of the benefits system, there is recent research addressing the experience of adults with ID (Saffer & O'Riordan, 2022b). Hence, autistic adults with a diagnosis of ID were excluded from the current study.

Autistic adults who were currently in the process of or awaiting the outcome for an application, mandatory reconsideration or tribunal were excluded from the study. This was to protect participants from the potential distress of recounting current experiences.

Similarly, people experiencing acute mental health distress, such as psychosis or suicidal intent, were excluded from this research. However, participant history of mental health difficulties was not an exclusion criterion. Given the high prevalence of mental health difficulties within the autistic population (Hossain et al., 2020), it was deemed likely that participants would often have experience navigating mental health challenges.

Recruitment

A stepped sampling approach was taken. Participants were recruited via multiple stages of advertisements placed by the university, voluntary-sector organisations and social media to maximise reach whilst avoiding over-subscription. Adverts were placed with non-NHS organisations to avoid limiting recruitment to individuals who had access to NHS autism services. Given that specialist autism services predominately have contact with people seeking a diagnosis in adulthood (Beresford et al., 2020), this would disadvantage autistic people who received a diagnosis less recently or from private practice. Furthermore, the

offer of post-diagnostic support varies substantially across NHS Trusts, with many autistic adults not remaining in contact with NHS services following diagnosis (Beresford et al., 2020).

The study was advertised initially via the University of Hertfordshire online news bulletin, and with two charities that support autistic adults in the community (step 1). Recruitment pathways were subsequently expanded to include autism-related social-media forums (step 2) and a national charity that develops and campaigns for autism-focused research (step 3).

Seventy-four autistic adults responded to the recruitment adverts, the majority of whom were recruited via the autistic research organisation newsletter The research team were wary of rejecting adults expressing an interest, potentially mirroring experiences of the benefits system. When responding to expressions of interest, all potential participants were informed of the high response rate and limitations on the number of participants to reduce potential disappointment should they not be invited to the interview. A summary of the research and the lead researcher's email were provided in the advert, allowing potential participants to contact the principal researcher directly.

All participants were provided with the Participant Information Sheet (PIS) and given opportunities to discuss queries or concerns before indicating further interest. Potential participants then completed an online screening questionnaire, which included inclusion criteria and questions regarding adjustments that may be helpful for the interview. Convenience sampling was then adopted; people who expressed interest and met inclusion criteria were invited to interview on a 'first-come-first-served' basis to ensure fairness, and all potential participants were notified when all spaces were filled (decided based on the

time limits and scope of the study, the richness of data collected, and through discussions

with the supervisory team).

Refining the research question. Gender was not purposively sampled, however the

majority of people who responded to the study advert were cis-gendered women, therefore

the eight participants invited to interview were all women diagnosed in adulthood. Focusing

on women's experiences provided opportunity to increase the sample homogeneity and

explore the impact of gendered experiences in greater depth. Whilst research suggests that

late-diagnosed autistic women face specific challenges in accessing diagnosis and

appropriate support due to diagnostic and gender stereotypes (Gosling et al., 2023), it was

unclear whether these experiences were significant to autistic women who claim PIP. The

research team collectively decided to revise the research question to better capture the

homogeneity of the sample and reflect the potential gender-specific experiences of

participants.

Participant Information

 Eight autistic women participated in this study, all of whom had a formal diagnosis of

autism. All women had applied for PIP between 2019 and 2022 and attended at least health

assessment in 2020-2022 as part of their PIP claim. All participants were cis-gendered

females who received an autism diagnosis in adulthood, although neither gender nor age at

diagnosis were purposively sampled. Participants were aged between 20-69 years old,

however most women were aged between 30-39 years old. The majority of women

described their ethnicity as White British.

Two participants stated a preference for written interviews and one for an audio-only

interview, whereas the remaining participants requested interviews via video call. All

interviews were conducted via MS Teams with either video/audio enabled or disabled as per

participant preference. Written interviews were via MS Teams chat function. Table 5 outlines

participants' self-chosen pseudonyms and demographic data.

Table 5

Participant Demographic Data

Participant pseudonym	Age	Ethnicity	Interview format	PIP History	Current employment status	Outcome of application
Anna	20-29	White British	Written	New application, Mandatory Reconsideration and appeal	Employed full-time	Declined
Marie	50-59	White British	Spoken	New application	Employed part-time	Awarded
Jade	30-39	Ashkenazi Jewish	Written	New application, Mandatory Reconsideration	Part-time student and volunteering	Awarded
Sakura	30-39	White British	Spoken	New application, Mandatory Reconsideration	Employed part-time	Awarded
Yvonne	30-39	White British	Spoken	PIP review x2	Unemployed	Awarded
Maat	60-69	White British	Spoken	1. New application 2. Review	Unemployed	Awarded
Dahlia	30-39	White British	Spoken	1. New application, Mandatory Reconsideration, and appeal 2. New application	Full time student	Declined
Alice	40-49	White British	Spoken	Application, Mandatory Reconsideration and appeal	Ad-hoc and voluntary work	Awarded

Ethical Considerations

Ethical approval was granted by the University of Hertfordshire's Health, Science, Engineering and Technology Ethics Committee in May 2022. The protocol number is LMS/PGR/UH/04977 (Appendix F). The British Psychological Society (BPS) guidance on ethical internet-mediated research was followed throughout this research, to ensure that the research was conducted with scientific integrity, took social responsibility, and remained respectful and minimised harm to participants (BPS, 2021). In line with University of Hertfordshire's COVID guidance, the research design minimised potential harm to participants by avoiding face-to-face contact.

Informed Consent

A Participant Information Sheet (PIS; Appendix G) was shared via email with potential participants who expressed interest in the research. Participants were provided with opportunities to ask questions about the research prior to the interview, to support them to make an informed decision about participating and given further opportunity at the end of the interview. Participants were required to read and sign the consent form before participating in any interviews (Appendix H). The PIS and consent form informed participants of their right to withdraw their data from the research at any time up until four weeks after their interview and were reminded of this at the interview. A four-week limit was chosen due to difficulties extracting data from analysis past this point.

Confidentiality and Data Protection

Confidentiality was maintained throughout the research process. Participants were made aware of confidentiality and the limits of this in writing and before their interview. All identifiable data (including consent forms, demographics forms, and audio files) was stored securely and separately in password-protected files on the University of Hertfordshire

OneDrive, as per UH data management policy and General Data Protection Regulations. All interviews were conducted using video call technology (MS Teams), audio/video recorded and stored in a password-protected file separately from other identifiable data. The transcripts of written interviews were downloaded and stored as above. As a trusted transcription service was used to transcribe spoken interviews, recordings were labelled via a pseudonym of participants' choice and the transcriber was required to sign a non-disclosure confidentiality agreement (Appendix I). All other person-identifiable (i.e., names, places) details in the transcripts were altered to ensure participant confidentiality. Consent forms, demographic data and audio and video recordings will be deleted upon completion of this study. Anonymised data will remain securely stored on the UH OneDrive for up to five years, at which time it will be destroyed.

Participant Wellbeing

Much consideration was given to the preferences and needs of the autistic community at all stages of this research from design through to dissemination. Prior to the interview, participants received a pre-interview survey requesting their preferred terminology for autism (to be used during the interview) and offering a variety of reasonable adjustments to be used before and during the interview (see Appendix J). Participants were free to choose from a list of adaptations suggested via prior research (Gowen et al., 2020; Heselton et al., 2021) and expert-by-experience consultation, as well as contribute their own choices. Example adaptations included a pre-interview meeting to meet the principal researcher, receiving the interview guide in advance and regular short breaks throughout the interview. All participants were also offered interviews via video-call, audio-only or synchronous messaging formats to ensure that the interview process was as convenient and comfortable as possible. Research suggests that autistic adults have a range of

communication preferences; therefore, offering a variety of interview methods allowed

participants to choose which suited their individual needs; for example: increased structure,

processing time and sensory sensitivities (Howard & Sedgewick, 2021).

Given the literature related to challenges faced by claimants seeking welfare support, the

research team anticipated that participants may feel some discomfort from reflecting upon

their experiences during the interview. Several safeguards were considered to minimise

distress and support participants throughout their participation. Participants were informed,

via the PIS and before the interview commenced, about the potential for distress and that

they did not have to talk about anything that they did not feel comfortable discussing. All

participants were reminded that they could choose to pause or terminate the interview at

any point and that the principal researcher could provide signposting to relevant support

should they feel distressed at any point.

At the end of the interview, participants were provided with an opportunity to

feedback on their experience of the interview and debrief. Participants were offered the

opportunity to book a follow-up meeting or be contacted via email a week after their

interview to check their well-being and offer an opportunity for further comments and

questions. All participants chose to be followed up via email and no participants required

signposting to mental health services.

Data Collection

Interview Schedule Development

A semi-structured interview schedule was developed in line with IPA guidance (Smith, et al.,

2022), relevant autism and welfare literature, and consultations with consultants and the

supervisory team. Particular attention was paid to phrasing of questions to ensure clarity for

participants and providing prompts to allow an in-depth exploration of personal meaning-

making. The interview schedule was used flexibly to cover participants' meaning-making around autism, moving on to their experience of their PIP application before exploring the impact on personal wellbeing and sense of identity.

The interview schedule was shared with consultants and further refined using their feedback on the clarity of questions and use of prompts to support communication between the researcher and participants. For example, one consultant suggested providing a list of possible thoughts and feelings that they could refer to and select from to support participants to express their internal world. This suggestion led to further prompts to the interview schedule. See Appendix J for the final interview schedule.

Interviewing Procedure

All interviews were conducted remotely via videocall technology (i.e., MS Teams) due to University of Hertfordshire research restrictions following the COVID-19 pandemic. Participants chose to communicate via speech (i.e. audio or video call) or in writing (i.e. via MS Teams chat function). Research has considered the possibilities and challenges of using online interviews within qualitative research (Archibald et al., 2019; Thunberg & Arnell, 2022). The advantages of online over in-person interviews are efficiency, flexibility, cost-effectiveness and convenience for participant and researcher. However, disadvantages may include technological issues and potential difficulties building rapport online and interpreting non-verbal communication (Lobe et al., 2022). Further consideration of the impact of using online and written interviews is provided in the discussion section.

Data Analysis

Data analysis was conducted following IPA guidance (Smith et al., 2022), alongside consultation with the supervisory team. Table 6 summarises Smith et al.'s guidance that acted as a framework for analysis. Due to project restrictions, four transcripts were

transcribed verbatim by an independent transcription service. I transcribed two transcripts independently and reviewed the prepared transcripts of two interviews conducted via instant messaging. Editing and amending transcripts formed a basis for immersing myself within the data, alongside listening to the interview and re-reading the transcript multiple times. Each transcript was transcribed and analysed individually to maintain IPA's idiographic commitment.

Initial notations of my overall impressions and reflections were noted within the research diary, alongside reflective notes made after each interview. For exploratory noting (step 2), I annotated transcripts in Microsoft Word with descriptive (i.e., content and words used), linguistic (i.e., laughter, pauses) and conceptual (i.e., interpretative) notes (see extract in Appendix L). I then uploaded transcripts into NVIVO v.1.7.1 (QSR International, 2022) to continue analysis, allowing me to organise the data and large number of experiential statements (step 3), which were linked directly to the transcript.

Table 6

Summary of IPA Procedure

Step	Procedure
1	**Immersion in the data** by listening to the interview recording and reading/re-reading of the transcript line-by-line several times. This included noting my initial reactions and striking aspects of the transcript.
2	**Exploratory noting** through reading the transcript line-by-line whilst noting descriptive, linguistic and initial conceptual comments on the content in the left-hand margin. Comments maintain a phenomenological focus on both the objects of concern (i.e. events, relationships, processes) and the meanings for the participant.
3	**Constructing experiential statements** in the right-hand margin of the transcript. Statements are developed to produce a concise summary of both the participant's words and the researcher's interpretations, capturing the important aspects at a conceptual level.
4	**Searching for connections across experiential statements**, by clustering and mapping relationships between statements to produce a structure highlighting the most interesting and important aspects of the participant's account.
5	**Naming the personal experiential themes (PETS).** Each cluster of experiential statements is named to capture the main characteristics and patterns of meaning that it encapsulates. PETs are then summarised into a table.
6	**Continue the analysis across other cases** (interviews). Repeating the above steps.
7	**Develop group experiential themes (GETs)** across the participant sample by looking for patterns of convergence and divergence across PETs.

Continuing the analysis within NVIVO, I searched for patterns of connection and contrast across the experiential statements to cluster statements into personal experiential themes (PETs) (see Appendix M). Constructing PETs was an iterative process, whereby I continually reviewed and amended initial groupings to best reflect the data. These stages were repeated for each transcript, ensuring that I created separate Word documents and NVIVO files for each participant.

Once I had developed PETs for each transcript, I began examining patterns of similarity and difference across participants' accounts to create group experiential themes (GETs). I printed out each PET table, allowing me to cut out and move themes into new configurations. I continued clustering, condensing, and renaming emerging groupings, often returning to individual transcripts to ensure that my analysis reflected participants' words and developing my interpretations (see clustering process evidenced in Appendix N). My research team and I reviewed my initial GETs to ensure that these captured the breadth and depth of participants' experiences. I then wrote a narrative account of the finalised GETs, highlighting similarities and differences between participants' accounts, and supporting my interpretations with transcript extracts.

Quality Assurance

An audit trail (see Appendices L, M, N) is provided to ensure that the reader can trace the analysis back to the original data, as per good practice guidance (Smith et al., 2011). Given the importance of reflexivity within IPA analysis, and my awareness of the double empathy problem (Milton, 2012), I regularly considered my position to the data (see extracts from my reflective journal in Appendix A). Further details on steps taken to ensure credibility and rigour are discussed within the Discussion section.

Results

Overview

This chapter outlines the findings from an interpretative analysis of interviews with eight autistic women who have experience applying for PIP. Five group experiential themes (GETs) and their subthemes were developed (see Table 7). The following GETs aim to highlight commonalities between interviews, whilst clarifying nuances in experience between participants. Each GET is described with verbatim extracts from participants' accounts to evidence the credibility of the analysis. See Appendix O for details of theme prevalence across participants. These results represent one of many possible interpretations of autistic women's experiences within the PIP application process, as patterns of data were selected for their relevance to the research question, rather than an exhaustive summary of every experience shared (Smith et al., 2022).

Table 7

Overview of GETs

Group Experiential Theme	Subtheme
Powerlessness and Threat	"They've got you under their thumb": Feeling Powerless
	"it just makes everything worse": Responding to Threat and Uncertainty
	A Poisoned Chalice: Opportunities and Threat
Communication: Caught in a Catch-22	-
Distance and Dependence: "It's really hard to know who to turn to"	Needing Knowledge to Navigate the System
	Feeling Isolated from Loved Ones
Being Misunderstood by the Assessor	"They don't see the struggle"
	Facing an Inhuman(e) System
	"It just brings all back": Reliving Past Invalidation
Changing Who I Am	"I really am the most useless person in the whole world"
	Resisting the Imposition

Powerlessness and Threat

This theme portrays participants' experiences of powerlessness, uncertainty, and threat throughout the application process and beyond. It attempts to describe the psychological impact of living within this climate of fear and the implications for autistic women's daily lives. Three subthemes are discussed: "They've got you under their thumb":

feeling powerless; "It just makes everything worse"; and A poisoned chalice: opportunities and threats.

"They've got you under their thumb": Feeling Powerless

Five participants described feeling under threat from a powerful system which appeared to them to be deliberately designed to harm, rather than support, applicants. Yvonne described how her experiences with the application form increased her initial distrust of the system: "They make it intentionally difficult from the moment you apply for a PIP. Um, extremely overwhelming, you know. [...] I just think they set it up to fail people, really, and I still stand by that.". Yvonne conjures a picture of a rigged system, designed to overwhelm applicants and prevent them from progressing their application.

The risk that "any kind of failing on your part could lose you the money you need to survive" (Maat) appeared to loom over the women, who described feeling helpless against the system's demands:

> ...they've got you under their thumb, I was just being squashed, and I was just like: 'I just need to follow, I just need to do what I'm told now and hope for the best'. It was … it was scary. Having worked since – fulltime – since I was 18, to, yeah, to then being in a … in a world of benefits. (Yvonne)

Yvonne's use of anthropomorphism depicts her as a small and insect-like creature at the mercy of a forceful and relentless system determined to force her to yield to the pressure. The use of scale within the metaphor highlights this power differential. She highlights her loss of power by contrasting her previous autonomy and agency, as a worker, and her new position where she feels that she has no other option but to "hope for the best". She finds herself displaced out of the known and into an unfamiliar and disorientating "world of benefits" which appears to run according to different rules and structures.

Jade compared the PIP experience with everyday struggles against bureaucratic systems: **"**it's like swimming through treacle, all the time, trying to get anything done, and government (national or local) officials are jumping on your head trying to drown you, instead of throwing you a lifeline."

Jade conjures the image of powerlessness and vulnerability. The juxtaposition of a "lifeline" with violence highlights her vulnerability and suggests intentional harm and abuse of power by powerful systems, keeping Jade trapped without escape. The sustained effort needed to navigate systems is evoked through metaphor ("swimming through treacle") and mirrored through slow pacing created by multiple commas.

"it just makes everything worse": Responding to Threat and Uncertainty

Five participants reflected on the negative psychological impact of powerlessness and threat. Several participants described feeling anxious – *"dreading a brown envelope"* (Dahlia)- whilst they awaited the assessment outcome and the struggle of sitting with uncertainty:

> I find uncertainty very difficult. So it's not just now that the outcome is still uncertain. But also how long it will take to resolve. And this is hanging over me all the time, again interfering with my daily life. […] just worrying about the outcome, and whether I would have to fight more. Had I done all this for nothing? Would I have to go to [mandatory reconsideration] or even appeal? (Jade)

Repeated hypothetical questions draw readers into the uncertainty and worry, which hang over Jade, suggesting an inescapable feeling of impending doom. As Jade highlighted, the prolonged uncertainty appeared to disorientate participants, making it difficult to continue the rhythm of daily life. The process appears uncertain in terms of outcome, and length,

leading Jade to implicitly question her stamina. She later described this uncertainty as exacerbating her pre-existing needs:

> It made my executive functioning skills even worse. So it's lucky I didn't have anything to go to at the time (because of coronavirus), as I wouldn't have been able to organise my normal life tasks as well. But even daily household tasks, such as washing up; it felt like there was no room in my brain to even do things like that.

Jade's description of "no room in my brain" creates a picture of the inescapable nature of worry and uncertainty, something that has taken over her mind and made it impossible to focus on daily tasks.

Several women described a decline in their mental health. Maat explained that anxiety and depression are a "part of [autistic women's] lives", which is exacerbated by PIP-related stress:

> …it makes you even less capable of doing things. It gives you more meltdowns. It, um, you … you know, you end up just eating toast all day because you can't do anything more than that (chuckles) […] um, it … it just makes everything worse.

For Maat, feelings of tiredness and paralysis showed as "the lack of self-care, the lack of ability to do anything, even the most basic things". Yvonne described feeling "wiped" by the emotional impact of her experience: "I guess I now understand what I believe that experience to be autistic burnout, following that awful experience, yeah. I was just in like bed for days."

Whilst most participants described a psychological and physical impact on their daily lives, Jade felt a cumulative impact of stress from PIP and other factors on her ability to remain connected to her emotions: "I have become more resilient. But also less capable of

joy. You can't continue dealing with negative things without toning them down over time, but it also tones down the positive things too."

Conversely, Anna and Marie described no negative psychological impact during the assessment process. For Anna, the length of the process rendered it irrelevant to her daily life which prevented the process from dominating her thoughts. Similarly, Marie explained that although she was aware of the ongoing process, a busy schedule of work and other commitments limited the impact of the process to "just a task which hadn't yet been, you know, been completed...". For Marie, the application's power is diminished to another mundane task that needs resolving rather than a looming threat. Interestingly, Anna and Marie were the only participants in full-time work during the application process, which may have offered a sense of purpose and financial stability unavailable to the other women.

A Poisoned Chalice: Opportunities and Threat

Receiving a PIP award appeared to bring a mixture of emotions. Yvonne and Maat described gratitude and relief at no longer living within the threat of the application:

"the letter came through to say that I'd been [awarded PIP], but for 3 years this time round, so I thought, 'Oh phew! I'm safe!' You know. I thought, 'I'm safe." (Yvonne)

"I felt not just relief but also lucky and gratitude as well because, even though I know that I need it, the attitude of the DWP is always that you don't." (Maat)

Alongside the relief of reaching safety, participants described of the benefits of receiving the payment. For many the financial relief opened previously impossible choices. For Marie, PIP provided the financial security to take pro bono work and gain new experience. Sakura described reducing her working hours to safeguard her mental health whilst remaining employed. Ultimately "allowing [her] to live a life like other people".

Several participants described independence through tangible accommodations. Sakura described the practical value of being able to buy noise-cancelling headphones due to sensory needs. Jade illustrated how PIP allowed her to buy prepared food to reduce the need to cook as often. For Maat, payments also offered hope to access otherwise inaccessible resources. PIP allowed her to access private therapy tailored to autistic clients, something unavailable via NHS mental health services and unobtainable on ESA alone:

> I needed the money really for that counselling to be paid for because I knew how desperately I needed it. [...] it wasn't so much for sort of daily living that I wanted the PIP, it was specifically for a counsellor, um, to try and help me cope with life.

For Alice and Sakura, PIP also appeared to implicitly certify them as 'disabled'. Alice described PIP as "proof that you've got a real disability". She felt this proof was needed to gain permission for reasonable adjustments and access to the community like any other citizen. For example, not needing to stand in queues for rides allowed Alice to enjoy her interest in theme parks without excess anxiety, and her bus pass "shows the driver that you've got a disability and to be patient...". However, Alice remained aware that these adjustments were contingent on PIP, adding to her worry about re-assessment.

Conversely, Sakura described feeling vulnerable due to being viewed as 'disabled'. She described PIP as exposing her as a target for financial abuse after telling someone about her entitlement to disability benefits:

> I said, 'Well, you know, I'm classed as being disabled' explaining all this to them. Didn't realise they were planning to abuse me [...], it makes people open to be abused, whether that's financially, or sexually, or emotionally, just, you know, the fact that, 'Oh you're disabled, so I can do whatever, you know, to you and take advantage'.

The relief at being awarded PIP was not long-lasting, as women described receiving reassessments at regular intervals. This highlighted assumptions about recovery inherent within the system, which Jade alluded to as she questioned the suitability of reassessment: "[PIP] was only awarded for 2.5 years [...] I am never going to stop being autistic, and by this age, if I haven't developed those skills, I am not likely to." The continued uncertainty of reassessment appeared to damage women's sense of safety. Yvonne spoke of her "dread" of being summoned for reassessment:

It's that horrible anticipation in your stomach, it's like you're about to go and do an exam.[...] I like to know. I … I can't …I like to try and be as organised as possible, and I have to hope for the best.

Yvonne alludes to the intolerability of the return to uncertainty, which she attempted to manage through preparation and research. Her analogy of awaiting an exam highlights the return to a state of hypervigilance and powerlessness. Alice also alluded to this sense of dread and feeling "constantly being monitored [...] I think sometimes it makes you feel…you…you don't feel free". Similarly, Sakura described her anxious anticipation of reassessment and whether this would mirror her previous experiences:

It feels like it's been a whirlwind [...] even now, it's like I'm now, I worry about [reassessment], about how that's going to go, and if I will be awarded it again? Um, am I going to have to go through all of this again? Um, and that terrifies me – it really does, because I genuinely like nearly lost my mind with it.

Her use of "whirlwind" to describe the process suggests a sense of unpredictability, helplessness, and disorientation through the application process. She reflects upon the

possible risk of re-entering the whirlwind and the potential destruction it could cause to her well-being.

Communication: Caught in a Catch-22

This theme summarises difficulties in communication between participants and the benefits system. A lack of accessibility reportedly created a catch-22 for participants: how to describe their difficulties whilst facing communication challenges without reasonable adjustments?

Many participants described difficulties conveying their needs in everyday life and reflected upon the inaccessibility of the disability benefits system, which compelled them to evidence their needs without offering reasonable adjustments for communicating this evidence. Sakura described this catch-22:

> ...it's like: 'Well, we want you to do this to be able to get anything.' And it's like 'OH!' (laughs) 'But I can't! I just told you I can't … I can't do these things!'… 'No, I know. But you've got to try and do them so you can get any help.' I don't know...It just seemed so backward.

Sakura's imagined conversation between herself and the system illustrates the tension between claimants' support needs and the requirements of the benefits system. Her laughter acknowledges the apparent contradiction and absurdity of the situation that she faces yet is powerless to change.

A common example of this paradox was the requirement for claimants to describe and evidence their needs whilst navigating unclear and ambiguous communication from DWP. Sakura illustrated how the ambiguous wording of the application form presented a barrier:

> I think my blood pressure was just sky-high throughout that whole time [...] just the panic of 'Am I … am I doing this right? What is it they're really asking? Is there some hidden meaning behind this?' Or …not really understanding because the questions were so like, um, broad [...]'Can you move this many metres?' Or 'Can you do this?' Or whatever, and it's like 'Well, yeah, some days but then other days, I'm literally, I can't do ANY of this at all' – so what do you write?" (Sakura).

The use of present tense draws us into Sakura's inner world whilst she attempts to make sense of the form in the absence of clear information and prompts. Her repeated rhetorical questions highlight her confusion and fear of missing the implicit meaning within the form questions. Ultimately, the mental effort required to understand each question leaves her paralysed by uncertainty and stress, compounding the struggle of completing the form.

Conversely, Marie repeatedly described the form as "straightforward" and compared the form to "filling evidence in an evidence log, which is something I've done so many times in other contexts […] it was just a routine task." Marie highlights the mundanity of the process by using 'just a routine task' to diminish the power of the form to something unextraordinary, with little meaning or significance to her daily life. It is important to note that Marie referenced her workplace throughout her interview. Her professional role may have provided a scaffolding of how to complete demanding administrative tasks and communicate complex information to others.

There was a sense of increasing pressure on communication skills as participants attended the interview stage. Dahlia and Maat explicitly described the pressure to prepare for the interaction:

> I had to prepare a massive script, that was … that would determine the outcome of something that important. And it was that one phone call, you know, it was do or die

kind of thing. Um, and it puts a lot of pressure on you. (Dahlia)

…it's a stranger who's going to decide whether I get some counselling to stop me wanting to kill myself […] it's a formative thing, um, you're terrified of saying the wrong thing, or of not saying enough, or not saying the right thing. (Maat)

The building pressure and panic are mirrored in participants' language (e.g. "do or die") depicting the assessment as a threat to their safety and futures. Participants described feeling forced to rely upon their communication skills to avoid losing this hoped-for future, whilst receiving little clarification about how well they had made themselves understood: "you need to get certain points across and it was whether…she was hearing me, you know." (Maat).

However, assessors did not appear to adapt their communication to applicants' needs or communication preferences. Anna appeared frustrated and described feeling misled by her assessor's unclear communication, describing her as "not ask[ing] the right questions" and cueing her "in the wrong direction". Her distress was compounded when her tribunal assessor refused to accommodate her needs:

 I felt so pressured and did not know how to answer them, I had a meltdown e.g., started crying and was not able to say anything […] I did say that I can't answer this question that I needed him to specify it and he said... he was like 'no, I can't do that. That's not how it works'. Yeah, then he didn't answer that question again, so the proportion that he was gonna find out about was lost completely.

Anna later described feeling "disempower[ed]" by the experience, highlighting the potential power of assessors to deny applicants the opportunity to fully engage in the process, silencing and excluding them.

For other women, the design of the system itself was silencing. Although a telephone interview was not accessible for Jade, due to auditory processing difficulties, no alternative was offered, and Jade relied on a volunteer from an autism organisation to speak on her behalf during the interview:

> ...she typed what they were saying to me, and I typed my answers back, which she read out to them [...] It would have been much easier if they just offered an online messaging appointment directly, so I could communicate for myself. Again, it was stressful, as although I was typing, not speaking, it's still time-limited, which I also struggle with. I need processing time, and to see their thoughts written to me, so I can think about how to respond best.

Her wish to "communicate for myself" highlights to power that an inaccessible system can have to silence applicants by not offering communication formats that meet their communication needs. Jade and Anna chose to participate in this research via instant messaging interviews, and both expressed that this supported them in processing their thoughts and expressing themselves.

Yvonne highlighted a disparity between the accessibility offered to people with physical disabilities (e.g. offering the application form in braille) which she felt indicated a lack of consideration for autistic people's needs:

> they don't … they … they obviously don't think, you know, they don't think of … I don't know, maybe (slight pause), just making it more accessible in general. You know, like the language used or … you know, some people, they may want to speak

their, say their words … do you know what I mean? Like a voice mail and record the

form that way. I don't know, they just don't … none of that's even in place.

Yvonne highlights the implausibility of a 'one size fits all' form whereby adjustments are only

available for applicants with needs related to physical disabilities. Her repeated assertion

that "they don't think of…" highlights inconsistencies in the system's thinking and

consideration of autistic applicants' needs. Her sense of frustration and inadequacy of the

current design is demonstrated through her repeated exasperation in "I don't know" and

"none of that is even in place".

Distance and Dependence: "It's really hard to know who to turn to"

This theme speaks to participants' experiences of connection and disconnection to

their support systems throughout the application process. It is comprised of two sub-

themes: 'Needing knowledge to navigate the system' and 'Feeling isolated from loved ones'.

Needing Knowledge to Navigate the System

This subtheme describes participants' experiences of seeking professional support to

navigate a complex and confusing application process. Four women spoke about the need

for help with their application and difficulties accessing it. Sakura described the difficulties

trying to navigate a system that required specific knowledge, which her family did not have:

they have no experience of this! […] it was a bit like applying for university. You just

got all these forms and my parents – well, only one of my parents went to university

– so, they're just like, 'Well-I-don't-know' and 'it's all changed since I was young' so

it's … it's really hard to know who to turn to.

Sakura directly compares the university system and the benefits system: the comparable

need for knowledge to successfully navigate these complex systems and the privilege of

having that knowledge. The application process appears a lonely process, as Sakura

questions "who to turn to" when loved ones can no longer support you.

Yvonne and Alice highlighted that the application is "hard work and stress even with

support" (Alice). Yvonne recounted her experience of asking for support from a benefit

advice service which was not able to offer her an appointment within the time limits of her

application. This placed her in a precarious dilemma: seek support and risk penalisation for

a late application or attempt to navigate the process alone:

> I had to just bite the bullet and go for it because I think if I'd put it off any longer, I
>
> didn't do anything myself, they could have said 'Oh well, you haven't redeemed, you
>
> haven't sent it back within the time frame, we're cancelling it all'.

The metaphor "biting the bullet" highlights Yvonne's feeling of powerlessness and fear,

alongside the risk and difficulty of proceeding without help. For Alice, powerlessness also

occurred in relationships with the professionals who support her applications. She

contrasted her most recent experience of her partner (an experienced advocate) supporting

her through the PIP application with her past experiences of seeking help when workers:

> [...] just took control [...] but we had to put up with her and her behaviour because
>
> she had to help us" leaving her feeling that "when you're in that vulnerable position
>
> and you just have to…um you're pushed into trusting someone.

This sense of powerlessness is highlighted in the experience of being "pushed" into a

vulnerable position in turning to a powerful other to guide her through the application, with

a risk of her agency becoming lost to professionals taking control. She describes feeling that

she had already surrendered control through her lack of choice in the decision to seek

support and who she consults, but feelings of vulnerability appear to trap Alice into "putting

up" with disempowering dynamics to access the available support.

Despite difficulties accessing support, Maat, Yvonne and Sakura described benefits advisors as vital advocates and trusted sources of information. It appeared that support provided some relief to the feelings of powerlessness induced by a confusing and unknown system. Yvonne described confidence that she had "done [the form] to the best of my ability" after consulting an advisor, whereas Sakura valued advisors reviewing her rejected claim: "just having that back-up of them saying, 'No, you know, they're wrong for doing this … this is wrong for that, you know, this is where we can score some points…'". For Yvonne, the advisors appeared to reassure her and restore a sense of confidence in her abilities to navigate the demands of the system. Similarly, Sakura draws on advisors as "back-up", suggesting feelings of solidarity and validation, that the assessor has misrepresented her needs in the assessment letter.

Feeling Isolated from Loved Ones

Whilst participants found themselves needing to rely upon others to navigate the application process, they described feeling distanced from their usual support networks. Some women experienced or feared othering from other people. Sakura, Dahlia, and Yvonne described feeling othered by their experience of claiming benefits. Sakura described herself as "very isolated through the whole process" of her application. She reflected on how her mother's difficulties accepting her autism diagnosis, combined with benefits stigma, impacted how she viewed Sakura's application:

> [she] was almost like just shuddering, and … and like, 'Urgh, I can't stand the thought of you know getting money for … for this', you know, couldn't accept that it was something I … I needed to be able to function more normally because I couldn't work full-time.

Sakura's language (i.e. "shuddering") and her mother's reluctance to name autism suggest disdain and reluctance to recognise the challenges that her daughter faces in daily life. Sakura's struggles are downplayed and diminished to a faceless "this" suggesting a sense of inadequacy and insufficient justification for claiming benefits.

For Yvonne and Dahlia, internalised shame appeared to contribute to their isolation. Yvonne initially avoided telling her mother about her PIP application due to internalised shame and feeling othered from her family's 'worker' identity, explaining "we're not like a benefits, um, related family […] everyone's always worked". She reflected how this family norm led to feeling embarrassed about her mental health and being unable to work: "I think the whole stigma, you know … because this is, we're not a – they've always worked and, um, I thought 'What's she going to think of me? What are my friends going to think of me?'" Yvonne juxtaposes her family as having "always worked" against her having to apply for benefits. A change in pronouns ("we're not" to "they") starkly differentiates Yvonne from her family, suggesting a sense of isolation and shame for becoming the 'odd one out'. Similarly, Dahlia described feeling increasingly different and reducing contact with lifelong friends who have never had experience of the benefits system:

>…we've been through absolutely everything together, but there are times, where because they haven't had to apply, or they haven't had to advocate for their partner in a tribunal, I don't think they'll ever quite understand that feeling, um, and I guess that does make me feel more guarded as well. (Slight pause) … I think it isolates me from other people of my own age who've known me all my life.

The emotional strain of the application period also diminished Yvonne and Maat's ability to seek out social support. Although Yvonne's family was supportive when she was

able to speak with them, her sense of isolation returned as application-related stress impacted her mental health. She described the impact of this on her relationships:

> […] everything I was doing at that particular time just got dropped, and you know, friends, you know, um, relationships I had with friends [...] [I] cancelled, wasn't replying to messages, just … didn't even want to speak to my partner. You know, just completely (slight pause), introvert, you know, go … in … went into myself.

Maat also found herself isolated due to stress associated with the application, as socialising, such as visiting her mother, became "completely out of the question […] I don't do it much as it is (chuckles) … it made it even worse." highlighting how her already limited social capacity was diminished by stress, isolating her from potential sources of support.

In contrast, Alice described a sense of understanding and comradery with people in her life despite acknowledgement that it was not always possible to be fully present for others:

> …most [people] were in the same boat anyway. Most either been through it or they were at similar levels […] but sometimes you're too wrapped up in your own problems to really support each other. So sometimes it's wishing each other luck.

Managing the PIP process seems to metaphorically encase Alice, restricting her freedom and ability to support others, and vice versa. Despite this, there is a sense of community within shared experience, as described by the journey within "the same boat" and holding others in mind as they embark on the application process.

A lone voice among participants, Marie described the separation between her application and others in her life as wanted. She explained that the only people aware of her application were the healthcare worker who encouraged her to apply and her assessor as "it just didn't seem relevant to talk about." Marie distances herself from the application process

by deeming it "irrelevant" to mention to loved ones. She appears to take a pragmatic stance towards the process, potentially mirroring her sense that her autism diagnosis is irrelevant to her and her life.

Being Misunderstood by the Assessor

This theme encapsulates tensions felt between autistic women and their assessors. It attempts to capture how disbelief, invalidation and dehumanisation shaped women's experiences of PIP, alongside the cumulative impact of invalidation in autistic women's lives. Three sub-themes are discussed: "They don't see the struggle", Facing an inhuman(e) system, and "It just brings it all back".

"They don't see the struggle"

Many participants felt that the system assumed that lying about their claim, placing an onus on them to prove their needs. Alice described feeling that "...you've done something wrong. They're trying to...they're trying to catch you out as if you've done something wrong [...] you may feel like a criminal." She describes feeling guilty and implies that this is imposed by the implication of wrongdoing within the system's attempts to 'catch out' claimants. She later explained that she felt "like their saying 'you're faking your disability'".

The analogy of the criminal justice system was used by several women, suggesting that women were criminalised by the system, leading to feelings of imposed guilt and feeling under intense scrutiny. Maat described this criminalisation during her tribunal: "It was like being on trial for a crime you know you didn't commit, but where the Judge was already donning the black cap [...] ...that's how it felt. You were already condemned as you entered the door." Maat's allusion to "the black cap" signifies the death penalty, conveying her feelings of powerlessness and hopelessness at being condemned by the system.

Autistic claimants found themselves attempting to justify and provide sufficient evidence for their claims. However, the complex nature of autism conflicted with assessors' assumptions about disability, leading them to doubt and invalidate applicants' experiences. Many women described having 'spiky profiles': strengths in some areas and needs in other areas. Reflecting on the assessment process, Alice explained how assessors used her strengths to make assumptions about her support needs:

> You've got a lot of different extremes in the same person. But for the extremes that are disabling you need a lot of support, but the people like PIP and some people in social services, like to big up the areas where you're talented and... and you know the high function areas and try and ...and put that onto you all the time so that they don't have to support you. That's like 'well, you're good at that.' It's like the memory thing; I've got extreme good memory for past events [...] But short term, especially the way things are now, I identify a lot with, um, someone with dementia...

Alice highlights the polarised nature of her abilities and systems inability to hold this 'both/and' within their frames of reference. Professionals appear to impose a 'high functioning' version of herself onto her, thereby dismissing and invalidating her need for support. This leads her to need to emphasise the impact of her ongoing memory issues and attempt to legitimise her memory difficulties through comparison with a condition that is not contested, such as dementia.

Several participants described assessors overlooking the complex management strategies required to manage daily tasks and the assessment process itself. Jade described the invisible effort required to follow recipes and cook, given her executive functioning and coordination difficulties. However, she felt these needs were overshadowed: "...people wouldn't necessarily understand, as when I make food, it's perfectly edible. But they don't

see the struggle that goes into that." Likewise, several women felt that the invisible coping

strategies that they had to use to manage day-to-day tasks, and the impact of these, were

overlooked by assessors. Dahlia expressed concern that the invisibility of her struggles led

assessors to belittle the impact of living with autism:

> I see not being able to rely on my communication abilities, and also the unseen
>
> labour of how many accommodations, how specific my daily routines are, um, how
>
> much work I have to put in to having that conversation with her. And how much the
>
> effect afterwards that it has on me. […] I think people just see [autism] as a set of
>
> quirks, as a … a personality type.

> Overall, participants reflected on these misunderstandings as evidence of assessors'

lack of autism-specific knowledge. This led Maat to explicitly question assessors' training:

> We need to be interviewed by people who understand autism, and I don't just mean
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> somebody who's had a 2-hour power-point presentation, I mean someone who really
>
> understands it, has somebody in the family who's autistic or who … who's autistic
>
> themselves maybe…

Maat's distinction between traditional training and expertise gained by lived experience

contrasts the power currently given to assessors' claimed knowledge and re-situates autistic

people as experts.

Facing an Inhuman(e) System

Many participants expressed distrust and fear towards assessors, often viewing them

as an extension of a malicious system. This was reflected in participants' language; assessors

were referred to as "they", symbolising the larger system. Most women described assessors

subjecting claimants to distressing interviews with little regard for the person in front of

them. Several participants alluded to assessors as shedding their empathy and humanity

through the role. Maat alluded to assessors lacking humanity in her description of the assessment process as a horrific and inhumane process, explaining that *"there's no room …* for humanity in it […] The assessment is a tick box and any kind of failing on your part could lose you the money you need to survive, and to me that's horrific.". She later described her assessor's lack of responsiveness to her distress: "I'd been crying me eyes out for quite some time and she'd not even mentioned that you know, how distressed I was by actually being at this interview and feeling awkward…".

Some participants appeared to feel that working as an assessor had 'corrupted' the humanity of workers, leaving them dehumanised and devoid of empathy for applicants. Dahlia alluded to her view that assessors acted inhumanely, through her incredulity that "…someone that calls themselves a health professional would ever do this to people willingly or for a wage". She recalled phrasing her responses in a medicalised format during the assessment, which she understood as "some sort of strange attempt to appeal to the being a medical professional in that person, whatever was left". Her language suggests scepticism about the assessor's status as a health professional, highlighting the incongruity between the connotations of "health professional " being a caring and empathetic individual and Dahlia's experiences of an uncaring system which is distressing for applicants.

Similarly, Alice described her assessor as: "'lawyers' botoxed fox' because she were very, very false, physically and behaviourally". She detailed feeling that the assessor had mislead her about her knowledge of autism and appeared "nice", however, "when they when you see what they've written about you, it comes across as a blow, a betrayal." Alice's comments revealed a sense of being misled by her PIP assessor's behaviour at assessment. Through the language of "lawyer's botoxed fox" Alice questions the assessor's genuineness, emphasising her perceived falseness and portrays herself as being tricked into trusting the

assessor. The assessor is anthropomorphised, metaphorically losing her humanity. After recalling the "betrayal" of the letter, the assessor also loses her individuality and is referred to as part of the larger "they" of the system.

Several women described feeling dehumanised by the assessment process, as their interactions left them feeling like a tick box rather than a human being:

"[I felt] Like I wasn't worth anything to these people. Like they value getting paid their wages and jumping through the hoops more than who is on the other end of the forms." (Jade)

When I read the assessor's feedback, I could see that none of it saw me as the person. It didn't see the fluctuating abilities. It didn't apply in any kind of way to me as a person, and my life. (Takes a deep breath) … and I thought 'I can't go through that and try and get someone to see my daily life for me as a person. I can't do it again'. (Dahlia)

Both women reflect on the sense of not being seen as a human being, but a form. Jade depicts assessors as robotic and unquestioningly 'jump through hoops' for their bosses. Their apparent disinterest in her experience appears to diminish Jade's 'value' as a human being, leaving her feeling worthless. Dahlia expresses a sense of resignation to not being 'seen', yet attempts to reassert her humanity through her language: referencing her personhood through repetition of 'me as a person' as opposed to a number in the system.

Conversely, Marie described a positive experience of being seen and listened to by the assessor. She described her as "a naturally friendly, warm, friendly person, you know, she came across […] as a human being". She explained how the assessor appeared attentive to her explanations about her difficulties and willing to "learn from me" regarding mental health risks. This may reflect Marie's professional knowledge and experience in researching

these topics. Her description humanises the assessor, who in turn has treated Marie as a human being worthy of attention and respect. Being treated as an expert in her own experience and listened to without incredulity appeared to be key to Marie's positive experience. This attunement between the assessor and assessed person was reflected in Maat's description of her assessor: "…they'd not broken her … broken her down yet […] she had some compassion left, and that she might understand what I was talking to her about." Maat depicts her assessor as having resisted moral contamination from the wider system and retaining her humanity and empathy. This appears to give Maat hope that they could form a mutual understanding of her needs.

"It just brings all back": Reliving Past Invalidation

Three participants described the rejection of their PIP application as a dismissal of their experiences, echoing past experiences of rejection and invalidation. Dahlia described how the rejection of her claim felt like a dismissal of her experience:

> They'd obviously listened […] – I've got stuff wrong with me… and will probably always be wrong with me, but choosing not to believe it, I don't know, it just makes it that little bit more calculated and callous on their behalf.

Dahlia's description conjures images of an unfeeling system which does not consider the potential emotional impact on claimants. She explained that for many late-diagnosed autistic women, the "impersonal" application process mirrored being disbelieved and invalidated in early life, which "could bring up really difficult things from childhood".

Likewise, Alice described the application process as compounding the "frustration of having to prove everything". She reflected on the judgements and memories triggered by the process:

I think the PIP... it just triggers if you've had a background of never been believed, umm like never been believed that I've got a real disability and being treated as umm... behaviour or attention seeking all...all your life, it just brings all that back.

Alice's hesitations and switching between first and second person suggest that she is avoiding difficult emotions linked to these memories. Most women described feeling shamed and invalidated by other people before receiving their autism diagnosis. Some women described having their needs overshadowed or misdiagnosed as mental health diagnoses – such as borderline personality disorder - or being told that they had a behavioural cause. Likewise, Alice described her experiences of disbelief: "The doctor wouldn't take it seriously that I had a real disability...'Oh behaviour can be learnt. You haven't got full-blown autism'." Alice distances her autism as "a real disability" from the 'behavioural' explanation, which carries connotations of intentional and controllable actions, suggesting that being disbelieved and misunderstood was painful and stigmatising.

Sakura illustrated the cumulative impact of having her needs dismissed. Sakura was awarded PIP after mandatory reconsideration. Although other people presumed that Sakura should be pleased, she explained that the lack of acknowledgement of her needs was as important as the award. She described feeling that "they'd ignored some of the real, huge issues for me" leaving her feeling invalidated: "I just want this acknowledgement that this is … this is how I struggle. Because […] on the report, they just said, you know, 'You don't have any problem with this' when I clearly did." She placed this within the context of her life:

…the thing that I wanted to get across with the PIP is that I felt like I needed this acknowledgement that this is …this is what I struggle with and have done all my life, and I've gone … I mean, at the time, [age] years without any financial help […] I've never had any support with my autism, I've never had anything that … that people

get if they're diagnosed and they're young. [...] when you're an adult and you're

diagnosed, it's like: 'Yeah. This is what you've got. Err, but there's very little resources

to support you with it, so off you go!' And it's like, 'Oh!' [small chuckle] that's

dropped this huge bombshell on you [...]

Sakura's experiences of applying for PIP appear to add to a greater, life-long pattern

of being overlooked and being denied support. She attempts to justify her deservingness by

highlighting the lack of support she has received in comparison with support offered to

people diagnosed in childhood, suggesting a sense of grief. Her comparison of diagnosis with

a "bombshell" suggests that receiving the diagnosis, without subsequent support to process

the information, may feel traumatic. Likewise, the ongoing invalidation appeared traumatic

for Sakura and preceded a deterioration in her mental health. She explained how this lack of

acknowledgement led to rumination which "was consuming me, and ... and I was starting to

lose, I think, sort of my ... lose ... lose myself" within a period of paranoia and anxiety.

Changing Who I Am

This theme explores how autistic women navigate their identity while facing stigma related

to disability benefits. The impact of these dynamics was evident in how women described

their identity and self-esteem. This theme encapsulates two subthemes: "I really am the

most useless person in the whole world" and Resisting the Imposition.

"I really am the most useless person in the whole world"

Four participants spoke about the damaging impact that completing the PIP form and

interview had upon their autistic identity and self-esteem, contrasting the destigmatising

impact of receiving their autism diagnosis. Participants described a process of acceptance

and change towards themselves after receiving their diagnosis, compared to feelings of

shame and confusion felt throughout early life. For example, Yvonne reflected on how her behaviour was misinterpreted pre-diagnosis:

> Because I'd always just been told 'Oh, you know, you're just stubborn, or you're rude, or you're this or you're that.' But having an actual diagnosis to cut against that … it was like, 'Oh well, actually, it's not my fault.' You know. It's … I've just got a different brain to you.

For Yvonne, the diagnosis creates a new internalised voice which normalises her way-of-being to counteract the criticism and blame apportioned to her throughout her childhood. Her evocation of autism as a neurological difference serves to increase the validity of her diagnosis which 'cuts against' the imposed blame suggested by others attributing her behaviour to personality traits and flaws.

> This compassionate approach to autism-related needs appeared to be challenged by the application process. Participants spoke about having to complete the long application form detailing areas of struggle and difficulties in their daily lives, requiring women to uncover and confront the extent of their needs:

> …you start reflecting on your daily life, and acknowledging all the hundred and one ways, the coping mechanisms you have, adaptations around the home, things you delegate to family members, so you have to start framing your life as less than and incapable. (Dahlia)

> I've been covering up, and masking for so many years, all these traits, I think they … they've become so … so normal to me that even just seeing them written down was really quite shocking, because these are things that I've struggled with my whole life but just had no choice but to manage. (Sakura)

Both Dahlia and Sakura appear to find this process confronting and jarring with their self-image. Sakura acknowledges the "shocking" nature of facing an unrecognisable version of herself, previously hidden through sustained effort to camouflage her needs. Externalising this unrecognisable self as "all these traits" creates distance between her identity and the unrecognisable self as she recalibrates her self-view. Dahlia draws a comparison between her past self-perception and the "incapable" self constructed through the application process. She appears to conflate neurotypical constructions of 'functioning' with 'worth'. Her use of 'you' instead of 'I' distances her from the "less than" self, suggesting that she feels uncomfortable with the perceived discrepancy.

Several participants described needing to reduce any possible ambiguity in their applications and present themselves "from the point of view as your worst day" (Yvonne). Yvonne described the pressure to prove her needs to assessors: "I got this vibe that they seem to just see certain words, like 'sometimes' or 'most', or anything that could be seen as like ambiguous, or questioned, or that they can pull apart."
Yvonne's description depicts PIP assessors as predatory, waiting to "pull apart" any words that created ambiguity or described nuances within her needs. This appeared to pressure her to create a description of absolutes that would make her evidence appear credible to assessors.

Whilst this strategy reduced the risk of being discredited and invalidated by assessors, it appeared to harm women's self-esteem:

> It…it doesn't make you feel good, because it's a reflection, isn't it? It's a reflection of your…your whole physical and…and mental being, really – abilities […] especially when it's **about** you, you're the one that's writing it (slight pause), um, yeah – I tried to see past that though. I try to see past that. (Yvonne)

Yvonne highlights the encapsulating and overwhelming feeling that her "whole" self is under judgement and her (lack of) worth is evidenced by her application form. She highlights how the very act of writing about herself in an unequivocally negative light strengthens this new identity imposed by the application form. She use of present tense suggests that this continues to impact her. Sakura echoed Yvonne's feeling that writing about herself on her worst days made her embarrassed and question her value:

> ..looking at what I'd written about myself made me feel like I really am the most useless person in the whole world. It … I can't even do, you know, on my worst day, I really can't do **anything**. Um, and just wri…, having it written there, it, I think it … it made me feel more disabled than I … I feel now, I think.

This "useless" self created through the application form seems to lead her to compare herself to others and shift her identity to disabled versus non-disabled. Disability-related stigma and narratives of incompetence appear to taint Sakura's self-esteem.

The imposition of a deficit-focused account of claimants' lives created a particularly strong sense of dissonance for Dahlia, who described facing a battle between her identity as an autistic woman and the demands to present herself at her most 'disabled':

> I kind of expected it would really take it out of me. But I didn't, I … I didn't project well enough in what ways, you know. Because there was a really strong contrast between who I am as an academic, as an autism advocate, as … as a mum who does everything, and then having to write down all the things that are wrong with me when I spend the rest of my life telling people 'there's nothing wrong with me. Autism's, you know, it's just a neuro-type, you know.' (Sighs heavily) … err, yeah. Yeah, it … it was emotionally draining, to say the least (gives a brief laugh).

For Dahlia, the application process actively created and imposed a most disabled 'wrong' version of herself that she struggled to reconcile with other aspects of her identity. She was faced with an impossible choice: defend her abilities and not receive any support or perform her most disabled self through cataloguing "all the things that are wrong with [her]" undermining her sense of self and competence. Equally, Dahlia described other valued parts of her identity being challenged by the assessment:

> I don't care what people think about me as an individual, but me as a mother, I like to think that that … you know, I'm bulletproof (gives a brief chuckle). And that, I either mask and I script, or I break down and start feeling angry (slight pause) … because there were some instances where [the assessor] asked 'Well, you can do that for your children, can't you?' (Takes a deep breath and sighs deeply)…

There is a sense of threat in Dahlia's words as she describes being asked to describe her parenting abilities. Her wish to appear bulletproof highlights how disability and perceived 'incompetence' threaten her identity as a mother. Dahlia reflected how she has since become "more guarded" about herself and any information that "reflects on my ability to be a mother and a carer".

Conversely, Marie described little impact on her sense of identity or self-esteem during the PIP process. This may be contextualised by the fact that she appeared ambivalent about her autism diagnosis and distanced herself from an autistic identity by spelling out the word 'autistic'. Therefore, the PIP assessment did not threaten her sense of identity. She described drawing upon her professional identity by using her knowledge to answer interview questions and complete the application form, which may have reaffirmed her identity as a professional and her competence whilst writing about disability and challenges.

Resisting the Imposition

Claimants did not assimilate this imposed self without questioning. For Dahlia, resistance against imposed incompetence took the form of reminding herself of her identity outside of her challenges:

> [...]you are loved, and you are funny, and you're intelligent, and you're caring – you know what I mean? I'm ... I kind of practised, um (slight pause) ... separating symptoms from the person's worth really. And I ... I kind of used that on myself.

Dahlia appears to repeatedly remind herself of her value as an antidote to internalised stigma and to regain control over her sense-making narrative. She later reflected that, whilst framing her life through the lens of impairment had had a negative impact, it had also acted as validation of the challenges that she faced in daily life compared to neurotypical people but that *"there's no value attributed to that – it's just a lived reality"*.

Alice and Jade also resisted the imposed disabled identity. Alice describes accepting her challenges and rejecting the ableist assumption that being neurotypical is an ideal state that she should strive for:

> I know some people and some people might think 'well, I wish I wasn't autistic because then I wouldn't have all this hassle' [...] but then you might have a different set of problems. If say, I wasn't disabled...umm... I'd probably... I'd still... I'd have **another** life and **another** set of problems. So, I am as I am.

Alice's emphasis on "another" undermines ableist narratives of autism as a personal tragedy that should be avoided if possible, by highlighting that all people face challenges in life. Jade highlighted the role of society in disabling her, rejecting the individual-focused narrative of disability. She reflected on the PIP process as "coalescing all the thoughts [she] had about my difficulties and barriers in society", rather than altering her view of being autistic. She

alluded to the tension between societal views of disability benefits and her personal views as she described her mother's response to her award: "I posted on Facebook when I was awarded, and my mum sent me asking what was wrong with me. Nothing is wrong with me; only society!"

Several participants described their experiences with the disability benefits system as an impetus to become more vocal in advocating for themselves and challenging injustice against autistic people:

> I think if someone called me, or called my husband, I'd feel more (slight pause), feel more confident in telling someone just how difficult it is to live with these conditions, day in, day out, I think […] having like … to advocate for friends who've gone through different things, because that's the sort of person I am, I just feel a bit more confident challenging them. (Yvonne)

Yvonne's experiences appear to have increased her confidence to explain her needs to others and strengthened her identity ("the sort of person I am") as an advocate for people's rights.

Discussion

In this chapter, I synthesise the main findings concerning the research question and within the context of existing literature. I then consider clinical implications of this research before appraising the quality, strengths, and weaknesses, followed by suggestions for future research. I conclude the chapter with my final reflections on the research.

Summary of Findings

This thesis intended to explore how late-diagnosed autistic women experience the process of applying for Personal Independence Payment (PIP) and aimed to answer two research questions:

1. How do autistic women experience the process of applying for PIP?

2. How do autistic women experience the impact of PIP applications on their mental well-being and sense of identity?

Eight autistic women were interviewed about their experiences of applying for PIP. Using IPA to analyse interview data, I developed five group experiential themes (GETs) which described autistic women's experiences, as summarised below.

The autistic women who participated in this study described the assessment process as unclear, uncertain and hostile, creating a pervasive sense of threat. Participants felt powerless against an all-powerful system which they feared did not have their best interests at heart. A pervasive sense of threat during the application process trapped autistic women with worry about the future and uncertainties, which appeared to lead to inescapable feelings of stress and anxiety. Stress and worry permeated many aspects of women's daily lives as their mental health deteriorated, worsening pre-existing difficulties with executive functioning, decreasing capacity for daily tasks, and making life increasingly difficult. Several women highlighted their reduced capacity to manage this stress alongside the cumulative impact of living as an autistic person in a neurotypical society. Whilst being awarded PIP relieved this stress temporarily and offered multiple financial and functional benefits to daily life, the feeling of threat remained beyond the immediate assessment process. The short-term nature of awards and the anticipation of re-assessment loomed over the women, limiting their sense of safety.

Autistic women felt pressured to evidence their needs through forms and interview processes designed to support neuro-typical communication. Communication was a double bind, whereby women appeared trapped within a catch-22: they were aware of pressure to communicate their needs clearly to evidence their claim and access financial aid for

reasonable adjustments, however, they were prevented from doing this by a lack of necessary adaptations for their communication needs. The women in this study noted the irony of this predicament.

Applying for benefits appeared to lead women into a polarised position of feeling isolated yet needing assistance. Other people's disapproval of their status as benefits claimants, feelings of personal shame and reduced personal resources isolated women from their loved ones. Claimants simultaneously felt reliant on professionals to help them navigate the complexities of the application process, however, this support was not always accessible.

Assessments were distressing and interactions with assessors appeared to lack humanity and compassion towards claimants. Simultaneously, claimants felt dehumanised and that assessors prioritised the content of assessment over understanding them as individual human beings. Claimants felt that they were mistrusted by assessors and felt pressure to evidence their disability needs via tangible evidence. Women described the difficulty in convincing assessors of the often invisible, fluctuating and idiosyncratic spectrum of strengths and difficulties. These traits were deemed incompatible with assessors' assumptions about disability and left claimants feeling that their needs and the invisible effort that they faced in daily life were misunderstood, disbelieved or overlooked. For some claimants, an implied lack of belief in their needs was especially distressing as it appeared to mirror invalidating experiences within society and reminded them of difficult feelings.

Autistic women appeared to find their identity challenged by limiting and medicalised narratives perpetuated within the application process. The process of writing and thinking about oneself within a deficit-focused framework required women to confront and highlight their difficulties in a way that negated their strengths and other skills. This process appeared

to construct a disabled and stigmatised self which threatened women's narratives of being autistic. This dissonance appeared to engender feelings of inferiority, and self-stigmatisation together with anger towards the welfare system for imposing this stigmatised self. Women resisted this imposed self and appeared to empower themselves through self-compassion, advocacy and emphasising the disabling impact of living within an unaccommodating neurotypical society.

Theoretical Lens

Minority stress theory (MST) was chosen to understand the impact of PIP-related stress on the psychological well-being of autistic women. MST aims to explain mental health disparities between minoritised and non-minoritised groups (Frost, 2023; Meyer, 2003). Initially applied to sexual minority communities, the theory has been extended to disabled and autistic populations (Botha & Frost, 2020). MST hypothesises that minoritised groups are exposed to general stress and 'minority stress'- stress originating in prejudice and stigma related to a disadvantaged social position (Frost & Meyer, 2023; Meyer, 2003). Minority stress reflects chronic stressors related to social processes and structural inequalities; these can be distal (i.e. external conditions or events) or proximal (i.e. internalised processes related to the personal meaning of minoritized status) (Frost & Meyer, 2023). Individual and group-level resources are suggested mediating factors in the relationship between minority stress and potential mental health outcomes. MST also considers the individual importance of minority identity (i.e. prominence to identity) and the intersection of multiple minority identities (Meyer, 2003). See Table 8 for further details.

Table 8

Stressors within Minority Stress Theory

Minority stress factors	Example	Example from this research	Relevant GET(s)
General stressors: stressors not unique to minority group	Moving home, difficulties at work, writing a thesis.	• Time pressure • Perceived hostility from DWP • Administration • Uncertainty of application outcome • Risk of financial hardship • Limited support	Powerlessness and threat Distance and dependence

Distal stressors: social and structurally based conditions and events	Discriminatory policies or laws, chronic stressors (e.g. living in poverty), major events (e.g. hate crime), everyday discrimination (including microaggressions)	• Managing the demands to present as visibly 'disabled'.
		• Pattern of invalidation of needs when seeking support
		
		• Inaccessible support:
		    ○ Application form
		    ○ Assessors' communication
			Being misunderstood by the assessor
			
			Communication as a double bind

Proximal: stressors internal reactions learnt from society	Internalised stigma, developing expectations of rejection, concealing minority identity to avoid distal stressors.	• Internalised stigma: related to being autistic and claiming benefits • Identity stress: imposition of a 'disabled self'	Changing who I am
Characteristics of minority identity: factors that alter self-perception	Relative prominence, valence, and integration of identity.	• Most participants described autism as a central part of their identity. Whereas autism was not a prominent identity for Marie. • Being autistic was described as positive and valued aspect of identity for most women.	Changing who I am

Links with Existing Literature

This section examines participants' experiences of applying for PIP pertaining to neurodiversity. The minority stress model is used as an overarching theoretical framework, given the dominant themes of minoritised identity, stigma and psychological distress. Other theories, research and findings of the Systematic Literature Review (SLR) are drawn upon where relevant.

Powerlessness and Threat

This theme connects women's experiences of PIP and the impact on their mental well-being. It emphasises participants' feelings of powerlessness against the reported unrelenting climate of threat within the welfare system, which corresponds to the austerity ailments of 'fear and distrust' and 'instability and insecurity' outlined by the Austerity Ailments framework (Mcgrath, et al., 2016). Participant's reported distrust of the system and sense of threatening precarity of their benefit entitlement aligns with findings from the SLR (e.g. Porter et al., 2021) and experiences of people with physical and learning disabilities (Saffer & O'Riordan, 2022a). As per previous literature, participants described feeling powerless and at the mercy of bureaucracy (Allan et al., 2022; Day & Shaw, 2022). The lingering threat and unpredictability of reviews described by participants aligns with the prolonged anxiety and precariousness described by the SLR (e.g. Machin & McCormack,2021; Ploetner et al., 2020). This is concerning as access to sufficient and stable income is an integral factor to financial well-being, which is associated with fewer depression symptoms amongst autistic adults (E. Pellicano et al., 2023).

Consistent with the SLR, participants regarded the PIP application process as harming their mental wellbeing, increasing anxiety and worry (e.g. Clifton et al., 2013; Pybus et al., 2021; Roberts et al., 2022). Participants emphasised the inescapable nature of uncertainty,

anxiety and worries, which has been highlighted in previous welfare literature (e.g. Roberts et al., 2022). Research suggests that autistic adults have difficulty managing uncertain or ambiguous situations, leading to heightened anxiety (Jenkinson et al., 2020; Riedelbauch et al., 2023), therefore the inherent ambiguity of PIP application may have exacerbated distress for autistic women. Nonetheless, the two participants in employment appeared to compartmentalise the PIP process and appeared less affected by it. This may be due to women having increased financial security, thereby decreasing the potential risk posed by the PIP process.

A novel finding in participants' accounts is the impact upon aspects of cognitive functioning and capacity to function in daily life. Some women highlighted an additive impact of PIP creating exhaustion and worsening executive functioning, reducing their capacity to manage self-care and other daily tasks, and leading to social withdrawal. These experiences could be understood through the concept of autistic burnout (Arnold et al., 2023; Higgins et al., 2021). Higgins and colleagues (2021) defined autistic burnout as:
 "a highly debilitating condition characterised by exhaustion, withdrawal, executive function problems and generally reduced functioning, with increased manifestation of autistic traits – and distinct from depression and non-autistic burnout" (pg.1).

This definition appears to fit with the exhaustion and increased functional difficulties described by participants in this study. Recent research suggests that autistic burnout is qualitatively different to depression, with people experiencing burnout feeling compelled to withdraw to recover and experiencing an inability to do activities rather than experiencing anhedonia (Higgins et al., 2021). Although participants described PIP-related stress as exacerbating pre-existing depression, they differentiated this from their experiences of PIP and consequent stress. This appears to align with findings that the onset of burnout is

preceded by a build-up of life stressors and feeling overloaded with information or stimuli

(Arnold et al., 2023). It may be that features of the PIP system amplify autistic burnout,

further reducing women's capacity to manage the process.

Similarly to the SLR (Machin & McCormack, 2021; Pybus et al., 2019; Shefer et al.,

2016), participants found benefits to PIP in supporting both disability-related costs and day-

to-day living expenses (i.e. utility bills). For one participant, PIP enabled access to

psychological services that the NHS was unable to provide (i.e. long-term therapy with a

therapist with autism expertise). This reflects the inaccessibility of mental health services for

autistic adults (Brede et al., 2022). Given the precarious nature of benefits, the reliance on

PIP raises concerns that some autistic women may be unable to access psychological support

appropriate to their needs if their application was denied.

Participants also spoke about PIP entitlement as defining them as officially 'disabled',

allowing access to reasonable adjustments; however, Sakura highlighted a tension between

these benefits and vulnerability, as receiving PIP made her a target for financial abuse. The

tensions of being identified as disabled were not explored within the SLR. The current

finding appears to mirror Botha et al.(2020), who described autistic people facing

discrimination and stigma after disclosing their diagnosis to others.

Communication: Caught in a Catch-22

Inaccessibility and miscommunication with the benefits system were key themes for

participants. This aligns with literature that suggests that poor communication is a barrier to

the welfare system, due to a lack of clear information (e.g., Machin & McCormack, 2021)

and complex forms, which appear especially overwhelming for people with mental health

needs or learning disabilities (Saffer & O'Riordan, 2022a; Watson et al., 2020). This study

extends these findings to demonstrate how PIP processes can disadvantage autistic people by encouraging miscommunication between applicants and assessors.

Recent research asking autistic people about financial well-being described claiming benefits as being stressful due to the complex concepts and language of the application process (E. Pellicano et al., 2023). Likewise, autistic women described difficulty answering assessment questions due to ambiguous wording on the application form and within interviews. This caused anxiety about omitting relevant information. Assessors not offering clarification or prompting exacerbated women's distress. This appears reflective of research that endorses using supportive prompting during interviews with autistic people (Norris et al., 2020; Norris & Maras, 2022).

Open-ended questions may not be suitable for autistic applicants as they may find it challenging to recall appropriate examples, select relevant details, and inhibit irrelevant information whilst considering the assessor's requirements and knowledge (Norris & Maras, 2022). Whilst autistic people report memories with less specificity and detail, this disadvantage is alleviated with appropriate prompting to recall specific details (Norris et al., 2020). Furthermore, autistic adults who received specific prompts were rated higher by assessors in mock job interviews (Maras et al., 2021). Therefore, a lack of supportive questioning places autistic women at a specific disadvantage in navigating the disability benefits system.

The role of communication medium was highlighted by autistic women accessing PIP. As in previous research, some women preferred written communication (i.e. instant messaging or letter) over telephone or face-to-face communication when interacting with unknown professionals (P. L. Howard & Sedgewick, 2021). Participants and wider literature attribute these preferences to difficulties in auditory processing, the exhaustion of masking,

and difficulties in verbally articulating thoughts creating overwhelm and anxiety during spoken conversations (Howard & Sedgewick, 2021; Nicolaidis, Raymaker, & McDonald, 2016; Raymaker et al., 2017). Service providers' refusal to accommodate requests for written communication and use of inaccessible language are noted barriers to healthcare for autistic adults (Nicolaidis, Raymaker, & McDonald, 2016). Mason et al.(2019) suggest that addressing healthcare providers' knowledge and attitudes towards communication adaptations is important in reducing barriers for autistic adults accessing services.

Taken together, the lack of knowledge or willingness to adapt communication for autistic people is another example of the double empathy problem (Milton, 2012): a 'failure' in neurotypical systems to empathise with autistic adults' needs appears to actively encourage misunderstandings between assessors and claimants and perpetuates inaccessibility.

Distance and Dependence: "It's really hard to know who to turn to"

Needing Knowledge to Navigate the System. Previous research has consistently highlighted the confusing and complex nature of the system creating barriers that leave some claimants feeling unable to navigate the application process alone (e.g. Machin & McCormack, 2021). What the current study adds is autistic claimants' need to seek specialist assistance to navigate the application system, although this was not always available. Ploetner and colleagues (2020) noted the challenge of finding welfare support services, given service cuts. When support was available, autistic women expressed gratitude for workers' support, reassurance, and validation during the application process. This aligns with research suggesting that accessing advice services increases wellbeing and reduces stress for people seeking welfare support (Dalkin et al., 2019; Mustafa et al., 2020; Young & Bates, 2022).

Whilst two SLR papers discussed support in the form of health professionals' testimony (Porter et al., 2021; Pybus et al., 2021), this was not discussed by participants of this study. This may have been because of the noted limited provision of post-diagnostic support for autistic adults (Beresford et al., 2020b). Given the documented importance of medical evidence, it is important to consider the implications for community welfare support services supporting autistic adults.

Feeling Isolated from Loved Ones. Whilst some benefits claimants find that supportive friends, family and community helps them to manage difficulties engendered by the benefits system (Saffer & O'Riordan, 2022a), autistic women described feeling isolated during the PIP application process. This appeared to link with perceived stigma, feeling misunderstood by others and having reduced capacity to socialise due to the emotional impact of their claim. Research suggests that people receiving disability benefits feel isolated and separated from their social networks, both through living with chronic illness and via benefit stigma (Garthwaite, 2015b; Garthwaite et al., 2014; Saffer et al., 2018). The current findings add to existing research and links with concerns that austerity policies perpetuate isolation (McGrath, 2016). Given that loneliness and low social support are associated with a greater likelihood of stressful events impacting autistic adults' mental health (Moseley et al., 2021), it is important to consider how autistic adults can feel supported by their social networks during the PIP process.

Being Misunderstood by the Assessor

This study supports the findings across the systematic review and wider research, including experiencing the assessor as unempathetic and the impersonal 'tick-box' nature as dehumanising (Saffer et al., 2018; Roberts et al., 2022; Shefer et al., 2016). Some participants suggested that assessors' lack of empathy and engagement were an expression

of the benefits system reducing workers' humanity over time. Whilst this is speculation, concerns have been raised about the ongoing practical and psychological impact of service demands placed upon healthcare professionals hired as disability benefit assessors (Mcrea, 2023). These factors may impact assessor's ability to work according to their values. Further research is required to clarify the burden of stress and dehumanisation of staff and the impact upon claimants.

Two participants in this study noted that their experience of compassion and being treated as experts of their own experience by the assessor created a positive experience of the PIP assessment. Several papers in the SLR highlighted that some people have positive experiences of attending an assessment (Machin & McCormack, 2021; Pybus et al., 2021; Roberts et al., 2022). These exceptions may help us to learn about what would constitute good practice during disability benefit assessments.

Similarly to previous findings, autistic women suggested that current disability assessment processes are ill-suited to people with invisible and fluctuating conditions (Price et al., 2020; Saffer & O'Riordan, 2022a). Similarly to the SLR and wider literature, participants felt that assessors lacked expertise to assess the invisible and fluctuating impact of their health conditions within the assessment's 'snapshot' (e.g. Dwyer et al., 2020; Porter et al. 2021; Saffer et al., 2018). Independent reviews have also highlighted difficulties in assessment, particularly when impairment is unseen and variable in presentation (e.g. Litchfield, 2013). This research adds to the existing literature by highlighting the role of stereotypes and service providers' limited autism understanding as a barrier to autistic women accessing services.

Women's apparent strengths were overgeneralised and used to invalidate their support needs. Assessors' autism knowledge appeared superficial, as evidenced by

assumptions that claimants would present with a standardised 'tick box' of behaviours. Where women were able to mask, assessors took this as evidence of 'high functioning', leading to women's needs going unrecognised. These conclusions clashed with participants' lived experience of the unseen effort required to complete tasks and the unreliability of their abilities and strengths.

Autistic advocates and researchers have consistently raised concerns about the inaccurate and divisive nature of functioning labels, as each autistic person has unique patterns of strengths and needs and fluctuations in functioning across contexts and time (Kapp, 2023; Keating et al., 2023; Kenny et al., 2016). Autistic women have specifically noted that the imposition of a 'high-functioning' identity implies doubt about the authenticity of their diagnosis and needs, pushing them into either conforming to stereotypes or risk having their needs overlooked (Seers & Hogg, 2021; Treweek et al., 2019). This aligns with literature which describes autistic women facing ongoing battles for support and recognition of their needs within health, employment and education contexts as services demand concrete evidence to access support (Harmens et al., 2022; Leedham et al., 2020; Tint & Weiss, 2018).

The painful cumulative effect of invalidation within the welfare system has been noted by Shefer et al. (2016) who suggested that claimants who had lived through a period of being mistrusted by people close to them found mistrusted by the welfare system "*even more traumatic*" (pg. 5). Some women in this study likened their PIP application to past experiences of invalidation and stigmatisation, describing a cumulative emotional burden of having to continually prove their needs to others. This appears to be a novel finding. As outlined by research, participants described facing invalidation and stigmatisation for autistic behaviours prior to receiving their diagnosis (e.g. being labelled as attention-seeking) (Bargiela et al., 2016; Leedham et al., 2020). Furthermore, many autistic women faced

continued pressure to justify themselves to avoid having their autism diagnosis invalidated by others (Harmen et al., 2022). This research extends this to the welfare system.

According to MST, continued invalidation and stigmatisation may become internalised by autistic women as self-stigma, adding to the risk of poorer mental health (Botha & Frost, 2020; Leedham et al., 2020). Across repeated invalidations, some individuals may develop more pervasive changes to their mood in keeping with traumatic invalidation (Bemmouna & Weiner, 2023; Cardona et al., 2022). Therefore, autistic women may be especially vulnerable to psychological distress linked to invalidation from the benefits system.

Changing Who I am

Research highlights that the stigma of applying for benefits accentuates disability-related stigma for some claimants (Hansford et al., 2019; Lowe & DeVerteuil, 2020; Saffer & O'Riordan, 2022). For the women in this study, the medical lens inherent within the assessment process seemed to stigmatise and threaten their hard-won autistic identity.

Many participants felt that it was important to contextualise their experiences of disability benefits within their lived experiences as autistic women. As described within the literature, many women recounted their experiences of confusion and shame before diagnosis, but had since renegotiated their identity away from self-blame and towards a compassionate understanding of their needs (Corden et al., 2021; Leedham et al., 2020). This new autistic identity aligned with the neurodiversity model, whereby women described feeling disabled by a neurotypical world that did not understand or respect their needs as autistic people (Anderson-Chavarria, 2021). This understanding appeared in direct contrast to women's experience of their identity within the PIP system.

Milton and Sims (2016) suggest that autistic identity is constructed within an uneven distribution of power; it could be argued that the application process mirrors this. Findings suggested that the application process forces autistic women to construct themselves within a medicalised deficit-focused narrative as it focused women on their limitations, disregarded their strengths and encouraged them to present their worst days. Participants described being required to present themselves as more disabled than they felt in their daily lives. Garthwaite (2015) described this need to adopt a deficit-focused lens, and provide public displays of disability, as adopting a 'disabled role'. Adopting the disabled role appeared stigmatising and painful, as described by the SLR findings (Hansford et al., 2019; Lowe & DeVerteuil, 2020; Porter et al., 2021).

This aligns with wider benefits research. Garthwaite (2015) noted that claimants struggled to accommodate a disabled role. Similarly, Saffer and O'Riordan, (2022) described participants struggling with internalised disability stigma and feeling worthless. The PIP application appeared to trigger autistic women's internalised beliefs and judgements about capability and dependence, leaving claimants feeling worthless.

These judgements appear to echo ableist narratives held by the neuro-typical majority (e.g. autistic people are incompetent) and historical medical narratives about autism as a deficit (Anderson-Chavarria, 2021; Han et al., 2022). Foucault (1997) describes this as the 'normalising gaze', which exerts control by self-policing one's behaviour to avoid transgressing societal expectations. This 'disciplinary power' becomes internalised to the extent that individuals feel compelled to make themselves conform with societal expectations. Failing to conform to perceived norms appeared to force women to adopt "the negative identity of a disabled person, someone who is abnormal and incapable" (Reeve, 2002, p.501) in contrast to their autistic identity.

Identity Process Theory (IPT; Breakwell, 1986) suggests that individuals assimilate new information into their identity and adjust their identity to accommodate changes. Identity is threatened when changes in social context endanger the value or meaning of identity or coherence between identities (Breakwell 2015; Jaspal & Cinnirella, 2010). For autistic women, adopting the 'disabled role' appeared to threaten their self-esteem and undermine the coherence of their autistic identity.

Many autistic people resist a 'disabled' identity due to connotations of 'disorder' and deficiency, instead viewing difficulties functioning as symptomatic of interactions between themselves and their environment (Bagatell, 2007; Keating et al., 2023; Seers & Hogg, 2021). Autistic people may attempt to reclaim the concept of 'normal' by avoiding 'disabled' and employing the value-neutral language of neurodiversity (Parsloe, 2015); however, participants were unable to do so without jeopardising their PIP claim. This appears to reproduce and reify a narrative of autistic people as deficit and abnormal, potentially reinforcing ableist narratives that being autistic is inferior to neurotypical, and a personal tragedy (Botha & Cage, 2022; Bottema-Beutel et al., 2021). Women struggled to reconcile these two identities, as the 'disabled self' constructed through the PIP application appeared to subordinate autistic women's beliefs about their diagnosis to a medicalised discourse. Moreover, the structure of the welfare system prevented autistic women from correcting these incongruencies without facing financial losses, leading to a catch-22 between autistic identity and disability benefits.

Thoits (1991) suggests that identity-incongruent feedback is especially distressing when it threatens self-schemas within highly developed or valued areas. Given the importance of an autistic identity to many participants, the PIP process appeared to create a high level of identity threat and emotional stress for some participants. From a theoretical

perspective, minority stress theory (Botha & Frost, 2020; Frost & Meyer, 2023; Meyer, 2003) suggests that the prominence of autistic identity (a minority identity) within the person's sense of self may be related to increased minority stress when threatened, contributing to mental health outcomes. Furthermore, reclaiming an autistic identity, in opposition to a medicalised-deficit narrative, has been suggested to have a protective impact against stress experienced as a stigmatised neuro-minority in a neurotypical society (Botha et al., 2020). Therefore, participants' experiences of PIP increases concerns about the implications for autistic claimants' mental health; as greater negative beliefs about autism as part of personal identity (i.e. perceived limitations in social life, work and quality of life) predict lower self-esteem and poorer well-being amongst autistic adults (Corden et al., 2021).

Notably, women who did not strongly identify as autistic, or drew upon a worker identity, did not describe the negative wellbeing and identity impacts described by other women. This may be because women in stable employment could externalise their autistic diagnosis as part of their identity (Corden et al., 2021; Hickey et al., 2018) and draw upon other salient aspects of identity, reducing the identity threat posed by the application process.

Participants reported various attempts to struggle to create their own identity beyond the normalising gaze (Foucault, 1973) of the benefits system. Some women reaffirmed their worth against stigmatising narratives, thereby maintaining an identity separate from the disability role (Saffer & O'Roidan, 2022). Counter to previous findings, participants did not attempt to distance themselves from stigmatised narratives by condemning other claimants as 'undeserving'(Greener & Moth, 2020; Ploetner et al., 2020; Porter et al., 2021; Roberts et al., 2022; Shefer et al., 2016). Instead, several women sought to 'return the normalising gaze' (Ord, 2013) by rejecting the medicalised narratives of

neurotypicality and affirming their identity by locating the 'problem' of requiring welfare support into both political structures and the in-accessibility of society. As in previous findings (e.g. Saffer & O'Riordan, 2022), some autistic women's experience of the benefits system strengthened their political identity, including increased activism and advocacy for the rights of other autistic and disabled people.

Clinical Implications

Interpretative Phenomenological Analysis focuses upon the potential transferability of findings from the original sample to wider groups and contexts, over creating widely generalisable results (Smith, 2021). Whilst the results presented in this thesis are directly applicable to the women who participated, it is anticipated that each reader will judge the applicability of this work to their own context and the potential implications for their practice. The findings should also be taken within the context of the wider literature. Given the identified areas of agreement across this research, previous literature and the SLR, this section draws upon the findings of this study and the wider context of existing literature pertaining to the disability benefits system (e.g. Saffer et al., 2018) and the wellbeing of autistic women.

Drawing upon ecological systems theory[4] (Bronfenbrenner, 1979), the findings of this study have implications for multiple structures, professionals within and outside the NHS and their relationships with autistic women. I will explore these implications from the view of the societal narratives (macrosystem), the welfare system and policy (exosystem), and

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[4] Bronfenbrenner (1979) outlined five environmental systems which impact individuals as they interact with them through the course of daily life. These systems are: the microsystem (immediate social and physical environment), mesosystem (interactions between elements of the microsystem), exosystem (social, political and economic conditions, such as policy) and macrosystem (beliefs and attitudes shared by members of society). This model highlights the multilayers and dynamic influences upon autistic women's experience of the benefit system.

clinical perspectives for psychologists within mental health and specialist autism services (microsystem).

Societal Level

This research suggests that benefits and disability stigma continue to have a significant impact for those attempting to navigate the welfare system and that autistic women's experiences within the PIP system reinforce stigma and invalidation experienced within society.

It is essential that efforts to address stigma are situated with a multi-level framework and that the burden of change is not placed on those most harmed by the effects of stigma (Han et al., 2023). Whilst there have been some encouraging steps towards improving public understanding of autism through public awareness campaigns, this research highlights the importance of raising awareness of the challenges and inequalities that autistic people experience within society among policymakers and politicians. The National Autistic Society (NAS) is currently partnering the All Party Parliamentary Group for Autism (APPGA)[5] to offer training to members of government (see Table 9). Autistica, an autism research and campaigning charity, also continue to contribute to shaping politician's understanding of autistic people through their policy briefings on a variety of topics (see Table 9). Clinical psychologists can contribute to this work by sharing our understanding of the psychological impacts of stigma via consultations and parliamentary briefings wherever possible.

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[5] All-Party Parliamentary Groups are informal, cross-party, interest groups open to MPs and Peers interested in a specific issue. The AAPGA's official aims are:
...to raise awareness of issues affecting autistic people, their families and carers; to raise parliamentary awareness of autism; to campaign for changes to government policy to benefit autistic people and improve diagnosis or support for autistic people (NAS, n.d.)

This study focused upon autistic women's experiences of the benefits system; however, this is against a continuing background of inequality and reduced access to meaningful and stable employment[6]. Given that societal conditions predispose autistic adults to rely upon the benefit system, addressing the barriers to autistic people's participation in the workplace is vital. The recent Autism Employment Review (Department for Work and Pensions, 2023) is a welcome step towards this goal, as it aims to support employers to employ and retain autistic staff.

Nevertheless, reducing stigma and improving public understanding of autism is a long-term challenge that requires sustained effort. As a society, we cannot relent in our efforts to combat stigma and strive for autistic rights. Clinical psychologists are well situated to join others in lobbying for policy changes and challenging harmful narratives in wider society.

Table 9

Implications for Societal Narratives -Increasing Public Understanding of Autism

Who?	How?
NAS	The NAS and APPGA ran their first Understanding Autism (NAS, n.d.) session in May 2019. The sessions are run by autistic members of NAS staff and offer MPs and staff the opportunity to gain a deeper understanding of autism and ways to support their autistic constituents. Over 75 MPs attended the initial session and many more have attended sessions run since that time, including the Minister for Care and Mental Health and the Secretary of State for Health and Social Care.

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[6] See page 21.

Autistica	Autistica have worked with autistic people, their families, researchers, and professionals to develop a series of practical policy briefing documents. The Autistica Briefings cover a variety of topics and include recommendations for policymakers. Current policy briefings include topics such as the impact of COVID-19 on autistic people, post-diagnostic support for adults, access to diagnosis (including women and girls), issues relating to employment and several briefing dedicated to mental health. The findings the Autistica Briefings are shared with services, charities and policy makers to advise them in making evidence-led changes, such as informing the National strategy for autistic children, young people and adults: 2021 to 2026 (HM Government, 2021).

Implications for the Benefit System

The results of this study closely align with the findings of both the SLR and wider literature which highlights the ongoing harmful impact of welfare reforms on claimants' wellbeing. Claimants have repeatedly shared their experiences of fear, powerlessness, isolation, shame and humiliation within the welfare system, which undermines the sense of agency, security, connection, meaning and trust demonstrative of a healthy society (Mcgrath, et al., 2016). These experiences occur against the backdrop of policy which deliberately attempts to restrict welfare entitlements (Roulstone, 2015), thereby corroding the welfare system and claimant wellbeing. Participants in this study argued for an improved understanding of autism in the hope of building a more empathetic welfare system.

Several implications arise from this study: for the design of the PIP system, assessors and decision-makers. These recommendations appear in Table 10, reflecting the overlap between autistic women's needs and previous recommendations generated by the experiences of claimants with physical disabilities (Saffer, 2018).

Table 10

Implications for the Benefits System

Who?	Implications for the Benefits System (adapted from Saffer, 2018)
Personal Independence Payment: DWP ministers, assessors, and decision makers	• Ensuring that assessors and decision makers are trained in how particular disabilities affect people and impact upon their lives. This could be achieved through training or employing advisors with expertise in different conditions to consult with assessors. • Allowing medical professionals, who already have knowledge of the person and their health, to assess eligibility for benefit support. • Re-structure the assessment that allows people to express the individual impact of their health condition, rather than a points based system which appears to disadvantage those with fluctuating or degenerative conditions. • Re-design the application forms to ensure that questions are clearly worded and to shorten the length of the form. • Offer electronic versions of the application form alongside paper copies. • Improve communication between DWP and people applying for disability-related benefits via a centralised resource explain the criteria and process of applying for benefits. E.g., creating a website with clear information. • Quicker decision making following assessment, with maximum waiting time to reduce stress and uncertainty for claimants. Clearer communication and advanced notice of decisions would also be beneficial. • Autistic women in this study highlighted the need for a system that offered a choice of communication pathways (i.e., video call, instant messaging, face-to-face) as per autistic people's

Who?	Implications for the Benefits System (adapted from Saffer, 2018)
	preferences (Howard & Sedgewick, 2019). A particular focus on meeting the needs of participants who communicate non-verbally is required to avoid disadvantaging people who have difficulties with auditory processing. • The DWP and assessment suppliers could consider adaptations required in interviewing procedures to minimise mutual misunderstandings as evidenced in this study. Any adaptations should draw upon the body of research on making adaptations to interviews between autistic and neurotypical professionals. For example, providing visual and verbal prompts (Norris et al., 2020) and providing clarity about the intent behind each question (Heselton et al., 2021). • This study suggests that assessors require more specific training and information on the impact of autism on autistic women, to address misunderstandings between the visible and less visible challenges that people face (e.g. masking). Assessors are supplied with Condition Insight Reports, outlining key information on specific conditions and their impact on functioning (Department for Work and Pensions, 2023c). It may be prudent for this to be reviewed considering this research, and barriers to implementation explored. • Matching applicants to a specialist advisor with expertise in autism, as proposed in the Health and Disability White paper (Department for Work and Pensions, 2023a), may be beneficial; however this may not be possible given system demands.

Efforts to implement these suggestions would benefit from clinical psychologists' understanding of the double empathy problem (Milton, 2012), and the cognitive and emotional processes underlying social communication, given the apparent mutual misunderstandings between autistic women and welfare staff.

Clinical psychologists appear well equipped to support the development of suitable adjustments and training for assessors and DWP staff. Participants suggested that it would be beneficial for autistic people to be equal partners in co-producing and delivering training, but voiced concern that one-off training is insufficient to develop the nuanced understanding that is necessary for assessing the needs of autistic claimants. Clinical psychologists may continue to offer their skills to DWP staff and assessors by offering consultations, reviewing existing assessor guidance and co-producing training with autistic people.

Implications for Clinicians

Similarly to SLR literature, the current study highlights that people navigating the welfare system value support from professionals familiar with the benefits system and the impact of their health condition. Professionals working alongside autistic adults may consider practical aspects of supporting PIP claims but also account for the psychological impact of stress and stigmatisation. Given that many autistic people are not currently in contact with NHS services (Beresford et al., 2020b; Crowson et al., 2023), the challenge lies in how to ensure that people can access adequate support in whichever service they access (i.e. specialist autism services, third sector support services or NHS mental health services).

Autism Services. Several participants described difficulties identifying and communicating their needs during the PIP assessment, highlighting the importance of needs

assessments at diagnosis. Typically, diagnostic reports focus on a formulation of deficits in line with diagnostic criteria, rather than a personalised profile of specific areas of strength and areas of struggle. Adopting a needs profile approach may help autistic adults understand their unique cognitive profile and needs, as per NICE guidelines for autism diagnosis[7] (NICE, 2012). Personalised reports may reduce barriers to services by providing specific guidance that can be utilised when accessing services such as the benefits system. For example, personalised recommendations for communication and sensory accommodations reduce communication barriers between autistic patients and healthcare staff (Nicolaidis et al., 2016). Whilst there is some initial research exploring the potential utility of digital strengths and a needs assessment toolkit (Autistica, 2023), further work is needed to expand this approach to diagnostic services.

Another finding of this study is the need for tailored support to apply for welfare benefits (i.e. supporting form completion and advocating for clients' needs). Participants highlighted the importance of having knowledge of the benefits system and the functional impacts of autism. Although this role may be fulfilled by independent charities, participants highlighted that this support was not always available. A minority of autistic adults report receiving financial support (i.e. welfare benefits) within a year of diagnosis (Wigham et al., 2023). This suggests a gap in service provision and highlights the importance of autism services having provision to support clients through the benefit system (see Table 11 for an example of good practice).

Psychologists may also wish to contribute their assessment skills to provide supporting evidence (I.e. the functional impact of autism and/or mental health) collected at assessment.

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[7] NICE (2012) guidance suggests that clinicians create a care plan incorporating needs such as "adaptations to the social or physical environment".

Clinicians may wish to offer their skills outside of the NHS, for example contributing to expanding community benefits clinics (see Table 11) or contributing to adapting current guidance for psychologists (e.g. Hutton & Mudie, 2023) for working with autistic clients affected by the benefit system.

Table 11

Implications for Services: Good Practice Examples

Who?	How?
Bristol Autism Spectrum Service	The Bristol Autism Spectrum Service (BASS) is well-recognised across the country as a best practice model for diagnostic and post-diagnostic services (Lorenc et al., 2018; NICE, 2014). BASS is a multidisciplinary, specialist autism team jointly commissioned between Avon and Wiltshire Mental Health Partnership NHS Trust and adult social care. The team offer a diagnostic service and post- diagnostic support including bookable one to one sessions with specialist autism professionals (e.g. psychologists, social workers and occupational therapists). Part of this provision is appointments with social workers who can provide social support assessments for people who had been diagnosed by the service. These appointments aim to provide personalised signposting and bridge the gap between diagnosis and a full community care needs assessment. Social workers are also available to discuss applying for disability-related benefits, support people to complete the required application forms and attend appointments with service users who do not have anyone to advocate for their needs.

Who?	How?
Psychologists for Social Change (Southwest branch)	Psychologists for Social Change (PSC) is a national network of groups for psychological professionals interested in applying psychology to policy and political action. The group maintain several projects, such as producing reports encapsulating the psychological impact of policy (e.g., the five austerity ailments by McGrath et al., 2019). The group launched 'the benefits project' (Camilleri et al., 2020) in 2017 to support people with disabilities and/or mental health problems going through the benefits system. The project includes multiple strands to influence policy and practice: 1. A pro-bono benefit clinic offering psychological assessments and medical evidence reports to support benefit assessments. Follow up support includes attending assessments and tribunals with the person being assessed. 2. Training and reflective practice offered to benefits workers. This aims to provide education and support in relation to various mental health problems and disabilities. 3. Ongoing campaigning, research and liaising with healthcare professionals and local government officials to highlight inequalities within the benefits system. This has also led the group to produce guidance for professionals on how to write an effective support letter for people applying for PIP or ESA.

The research findings underline the lingering emotional impact of invalidation and internalised stigma on autistic women's mental health. Alongside systemic efforts to reduce stigma, clinical psychologists can support clients to co-create narratives that counter the stigmatising and dehumanising narratives that people encounter within the welfare system. For example, clinicians may draw upon concepts from narrative therapy: externalising feelings of worthlessness (White, 2007) and 'returning the normalising gaze' (Hutton, 2008)

to question narratives of individual deficit and normality. Clients and psychologists could co-write narrative letters which celebrate personal strengths and uniqueness to counterbalance the deficit-focused narrative of the welfare application (Watts, 2018). Sharing power and returning narrative agency to autistic women within therapeutic work may help to correct experiences of powerlessness and dehumanisation experienced during the PIP process.

Given links between women's autistic identity, internalised stigma and wellbeing in this research, services may benefit from developing interventions that support autistic women's self-esteem. For example, group interventions that foster self-acceptance alongside pragmatic strategies for disclosing their autism diagnosis and responding to stigma (Han et al., 2023). Whilst stigma interventions have been linked to increased advocacy and connection amongst people with learning disabilities (Scior et al., 2022), further research is required to develop interventions for autistic adults (Han et al., 2023). Clinical psychologists could spearhead these efforts by developing practice-based evidence within services.

However, not all autistic adults have access to post-diagnostic support. Provision is dependent upon local commissioning and funding (Beresford et al., 2020; Crowson et al., 2023; Wigham et al., 2023); therefore, the functional and psychological needs of autistic adults applying for PIP may be outsourced to non-specialist services. Clinical psychologists should endeavour to upskill and support mainstream services to work with autistic adults. For example, offering consultations on topics such as: adapting communication to help minimise mutual misunderstandings and providing autism-specific supporting evidence.

Mental Health Teams. The findings of this study have implications for mental health services which serve autistic adults. The results encourage recognition of the PIP process as a precipitating and perpetuating factor in understanding autistic women's mental health. Clinicians should enquire about benefits during assessments and consider signposting to

welfare support as required. Psychologists may need to provide clinical evidence letters and should be aware of available guides on how to do this (e.g. Hewitt et al., 2017). As above, co-creating a strengths-based narrative with clients may be beneficial to counterbalance internalised stigma.

Psychologists play a key role in validating clients' distress from experiences of stigma and invalidation, as mirrored within the benefits system. Utilising the concepts of minority stress theory (Botha & Frost, 2020) and autistic burnout (Higgins et al., 2021) may be useful to contextualise clients' distress and recognise the impact of the benefits system and stigmatising experiences on mental health and identity. Clinicians may wish to incorporate compassion-focused theory to support autistic women, given the findings of this study and emerging research within this area (Cai, Gibbs, et al., 2023; Cai & Brown, 2021). It will also be important for clinicians to differentiate between clients presenting with autistic burnout and depression, as research suggests that would not benefit from traditional CBT for depression techniques [8](Arnold et al., 2023; Higgins et al., 2021).

Critical Appraisal

There are many well-established guidelines for evaluating qualitative research (e.g., Yardley, 2000; Tracy, 2010; Levitt et al., 2017), which offer a comprehensive set of reporting criteria to determine the validity of qualitative studies. Although such criteria establish the credibility of research, it has been argued that these criteria lack the specificity to evaluate the quality of IPA studies (Smith, 2011; Smith, et al., 2022). The current research is evaluated against IPA-specific criteria (Nizza et al., 2021; Smith, 2011; Smith, et al., 2022) and the Critical Appraisal Skills Programme Qualitative Studies Checklist (CASP, 2018). See Tables 12

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[8] Such as behavioural activation

and 13 below. See Appendix A for further reflection on the heterogeneity of the sample and

the use of written and verbal interviews.

Table 12

Quality Appraisal of Research: IPA Specific

Quality criteria	Relevance to this research
The paper should have a clear focus	Smith (2011) states that research that provides an in-depth analysis on a particular aspect of experience, rather than broad focus, are most likely to be higher quality. This research purposively samples autistic adults and their experiences of applying for Personal independence Payments since 2019.
The paper will have strong data	Interviewing technique is integral to obtaining high quality data, which begets high quality analysis (Smith, et al., 2022). This research has demonstrated steps taken to ensure good quality interviewing throughout the research process. The interview schedule was carefully constructed with reference to current welfare and autism literature, and consultation with autistic consultants and the supervisory team. Consideration was given to challenges and adaptations required when interviewing autistic adults (e.g., structure and prompts) and conducting interviews online. Interview technique was continuously refined through feedback and post-interview reflections documented within the researcher's diary to develop reflexivity throughout data collection. For example, careful consideration of researcher assumptions led to increased awareness and effort to question further to "reveal the strange in the familiar" (Smith, et al., 2022; p.65) beyond assuming a shared understanding between the researcher and the participants.
The paper should be rigorous	This criterion is demonstrated through transparent account of the analytic process (Smith, et al., 2022). The complexity of analysis is detailed above and illustrated with examples from each stage (Appendices L, M and N). Smith (2011) suggests that researchers select extracts to show the "convergence, divergence, representativeness and variability" of themes (pg. 24) to demonstrate the breadth and depth of analysis. For research of 4-8 participants, themes should be supported with extracts from half of the participants (Smith, 2011). This study meets these requirements and the prevalence of themes within the sample is also indicated (Appendix O). A reflective journal was kept throughout the research process to ensure that I acknowledged my own assumptions from my personal and clinical experiences. Extracts of this can be seen in Appendix A.

Quality criteria	Relevance to this research
	Furthermore, the supervisory team supported the analysis process through consultation and audit of coding and theme development.
Sufficient space must be given to the elaboration of each theme	Research is enhanced through providing "extended and elaborate" accounts of themes, over superficial presentations of results (Smith, 2011, pg. 24). This study provides an extensive presentation of themes within the Results chapter.
The analysis should be interpretative not just descriptive	A close analytic reading of participants' words, drawing on a range of linguistic features (e.g., repetition, tone and imagery), was employed throughout analysis (see coding extract in Appendix L). This provided a "vigorous experiential account" by explicitly engaging with the experiential significance of participants' reports and giving specific attention to meaning making around them (Nizza et al., 2021).
The analysis should be pointing to both convergence and divergence	This guideline is evidenced through nuanced interpretative analysis of how participants manifest the same theme in connecting patterns and unique ways. Idiographic depth and systematic comparison create interweaving patterns of similarity and individual idiosyncrasy (Nizza et al., 2021). This is demonstrated in the Results section and elaborated upon in the Discussion section.
The paper needs to be carefully written	I hope that the Results section has provided the reader with an enlightening and compelling narrative capturing detail of participants' experience of the welfare system. Narrative progression is shown through combination of carefully selected quotes and interpretation within themes, and a coherence across overall findings through interconnection of themes (Nizza et al., 2021). This was achieved through a process of continuous revision incorporating feedback from the supervisory team.

Table 13

Quality Appraisal of Research: CASP

Quality Criteria	Strengths	Weaknesses
1. Was there a clear statement of the aims of the research?	Yes. See p. 52.	
2. Is a qualitative methodology appropriate?	Yes. The use of IPA was aligned with the study aims and provides an in-depth exploration of participant experiences and meaning-making, whilst remaining aware of the double empathy problem (Milton, 2012) and potential differences in interpretation between myself and the women who participated in this study. The focus on a double hermeneutic and reflexive approach was useful given my closeness to the study topic and allowed me to draw on my own knowledges and interpretations without overshadowing participants' experiences.	
3. Was the research design appropriate to address the aims of the research?	Yes – see discussion on p. 52.	
4. Was the recruitment strategy	It is important to consider how the recruitment approach of this study potentially impacted the inclusion	The over-representation of women within this sample may be due to the self-selection bias, as autistic women are overrepresented online, leading to a higher

Quality Criteria	Strengths	Weaknesses
appropriate to the aims of the research?	and exclusion of different voices, as well as the homogeneity of the participant sample. All participants in this study were recruited via the Autistica research database. All participants are late-diagnosed autistic women, despite this not being specific inclusion criteria, and had had experience of applying for PIP. Whilst participants were homogeneous in terms of being female and age at diagnosis, there was heterogeneity in participant views of diagnosis and employment status. It may be useful to consider potential differences for participants in stable employment and with differing views on their autism diagnosis.	proportion of women taking part in online research (Arnold et al., 2019; Rødgaard et al., 2022). Given that autistic women view research that centres on neurodiversity as a priority compared to autistic men (Putnam, 2023), the current research may be more representative of proponents of neurodiversity. Recruitment from another source may have led to more males or the inclusion of adults diagnosed in childhood. The inclusion of adults with a childhood diagnosis, who may have varying ideas on autistic identity, could further illuminate how this influences identity and wellbeing whilst applying for PIP. It is also important to consider that a self-selecting sample is potentially open to bias towards people with the most negative experiences in PIP, leading to positive and neutral viewpoints being less heard. The decision to exclude people without an official diagnosis increased the homogeneity of the sample, however, it may have excluded those who have been unable to access diagnosis due to systemic bias, extensive waiting lists or personal circumstances. For example, disparities in diagnosis rates remain, with people from ethnic minority groups being under-represented and misdiagnosed before receiving an

Quality Criteria	Strengths	Weaknesses
		autism diagnosis (Mandell et al., 2007; Tromans et al., 2021).
5. Was the data collected in a way that addressed the research issue?	Given COVID-19 precautions all interviews were conducted remotely. Research has documented limitations of online interviews and cited concerns of the negative impact on rapport building between researchers and participants (Deakin & Wakefield, 2014) and reduced non-verbal cues (Lobe et al., 2022). However, concerns appear to be based on neuro-typical normative assumptions about communication, as research suggests that autistic participants prefer being offered a choice of communication mediums (Haas et al., 2016). Research suggests that for some autistic people, online messaging is preferred over face-to-face due to increased thinking time and increased structure (Howard & Sedgewick, 2021). For some people, videoconferencing is preferred over face-to-face due to increased containment and being able to participate from a predictable and familiar environment (Zolyomi et al., 2019). Most importantly, the two participants who participated via writing commented on how helpful it was to have a choice to participate according to their preferences.	A common concern is that data collected online lacks qualitative depth (i.e. does not create equivalent codes or a variety of codes) compared to face-to-face interviews (Johnson et al., 2021). Whilst written interviews did produce smaller volumes of data, although this did not necessarily hinder the quality of resultant themes in all cases (Johnson et al., 2021; Namey et al., 2020). See reflection in Appendix A and below. The use of written and remote interviewing modalities may have had an adverse impact on data quality for some interviews; however, this did not appear to have a significantly adverse impact on overall data quality. The use of other visual methods such as 'PhotoVoice' may have offered creative avenues to explore autistic women's experiences and created opportunities for further interpretative work.
6. Has the relationship between the researcher and participants been	This study benefitted from careful consideration of the relationship between me and the participants. The method was designed using the extensive literature on	My status as a neurotypical researcher may have influenced findings, through topics discussed, what participants felt able to voice and my analytic

Quality Criteria	Strengths	Weaknesses
adequately considered?	conducting ethical autism research (e.g. (Chown et al., 2017) to ensure that all aspects of the study were acceptable to potential participants and to reduce power differentials. Participants' preferences in communication modes were respected throughout by offering a variety of possible ways to participate, however face-to-face interviews were not available due to ongoing COVID-19 precautions.	interpretations of participants' narratives. Although IPA offered important insights, a Participatory Action Research (PAR) may also have been beneficial to reduce potential power imbalances.
7. Have ethical issues been taken into consideration?	See Methodology.	
8. Was the data analysis sufficiently rigorous?	See Table 12 for detailed discussion.	
9. Is there a clear statement of findings?	See Results section	
10. How valuable is the research?	This research offers a unique perspective by uniting two established fields of research to support previous findings on the impact of applying to disability benefits, whilst identifying new insights specific to autistic women (i.e. communication creating a double bind and the cumulative impact of invalidation on identity).	Whilst this study has a small sample size, IPA does not aim for generalisability but for transferability based upon a detailed account of study context and participant characteristics (Nizza et al., 2021). Participant context and details have been anonymised to prevent recognition. This may impact the reader's ability

Quality Criteria	Strengths	Weaknesses
	It contributes to a wider literature considering the intersectional identity of autistic women and barriers to services. The recommendations from this research will inform wider practice within the benefits system and professionals working with autistic women.	to determine whether results are transferable to their own context.

Suggestions for Further Research

This study offers new perspectives on the disability welfare system in relation to neurodivergence and suggests several avenues for future research. Whilst an IPA methodology allowed for exploration of the specific experiences of women diagnosed in adulthood and implications for identity and psychological well-being, researchers may wish to explore these themes on a wider scale. A quantitative study could explore the relationships between autistic identity, internalised stigma, community connectedness and psychological well-being (e.g. anxiety, autistic burnout) in autistic women applying for benefits. Such information could continue to contribute to our understanding of minority stress within autistic populations (Botha & Frost, 2020) and support the development of projects to support autistic women's well-being.

Research is needed to understand the experiences of autistic men and those with multiple marginalised identities (e.g. minoritised gender or cultural identities), especially given the historic neglect of intersectionality within autism research (e.g. Diemer et al., 2022; Lovelace et al., 2022).

Whilst I hope that offering training to welfare staff and making necessary adaptations will improve autistic adults' experiences of the PIP system, this study also suggested that assessors may be negatively impacted by working within the benefits system. Given the described similarities to burnout and compassion fatigue reported among American government workers (Sciepura & Linos, 2022), it will be important to assess the experiences of assessors and the systemic conditions and factors that impact their well-being. In short: to re-humanise applicants, it is vital to humanise assessors and address their working conditions.

Final Conclusions

This research sought to explore autistic women's experiences of applying for disability benefits and any impact on their mental well-being and sense of identity. The findings from this study suggest that autistic women experience the PIP system as failing to understand and accommodate their distinctive needs and replicating barriers faced by autistic women in society (i.e. lack of communication adjustments, being disbelieved, pathologized and stereotyped). Similarly to the wider literature, the anxiety-provoking nature of the application process, combined with the aforementioned factors, was described as creating additional stress for women and exacerbating the emotional burden of navigating their existing challenges.

Autistic women in this study highlighted the psychological impact of their experiences: increasing levels of anxiety and risk of autistic burnout. Consistent with previous research, this study has shown the detrimental impact of internalised stigma and shame among autistic women. Women's experiences of the deficit-focused application process appeared to undermine their narratives of autistic identity and their self-esteem. However, this research also demonstrated the importance of supporting self-compassion and developing positive autistic identity amongst late-diagnosed autistic women. These findings continue to underscore the need for a systemic shift in how society and services relate to and support autistic women.

References

Allan, S., Roberts, H., Clancy, M., Nair, V., MacKenzie-Nash, C., Braekken, K., Matrunola, C.,

    Blanche, M., Jamieson, M., Stuart, S., & Gumley, A. (2022). *What researching the*

    benefits system has taught us about being trauma informed when people encounter

    traumatising systems. 8.

Anderson-Chavarria, M. (2021). The autism predicament: Models of autism and their impact

    on autistic identity. *Disability & Society*, 1–21.

    https://doi.org/10.1080/09687599.2021.1877117

Andersson, J. (2022). *'I had no income for three years because PIP assessor said I wasn't*

    autistic enough'. iNews. https://inews.co.uk/news/health/pip-assessment-lived-

    without-income-three-years-not-autistic-enough-1344728

Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom

    Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of

    Researchers and Participants. *International Journal of Qualitative Methods*, *18*,

    160940691987459. https://doi.org/10.1177/1609406919874596

Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023).

    Confirming the nature of autistic burnout. *Autism*, *27*(7), 1906–1918.

    https://doi.org/10.1177/13623613221147410

Bagatell, N. (2007). Orchestrating voices: Autism, identity and the power of discourse.

    Disability & Society, *22*(4), 413–426. https://doi.org/10.1080/09687590701337967

Bargiela, S., Steward, R., & Mandy, W. (2016). The Experiences of Late-diagnosed Women

    with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype.

    Journal of Autism and Developmental Disorders, *46*(10), 3281–3294.

    https://doi.org/10.1007/s10803-016-2872-8

Barr, B., Taylor-Robinson, D., Stuckler, D., Loopstra, R., Reeves, A., & Whitehead, M. (2015). 'First, do no harm': Are disability assessments associated with adverse trends in mental health? A longitudinal ecological study. *Journal of Epidemiology and Community Health*, *70*(4), 339–345. https://doi.org/10.1136/jech-2015-206209

Baumberg Geiger, B. (2015). Psychologists' association calls for reform of WCA. *Rethinking Incapacity*. https://research.kent.ac.uk/rethinkingincapacity/2015/06/18/psychologists-association-calls-for-reform-of-wca-2/

Bemmouna, D., & Weiner, L. (2023). Linehan's biosocial model applied to emotion dysregulation in autism: A narrative review of the literature and an illustrative case conceptualization. *Frontiers in Psychiatry*, *14*, 1238116. https://doi.org/10.3389/fpsyt.2023.1238116

Beresford, B., Mukherjee, S., Mayhew, E., Heavey, E., Park, A.-L., Stuttard, L., Allgar, V., & Knapp, M. (2020a). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: The SHAPE mixed-methods study. *Health Services and Delivery Research*, *8*(48), 1–200. https://doi.org/10.3310/hsdr08480

Beresford, B., Mukherjee, S., Mayhew, E., Heavey, E., Park, A.-L., Stuttard, L., Allgar, V., & Knapp, M. (2020b). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: The SHAPE mixed-methods study. *Health Services and Delivery Research*, *8*(48), 1–200. https://doi.org/10.3310/hsdr08480

Botha, M. (2021). Academic, Activist, or Advocate? Angry, Entangled, and Emerging: A

Critical Reflection on Autism Knowledge Production. *Frontiers in Psychology*, *12*,

727542. https://doi.org/10.3389/fpsyg.2021.727542

Botha, M., & Cage, E. (2022). "Autism research is in crisis": A mixed method study of

researcher's constructions of autistic people and autism research. *Frontiers in

Psychology*, *13*, 1050897. https://doi.org/10.3389/fpsyg.2022.1050897

Botha, M., Dibb, B., & Frost, D. M. (2020). 'Autism is me': An investigation of how autistic

individuals make sense of autism and stigma. *Disability & Society*, 1–27.

https://doi.org/10.1080/09687599.2020.1822782

Botha, M., & Frost, D. M. (2020). Extending the Minority Stress Model to Understand Mental

Health Problems Experienced by the Autistic Population. *Society and Mental Health*,

10(1), 20–34. https://doi.org/10.1177/2156869318804297

Botha, M., Hanlon, J., & Williams, G. L. (2021). Does Language Matter? Identity-First Versus

Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of

Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04858-w

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding

Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, *3*(1), 18–

29. https://doi.org/10.1089/aut.2020.0014

Bramer, W. M., Rethlefsen, M. L., Kleijnen, J., & Franco, O. H. (2017). Optimal database

combinations for literature searches in systematic reviews: A prospective exploratory

study. *Systematic Reviews*, *6*(1), 245. https://doi.org/10.1186/s13643-017-0644-y

Brede, J., Cage, E., Trott, J., Palmer, L., Smith, A., Serpell, L., Mandy, W., & Russell, A. (2022).

"We Have to Try to Find a Way, a Clinical Bridge" - autistic adults' experience of

accessing and receiving support for mental health difficulties: A systematic review

and thematic meta-synthesis. *Clinical Psychology Review*, *93*, 102131.

https://doi.org/10.1016/j.cpr.2022.102131

Brice, S., Rodgers, J., Ingham, B., Mason, D., Wilson, C., Freeston, M., Le Couteur, A., & Parr,

J. R. (2021). The importance and availability of adjustments to improve access for

autistic adults who need mental and physical healthcare: Findings from UK surveys.

BMJ Open, *11*(3), e043336. https://doi.org/10.1136/bmjopen-2020-043336

British Psychological Society. (2017). *Practice Guidelines (Third Edition)*.

British Psychological Society. (n.d.). *Written evidence from the British Psychological Society

(WTW0055)*. https://committees.parliament.uk/writtenevidence/58269/html/

Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It Defines Who I Am" or "It's

Something I Have": What Language Do [Autistic] Australian Adults [on the Autism

Spectrum] Prefer? *Journal of Autism and Developmental Disorders*.

https://doi.org/10.1007/s10803-020-04425-3

Butler, P. (2018, January 29). Government to review 1.6m disability benefit claims after U-

turn. *The Guardian*.

https://www.theguardian.com/society/2018/jan/29/government-to-review-16m-

disability-benefit-claims-after-u-turn

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of Autism Acceptance and Mental

Health in Autistic Adults. *Journal of Autism and Developmental Disorders*, *48*(2), 473–

484. https://doi.org/10.1007/s10803-017-3342-7

Cai, R. Y., & Brown, L. (2021). Cultivating Self-Compassion to Improve Mental Health in

Autistic Adults. *Autism in Adulthood*, *3*(3), 230–237.

https://doi.org/10.1089/aut.2020.0034

Cai, R. Y., Gibbs, V., Love, A., Robinson, A., Fung, L., & Brown, L. (2023). "Self-compassion changed my life": The self-compassion experiences of autistic and non-autistic adults and its relationship with mental health and psychological wellbeing. *Journal of Autism and Developmental Disorders*, *53*(3), 1066–1081. https://doi.org/10.1007/s10803-022-05668-y

Cai, R. Y., Hall, G., & Pellicano, E. (2023). Predicting the financial wellbeing of autistic adults: Part I. *Autism*, 13623613231196085. https://doi.org/10.1177/13623613231196085

Camilleri, K., Voss, K., & Weare, V. (2020, May 14). *The Benefits Project in Covid Times*. The Psychologist. https://thepsychologist.bps.org.uk/benefits-project-covid-times

Cantrell, E., Weatherhead, S., & Higson, H. (2021). Exploring the interface between mental health provision and the benefits system: Clinical psychologists' experiences of working in the context of the UK benefits system. *Mental Health Review Journal*, *ahead-of-print*(ahead-of-print). https://doi.org/10.1108/MHRJ-02-2021-0013

Cardona, N. D., Madigan, R. J., & Sauer-Zavala, S. (2022). How minority stress becomes traumatic invalidation: An emotion-focused conceptualization of minority stress in sexual and gender minority people. *Clinical Psychology: Science and Practice*, *29*(2), 185–195. https://doi.org/10.1037/cps0000054

Clarke, H., Carmichael, F., & Al-Janabi, H. (2019). Adverse Effects of Social Security on Disabled People and Their Families in the UK: Iatrogenic Outcomes of Quasi-Clinical Administration. *Scandinavian Journal of Disability Research*, *21*(1), 218. https://doi.org/10.16993/sjdr.607

Clifton, A., Reynolds, J., Remnant, J., & Noble, J. (2013). The age of austerity: The impact of welfare refor on people in the North East of England. *Mental Health Nursing*, *33*(9), 30–32.

Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental

health in autism: Social identity, self-esteem, and mental health in autism. *European

Journal of Social Psychology*, *47*(7), 844–854. https://doi.org/10.1002/ejsp.2297

Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. E. (2021). "I'm Proud to be a Little Bit

Different": The Effects of Autistic Individuals' Perceptions of Autism and Autism

Social Identity on Their Collective Self-esteem. *Journal of Autism and Developmental

Disorders*, *51*(2), 704–714. https://doi.org/10.1007/s10803-020-04575-4

Corden, K., Brewer, R., & Cage, E. (2021). Personal Identity After an Autism Diagnosis:

Relationships With Self-Esteem, Mental Wellbeing, and Diagnostic Timing. *Frontiers

in Psychology*, *12*, 699335. https://doi.org/10.3389/fpsyg.2021.699335

Crowson, S., Poole, D., Scargill, K., & Freeth, M. (2023). Understanding the post-diagnostic

support priorities of autistic adults in the United Kingdom: A co-produced modified

Delphi study. *Autism*, 13623613231196805.

https://doi.org/10.1177/13623613231196805

Dalkin, S. M., Forster, N., Hodgson, P., Lhussier, M., Philipson, P., & Carr, S. M. (2019).

Exposing the impact of intensive advice services on health: A realist evaluation.

Health & Social Care in the Community, *27*(3), 767–776.

https://doi.org/10.1111/hsc.12695

Davies, J., Cooper, K., Killick, E., Sam, E., Healy, M., Thompson, G., Mandy, W., Redmayne, B.,

& Crane, L. (2024). Autistic identity: A systematic review of quantitative research.

Autism Research, aur.3105. https://doi.org/10.1002/aur.3105

Davies, J., Heasman, B., Livesey, A., Walker, A., Pellicano, E., & Remington, A. (2022). Autistic

adults' views and experiences of requesting and receiving workplace adjustments in

the UK. *PLOS ONE*, *17*(8), e0272420. https://doi.org/10.1371/journal.pone.0272420

Day, W., & Shaw, R. (2022). When benefit eligibility and patient-led care intersect. Living in the UK with chronic illness: Experiences of the work capability assessment. *Journal of Health Psychology*, *27*(2), 456–469. https://doi.org/10.1177/1359105320953476

den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, *23*(2), 271–273.

Department for Work and Pensions. (2023, April 2). *New review to boost employment prospects of autistic people*. https://www.gov.uk/government/news/new-review-to-boost-employment-prospects-of-autistic-people

Dewinter, J., Van Parys, H., Vermeiren, R., & van Nieuwenhuizen, C. (2017). Adolescent boys with an autism spectrum disorder and their experience of sexuality: An interpretative phenomenological analysis. *Autism*, *21*(1), 75–82. https://doi.org/10.1177/1362361315627134

Diemer, M. C., Gerstein, E. D., & Regester, A. (2022). Autism presentation in female and Black populations: Examining the roles of identity, theory, and systemic inequalities. *Autism*, *26*(8), 1931–1946. https://doi.org/10.1177/13623613221113501

Dwyer, P., Scullion, L., Jones, K., McNeill, J., & Stewart, A. B. R. (2020). Work, welfare, and wellbeing: The impacts of welfare conditionality on people with mental health impairments in the UK. *Social Policy & Administration*, *54*(2), 311–326. https://doi.org/10.1111/spol.12560

Dwyer, S. C., & Buckle, J. L. (2009). The Space Between: On Being an Insider-Outsider in Qualitative Research. *International Journal of Qualitative Methods*, *8*(1), 54–63. https://doi.org/10.1177/160940690900800105

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Koss, M. P., & Marks, J. S. (1998). Relationship of Childhood Abuse and Household Dysfunction

to Many of the Leading Causes of Death in Adults. *American Journal of Preventive Medicine*, *14*(4), 245–258. https://doi.org/10.1016/S0749-3797(98)00017-8

Fletcher, A. J. (2017). Applying critical realism in qualitative research: Methodology meets method. *International Journal of Social Research Methodology*, *20*(2), 181–194. https://doi.org/10.1080/13645579.2016.1144401

Forber-Pratt, A. J., & Zape, M. P. (2017). Disability identity development model: Voices from the ADA-generation. *Disability and Health Journal*, *10*(2), 350–355. https://doi.org/10.1016/j.dhjo.2016.12.013

Foster, H., & Elntib, S. (2020). Stress and well-being of unpaid carers supporting claimants through disability benefit assessments. *Health & Social Care in the Community*, *28*(5), 1525–1534. https://doi.org/10.1111/hsc.12975

Frost, D. M., & Meyer, I. H. (2023). Minority stress theory: Application, critique, and continued relevance. *Current Opinion in Psychology*, *51*, Article 101579.

Garthwaite, K. (2014). Fear of the Brown Envelope: Exploring Welfare Reform with Long-Term Sickness Benefits Recipients. *Social Policy & Administration*, *48*(7), 782–798. https://doi.org/10.1111/spol.12049

Garthwaite, K. (2015a). Becoming incapacitated? Long-term sickness benefit recipients and the construction of stigma and identity narratives. *Sociology of Health & Illness*, *37*(1), 1–13. https://doi.org/10.1111/1467-9566.12168

Garthwaite, K. (2015b). 'Keeping meself to meself'—How Social Networks Can Influence Narratives of Stigma and Identity for Long-term Sickness Benefits Recipients. *Social Policy & Administration*, *49*(2), 199–212. https://doi.org/10.1111/spol.12119

Garthwaite, K., Bambra, C., Warren, J., Kasim, A., & Greig, G. (2014). Shifting the Goalposts: A Longitudinal Mixed-Methods Study of the Health of Long-Term Incapacity Benefit

Recipients during a Period of Substantial Change to the UK Social Security System. *Journal of Social Policy*, *43*(2), 311–330. https://doi.org/10.1017/S0047279413000974

Gill, S. L. (2020). Qualitative Sampling Methods. *Journal of Human Lactation*, *36*(4), 579–581. https://doi.org/10.1177/0890334420949218

Gosling, J., Purrington, J., & Hartley, G. (2023). Exploring the Lived Experiences of Autistic Women: A Thematic Synthesis. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-023-00367-5

Gowen, E., Taylor, R., Bleazard, T., Greenstein, A., Baimbridge, P., & Poole, D. (2020). *Guidelines for conducting research studies with the autism community*.

Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living Stigma: The Impact of Labeling, StereLIoVtIyNpGiSnTgIG,MA 197 Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families. *Sociological Inquiry*, *75*(2), 197–215.

Greener, J., & Moth, R. (2020). From shame to blame: Institutionalising oppression through the moralisation of mental distress in austerity England. *Social Theory & Health*. https://doi.org/10.1057/s41285-020-00148-8

Grove, R., Clapham, H., Moodie, T., Gurrin, S., & Hall, G. (2023). 'Living in a world that's not about us': The impact of everyday life on the health and wellbeing of autistic women and gender diverse people. *Women's Health*, *19*, 17455057231189542. https://doi.org/10.1177/17455057231189542

Han, E., Scior, K., Avramides, K., & Crane, L. (2022). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Research*, *15*(1), 12–26. https://doi.org/10.1002/aur.2652

Han, E., Scior, K., Heath, E., Umagami, K., & Crane, L. (2023). *Development of stigma-related support for autistic adults: Insights from the autism community*.

Hansford, L., Thomas, F., & Wyatt, K. (2019). The impact of the Work Capability Assessment on mental health: Claimants' lived experiences and GP perspectives in low-income communities. *Journal of Poverty and Social Justice*, *27*(3), 351–368. https://doi.org/10.1332/175982719X15637716050550

Harmens, M., Sedgewick, F., & Hobson, H. (2022). The Quest for Acceptance: A Blog-Based Study of Autistic Women's Experiences and Well-Being During Autism Identification and Diagnosis. *Autism in Adulthood*, *4*(1), 42–51. https://doi.org/10.1089/aut.2021.0016

Heselton, G. A., Rempel, G. R., & Nicholas, D. B. (2021). Integrating Community Participation With Interpretative Phenomenological Analysis: Reflections on Engaging the Autism Community. *International Journal of Qualitative Methods*, *20*, 160940692110555. https://doi.org/10.1177/16094069211055575

Hewitt, L., Camilleri, K., & Bolt, C. (2017). *Guidance on writing a good letter of support for pip or esa applications by clients with mental health difficulties or disabilities*. Westcountry Community Psychology Group. https://www.psychchange.org/uploads/9/7/9/7/97971280/wcp_guidance_on_supp orting_letters_pip___esa.pdf

Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021a). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism*, *25*(8), 2356–2369. https://doi.org/10.1177/13623613211019858

Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021b). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism*, *25*(8), 2356–2369. https://doi.org/10.1177/13623613211019858

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, *208*(3), 232–238. https://doi.org/10.1192/bjp.bp.114.160192

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine*, *49*(4), 559–572. https://doi.org/10.1017/S0033291718002283

Honey, A., Emerson, E., & Llewellyn, G. (2011). *The mental health of young people with disabilities: Impact of social conditions*.

Hossain, M. M., Khan, N., Sultana, A., Ma, P., McKyer, E. L. J., Ahmed, H. U., & Purohit, N. (2020). Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. *Psychiatry Research*, *287*, 112922. https://doi.org/10.1016/j.psychres.2020.112922

House of Commons Work and Pensions Committee. (2023). *Health assessments for benefits*. https://committees.parliament.uk/publications/34727/documents/191178/default/

Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism*, *23*(7), 1871–1876. https://doi.org/10.1177/1362361318823902

Howard, P. L., & Sedgewick, F. (2021). 'Anything but the phone!': Communication mode

preferences in the autism community. *Autism*, *25*(8), 2265–2278.

https://doi.org/10.1177/13623613211014995

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017).

"Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum

Conditions. *Journal of Autism and Developmental Disorders*, *47*(8), 2519–2534.

https://doi.org/10.1007/s10803-017-3166-5

Hull, L., Petrides, K. V., & Mandy, W. (2020). The Female Autism Phenotype and

Camouflaging: A Narrative Review. *Review Journal of Autism and Developmental*

Disorders, *7*(4), 306–317. https://doi.org/10.1007/s40489-020-00197-9

Hunt, R. (2018, October 23). *People with autism spectrum conditions are unfairly treated for*

PIP claims. Morning Star. https://morningstaronline.co.uk/article/people-autism-

spectrum-conditions-are-unfairly-treated-pip-claims

Hutton, J., & Mudie, S. (2023). *Guidance for Psychologists on Supporting Clients with Physical*

Health Needs through DWP Benefits Processes. Association of Clinical Psychologists-

UK Clinical Health Psychology Network. https://acpuk.org.uk/guidance-for-

psychologists-on-supporting-clients-with-physical-health-needs-through-dwp-

benefits-processes/

Jaspal, R., & Cinnirella, M. (2010). Coping with potentially incompatible identities: Accounts

of religious, ethnic and sexual identities from British Pakistani men who identify as

Muslim and gay. *British Journal of Social Psychology*, *49*(4), 849–870.

Jenkinson, R., Milne, E., & Thompson, A. (2020). The relationship between intolerance of

uncertainty and anxiety in autism: A systematic literature review and meta-analysis.

Autism, *24*(8), 1933–1944. https://doi.org/10.1177/1362361320932437

Jordan, U. (2022). "I feel like I'm useful. I'm not useless, you know?": Exploring Volunteering as Resistance to Stigma for Men Who Experience Mental Illness. *Social Policy and Society*, 1–11. https://doi.org/10.1017/S1474746422000045

Kapp, S. K. (2023). Profound Concerns about "Profound Autism": Dangers of Severity Scales and Functioning Labels for Support Needs. *Education Sciences*, *13*(2), 106. https://doi.org/10.3390/educsci13020106

Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of ENGLISH -speaking individuals across the globe: A mixed methods investigation. *Autism Research*, *16*(2), 406–428. https://doi.org/10.1002/aur.2864

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Koltai, J., McKee, M., & Stuckler, D. (2021). Association between disability-related budget reductions and increasing drug-related mortality across local authorities in Great Britain. *Social Science & Medicine*, *284*, 114225. https://doi.org/10.1016/j.socscimed.2021.114225

Lai, M.-C., Kassee, C., Besney, R., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (n.d.). *Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis*. 206.

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*(1), 135–146. https://doi.org/10.1177/1362361319853442

Levitt, H. M., Motulsky, S. L., Wertz, F. J., Morrow, S. L., & Ponterotto, J. G. (2017).

    Recommendations for designing and reviewing qualitative research in psychology:

    Promoting methodological integrity. *Qualitative Psychology*, *4*(1), 2–

    22. https://doi.org/10.1037/qup0000082

Lobe, B., Morgan, D. L., & Hoffman, K. (2022). A Systematic Comparison of In-Person and

    Video-Based Online Interviewing. *International Journal of Qualitative Methods*, *21*,

    160940692211270. https://doi.org/10.1177/16094069221127068

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal

    skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis.

    Research Methods in Medicine & Health Sciences, *1*(1), 31–42.

    https://doi.org/10.1177/2632084320947559

Lorenc, T., Rodgers, M., Marshall, D., Melton, H., Rees, R., Wright, K., & Sowden, A. (2018).

    Support for adults with autism spectrum disorder without intellectual impairment:

    Systematic review. *Autism*, *22*(6), 654–668.

    https://doi.org/10.1177/1362361317698939

Lovelace, T. S., Comis, M. P., Tabb, J. M., & Oshokoya, O. E. (2022). Missing from the

    Narrative: A Seven-Decade Scoping Review of the Inclusion of Black Autistic Women

    and Girls in Autism Research. *Behavior Analysis in Practice*, *15*(4), 1093–1105.

    https://doi.org/10.1007/s40617-021-00654-9

Lowe, J., & DeVerteuil, G. (2020). Austerity Britain, poverty management and the missing

    geographies of mental health. *Health & Place*, *64*, 102358.

    https://doi.org/10.1016/j.healthplace.2020.102358

Lupindo, B. M., Maw, A., & Shabalala, N. (2023). Late diagnosis of autism: Exploring experiences of males diagnosed with autism in adulthood. *Current Psychology*, *42*(28), 24181–24197. https://doi.org/10.1007/s12144-022-03514-z

Machin, R., & McCormack, F. (2021). The impact of the transition to Personal Independence Payment on claimants with mental health problems. *Disability & Society*, 1–24. https://doi.org/10.1080/09687599.2021.1972409

MacLennan, K., O'Brien, S., & Tavassoli, T. (2022). In Our Own Words: The Complex Sensory Experiences of Autistic Adults. *Journal of Autism and Developmental Disorders*, *52*(7), 3061–3075. https://doi.org/10.1007/s10803-021-05186-3

MacLeod, A. (2019). Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Research in Autism Spectrum Disorders*, *64*, 49–62. https://doi.org/10.1016/j.rasd.2019.04.005

Maras, K., Norris, J. E., Nicholson, J., Heasman, B., Remington, A., & Crane, L. (2021). Ameliorating the disadvantage for autistic job seekers: An initial evaluation of adapted employment interview questions. *Autism*, *25*(4), 1060–1075. https://doi.org/10.1177/1362361320981319

Marmot, M. (2020). Health equity in England: The Marmot review 10 years on. *BMJ*, m693. https://doi.org/10.1136/bmj.m693

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., Brown, T., James, I., Scarlett, C., Nicolaidis, C., & Parr, J. R. (2019). A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *Journal of Autism and Developmental Disorders*, *49*(8), 3387–3400. https://doi.org/10.1007/s10803-019-04049-2

Mattheys, K., Warren, J., & Bambra, C. (2018). "Treading in sand": A qualitative study of the impact of austerity on inequalities in mental health. *Social Policy & Administration*, *52*(7), 1275–1289. https://doi.org/10.1111/spol.12348

McEvoy, P., & Richards, D. (2003). Critical realism: A way forward for evaluation research in nursing? *Journal of Advanced Nursing*, *43*(4), 411–420. https://doi.org/10.1046/j.1365-2648.2003.02730.x

Mcgrath, L., Griffin, V., Mundy, E., Curno, T., Weerasinghe, D., & Zlotowitz, S. (2016). *The Psychological Impact of Austerity: A Briefing Paper*. https://doi.org/10.15123/UEL.885XW

Mcrea, I. (2023, July 18). *Panic attacks, pressure to 'ramp up numbers' and a 'bullying atmosphere': Life as a DWP disability benefits assessor*. Panic Attacks, Pressure to 'Ramp up Numbers' and a 'Bullying Atmosphere': Life as a DWP Disability Benefits Assessor. https://www.bigissue.com/news/social-justice/dwp-disability-benefits-assessors-pressure-ramp-up-numbers/).

Meyer, I. H. (2003). *Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence*.

Milton, D. E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, *18*(7), 794–802. https://doi.org/10.1177/1362361314525281

Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, *27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society*, *31*(4), 520–534. https://doi.org/10.1080/09687599.2016.1186529

Mind. (2013, December 4). *Victory for welfare campaigners as government loses appeal*

    against benefits ruling. https://www.mind.org.uk/news-campaigns/news/victory-for-

    welfare-campaigners-as-government-loses-appeal-against-benefits-ruling/

Moffatt, S., & Noble, E. (2015). Work or welfare after cancer? Explorations of identity and

    stigma. *Sociology of Health & Illness*, *37*(8), 1191–1205.

    https://doi.org/10.1111/1467-9566.12303

Monteiro, M. J. (2021). Narrative therapy and the autism spectrum: A model for clinicians.

    Human Systems: Therapy, Culture and Attachments, *1*(2–3), 150–164.

    https://doi.org/10.1177/26344041211049763

Morris, R. (2013). 'Unjust, inhumane and highly inaccurate': The impact of changes to

    disability benefits and services – social media as a tool in research and activism.

    Disability & Society, *28*(5), 724–728. https://doi.org/10.1080/09687599.2013.808093

Mustafa, J., Hodgson, P., Lhussier, M., Forster, N., Carr, S. M., & Dalkin, S. M. (2020).

    'Everything takes too long and nobody is listening': Developing theory to understand

    the impact of advice on stress and the ability to cope. *PLOS ONE*, *15*(4), e0231014.

    https://doi.org/10.1371/journal.pone.0231014

National Autistic Society. (2011). *Who benefits? The impact of DLA reform on people with an*

    autism spectrum disorder.

NICE. (2014). *Implementation pack: Developing a multi-agency local autism team*

    Implementing the NICE guidelines on autism (CG128, CG142 and CG170).

Nicolaidis, C., Raymaker, D. M., & McDonald, K. E. (2016). *"Respect the way I need to*

    communicate with you": Healthcare experiences of adults on the autism spectrum.

Nicolaidis, C., Raymaker, D., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., Gerrity, M.,

    Kripke, C., Platt, L., & Baggs, A. (2016). The Development and Evaluation of an Online

Healthcare Toolkit for Autistic Adults and their Primary Care Providers. *Journal of General Internal Medicine*, *31*(10), 1180–1189. https://doi.org/10.1007/s11606-016-3763-6

Norris, J. E., Crane, L., & Maras, K. (2020). Interviewing autistic adults: Adaptations to support recall in police, employment, and healthcare interviews. *Autism*, *24*(6), 1506–1520. https://doi.org/10.1177/1362361320909174

Norris, J. E., & Maras, K. (2022). Supporting autistic adults' episodic memory recall in interviews: The role of executive functions, theory of mind, and language abilities. *Autism*, *26*(2), 513–524. https://doi.org/10.1177/13623613211030772

Nyrenius, J., Eberhard, J., Ghaziuddin, M., Gillberg, C., & Billstedt, E. (2022). Prevalence of Autism Spectrum Disorders in Adult Outpatient Psychiatry. *Journal of Autism and Developmental Disorders*, *52*(9), 3769–3779. https://doi.org/10.1007/s10803-021-05411-z

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, *28*(7), 1024–1026. https://doi.org/10.1080/09687599.2013.818773

Parsloe, S. M. (2015). Discourses of Disability, Narratives of Community: Reclaiming an Autistic Identity Online. *Journal of Applied Communication Research*, *43*(3), 336–356. https://doi.org/10.1080/00909882.2015.1052829

Patrick, R. (2016). Living with and responding to the 'scrounger' narrative in the UK: Exploring everyday strategies of acceptance, resistance and deflection. *Journal of Poverty and Social Justice*, *24*(3), 245–259. https://doi.org/10.1332/175982716X14721954314887

Pellicano, E., Hall, G., & Ying Cai, R. (2023). Autistic adults' experiences of financial wellbeing: Part II. *Autism*, 13623613231191594. https://doi.org/10.1177/13623613231191594

Pellicano, L., Dinsmore, A., & Charman, T. (2013). *A FUTURE MADE TOGETHER*.

Perry, E., Mandy, W., Hull, L., & Cage, E. (2021). Understanding Camouflaging as a Response

to Autism-Related Stigma: A Social Identity Theory Approach. *Journal of Autism and*

Developmental Disorders. https://doi.org/10.1007/s10803-021-04987-w

Phenomenology and Psychology (1st ed.). (2013). McGraw-Hill Education.

ebookcentral.proquest.com/lib/herts/detail.action?docID=1220260

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using Interpretative

Phenomenological Analysis in qualitative research psychology. *Czasopismo*

Psychologiczne Psychological Journal, *20*(1). https://doi.org/10.14691/CPPJ.20.1.7

Ploetner, C., Telford, M., Brækkan, K., Mullen, K., Turnbull, S., Gumley, A., & Allan, S. (2020).

Understanding and improving the experience of claiming social security for mental

health problems in the west of Scotland: A participatory social welfare study. *Journal*

of Community Psychology, *48*(3), 675–692. https://doi.org/10.1002/jcop.22278

Porter, T., Pearson, C., & Watson, N. (2021). Evidence, objectivity and welfare reform: A

qualitative study of disability benefit assessments. *Evidence & Policy: A Journal of*

Research, Debate and Practice, *17*(2), 279–296.

https://doi.org/10.1332/174426421X16146990181049

Porter, T., Watson, N., & Pearson, C. (2022). Epistemic sabotage: The production and

disqualification of evidence in disability benefit claims. *Sociology of Health & Illness*,

1467-9566.13593. https://doi.org/10.1111/1467-9566.13593

Price, E., Walker, L., & Booth, S. (2020). Feeling the benefit? Fluctuating illness and the world

of welfare. *Disability & Society*, *35*(8), 1315–1336.

https://doi.org/10.1080/09687599.2019.1680346

Prilleltensky, I. (2008). The role of power in wellness, oppression, and liberation: The

promise of psychopolitical validity. *Journal of Community Psychology*, *36*(2), 116–136.

https://doi.org/10.1002/jcop.20225

Pybus, K., Pickett, K. E., Prady, S. L., Lloyd, C., & Wilkinson, R. (2019). Discrediting

experiences: Outcomes of eligibility assessments for claimants with psychiatric

compared with non-psychiatric conditions transferring to personal independence

payments in England. *BJPsych Open*, *5*(2), e19. https://doi.org/10.1192/bjo.2019.3

Pybus, K., Pickett, Kate. E., Lloyd, C., Prady, S., & Wilkinson, E. R. (2021). Functional

assessments in the UK social security system: The experiences of claimants with

mental health conditions. *Journal of Social Policy*, *50*(2), 305–322.

https://doi.org/10.1017/S0047279420000094

QSR International Pty Ltd. (2022). NVivo qualitative data analysis. Version 1.7.1 [Software].

https://support.qsrinternational.com/nvivo/s/

Rahim, M., & Cooke, A. (2019). Should clinical psychologists be political? In *Professional

issues in clinical psychology* (pp. 81–91). Routledge.

Raymaker, D. M., McDonald, K. E., Ashkenazy, E., Gerrity, M., Baggs, A. M., Kripke, C.,

Hourston, S., & Nicolaidis, C. (2017). Barriers to healthcare: Instrument development

and comparison between autistic adults and adults with and without other

disabilities. *Autism*, *21*(8), 972–984. https://doi.org/10.1177/1362361316661261

Ray-Chaudhuri, S., & Waters, T. (2024). *Recent trends in and the outlook for health-related

benefits.* (Report No. R311). Institute for Fiscal Studies.

https://ifs.org.uk/sites/default/files/2024-04/Recent-trends-in-and-the-outlook-for-

health-related-benefits-IFS-Report-R311.pdf

Reeve, D. (2002). Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity Constructions. *Disability & Society*, *17*(5), 493–508. https://doi.org/10.1080/09687590220148487

Riedelbauch, S., Gaigg, S. B., Thiel, T., Roessner, V., & Ring, M. (2023). Examining a model of anxiety in autistic adults. *Autism*, 13623613231177777. https://doi.org/10.1177/13623613231177777

Roberts, H., Stuart, S. R., Allan, S., & Gumley, A. (2022). 'It's Like the Sword of Damocles' – A Trauma-Informed Framework Analysis of Individuals' Experiences of Assessment for the Personal Independence Payment Benefit in the UK. *Journal of Social Policy*, 1–16. https://doi.org/10.1017/S0047279422000800

Rosqvist, H. B., Botha, M., Hens, K., O'Donoghue, S., Pearson, A., & Stenning, A. (2022). *Being, Knowing, and Doing: Importing Theoretical Toolboxes for Autism Studies*. 9.

Roulstone, A. (2015). Personal Independence Payments, welfare reform and the shrinking disability category. *Disability & Society*, *30*(5), 673–688. https://doi.org/10.1080/09687599.2015.1021759

Royal College of Psychiatrists. (2019). *Royal College of Psychiatrists' briefing: Mental health and the benefits assessment process*. https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/parliamentary/rcpsych-briefing---mental-health-and-benefits-assessment-process.pdf?sfvrsn=8f30853e_2#:~:text=The%20College%20wishes%20to%20see,lives%20they%20wish%20to%20lead.

Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A., & Ford, T. (2022). Time trends in autism diagnosis over 20 years: A UK population-based

cohort study. *Journal of Child Psychology and Psychiatry*, *63*(6), 674–682.

https://doi.org/10.1111/jcpp.13505

Saffer, J., Nolte, L., & Duffy, S. (2018). Living on a knife edge: The responses of people with

physical health conditions to changes in disability benefits. *Disability & Society*,

33(10), 1555–1578. https://doi.org/10.1080/09687599.2018.1514292

Saffer, J., & O'Riordan, E. (2022a). *'People don't fit boxes': The responses of people with*

disabilities to the disability benefits system. 9.

Saffer, J., & O'Riordan, E. (2022b). *'People don't fit boxes': The responses of people with*

disabilities to the disability benefits system. 9.

Scattoni, M. L., Micai, M., Ciaramella, A., Salvitti, T., Fulceri, F., Fatta, L. M., Poustka, L.,

Diehm, R., Iskrov, G., Stefanov, R., Guillon, Q., Rogé, B., Staines, A., Sweeney, M. R.,

Boilson, A. M., Leósdóttir, T., Saemundsen, E., Moilanen, I., Ebeling, H., … Schendel,

D. (2021). Real-World Experiences in Autistic Adult Diagnostic Services and Post-

diagnostic Support and Alignment with Services Guidelines: Results from the ASDEU

Study. *Journal of Autism and Developmental Disorders*, *51*(11), 4129–4146.

https://doi.org/10.1007/s10803-021-04873-5

Sciepura, B., & Linos, E. (2022). When Perceptions of Public Service Harms the Public

Servant: Predictors of Burnout and Compassion Fatigue in Government. *Review of*

Public Personnel Administration, 0734371X2210815.

https://doi.org/10.1177/0734371X221081508

Scior, K., Cooper, R., Fenn, K., Poole, L., Colman, S., Ali, A., Baum, S., Crabtree, J., Doswell, S.,

Jahoda, A., Hastings, R., & Richardson, L. (2022). 'Standing up for Myself' (STORM):

Development and qualitative evaluation of a psychosocial group intervention

designed to increase the capacity of people with intellectual disabilities to manage

and resist stigma. *Journal of Applied Research in Intellectual Disabilities*, *35*(6), 1297–

1306. https://doi.org/10.1111/jar.13018

Scullion, L., & Curchin, K. (2022). Examining Veterans' Interactions with the UK Social

Security System through a Trauma-Informed Lens. *Journal of Social Policy*, *51*(1), 96–

113. https://doi.org/10.1017/S0047279420000719

Seers, K., & Hogg, R. C. (2021). 'You don't look autistic': A qualitative exploration of women's

experiences of being the 'autistic other'. *Autism*, *25*(6), 1553–1564.

https://doi.org/10.1177/1362361321993722

Shefer, G., Henderson, C., Frost-Gaskin, M., & Pacitti, R. (2016). Only Making Things Worse: A

Qualitative Study of the Impact of Wrongly Removing Disability Benefits from People

with Mental Illness. *Community Mental Health Journal*, *52*(7), 834–841.

https://doi.org/10.1007/s10597-016-0012-8

Simpson, J., Albani, V., Bell, Z., Bambra, C., & Brown, H. (2021). Effects of social security

policy reforms on mental health and inequalities: A systematic review of

observational studies in high-income countries. *Social Science & Medicine*, *272*,

113717. https://doi.org/10.1016/j.socscimed.2021.113717

Singh, V. K., Singh, P., Karmakar, M., Leta, J., & Mayr, P. (2021). The journal coverage of Web

of Science, Scopus and Dimensions: A comparative analysis. *Scientometrics*, *126*(6),

5113–5142. https://doi.org/10.1007/s11192-021-03948-5

Smart, J. F. (2006). Challenges to the Biomedical Model of Disability. *Advances in Medical

Psychotherapy & Psychodiagnosis*, *12*, 41–44.

Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative Phenomenologial Analysis:

Theory, Method and Research.* SAGE Publications Ltd.

St. John, T., Woods, S., Bode, T., Ritter, C., & Estes, A. (2022). A review of executive

functioning challenges and strengths in autistic adults. *The Clinical

Neuropsychologist*, *36*(5), 1116–1147.

https://doi.org/10.1080/13854046.2021.1971767

Stuart, R., Campbell, S., Osumili, B., Robinson, E. J., Frost-Gaskin, M., Pacitti, R., McCrone, P.,

& Henderson, C. (2020). Do welfare benefit reassessments of people with mental

health conditions lead to worse mental health? A prospective cohort study.

International Journal of Social Psychiatry, *66*(2), 136–149.

https://doi.org/10.1177/0020764019888955

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative

research. *Qualitative Inquiry*, *16*(10), 837-851.

Thomas, A. (2023, September 10). *DWP left autistic man suicidal after 'obstructive' PIP

assessments*. Swindon Advertiser.

https://www.swindonadvertiser.co.uk/news/23777209.dwp-left-autistic-man-

suicidal-obstructive-pip-assessments/

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research

in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45.

https://doi.org/10.1186/1471-2288-8-45

Thomson, R. M., Igelström, E., Purba, A. K., Shimonovich, M., Thomson, H., McCartney, G.,

Reeves, A., Leyland, A., Pearce, A., & Katikireddi, S. V. (2022). How do income

changes impact on mental health and wellbeing for working-age adults? A systematic

review and meta-analysis. *The Lancet Public Health*, *7*(6), e515–e528.

https://doi.org/10.1016/S2468-2667(22)00058-5

Thunberg, S., & Arnell, L. (2022). Pioneering the use of technologies in qualitative research –

A research review of the use of digital interviews. *International Journal of Social

Research Methodology*, *25*(6), 757–768.

https://doi.org/10.1080/13645579.2021.1935565

Tint, A., & Weiss, J. A. (2018). A qualitative study of the service experiences of women with

autism spectrum disorder. *Autism*, *22*(8), 928–937.

https://doi.org/10.1177/1362361317702561

Treweek, C., Wood, C., Martin, J., & Freeth, M. (2019). Autistic people's perspectives on

stereotypes: An interpretative phenomenological analysis. *Autism*, *23*(3), 759–769.

https://doi.org/10.1177/1362361318778286

Tromans, S., Chester, V., Kiani, R., Alexander, R., & Brugha, T. (2018). The Prevalence of

Autism Spectrum Disorders in Adult Psychiatric Inpatients: A Systematic Review.

Clinical Practice & Epidemiology in Mental Health, *14*(1), 177–187.

https://doi.org/10.2174/1745017901814010177

Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A

Contemporary Qualitative Research Approach. *Journal of Healthcare

Communications*, *02*(04). https://doi.org/10.4172/2472-1654.100093

Wallace, G. L., Kenworthy, L., Pugliese, C. E., Popal, H. S., White, E. I., Brodsky, E., & Martin,

A. (2016). Real-World Executive Functions in Adults with Autism Spectrum Disorder:

Profiles of Impairment and Associations with Adaptive Functioning and Co-morbid

Anxiety and Depression. *Journal of Autism and Developmental Disorders*, *46*(3),

1071–1083. https://doi.org/10.1007/s10803-015-2655-7

Watson, C., Kirkham, R., & Kharrufa, A. (2020). PIP Kit: An Exploratory Investigation into

using Lifelogging to support Disability Benefit Claimants. *Proceedings of the 2020 CHI*

Conference on Human Factors in Computing Systems, 1–14.

https://doi.org/10.1145/3313831.3376215

Watts, J. (2018). Supporting claimants: A practical guide. *Asylum Magazine*.

https://asylummagazine.org/2018/08/supporting-claimants-a-practical-guide-by-jay-watts/

Wigham, S., Ingham, B., Le Couteur, A., Wilson, C., Ensum, I., & Parr, J. R. (2023). Consensus

statements on optimal adult post-autism diagnosis support and services: Delphi

process following a UK survey of autistic adults, relatives and clinicians. *Autism*,

27(2), 344–355. https://doi.org/10.1177/13623613221097502

Wright, S. (2016). Conceptualising the active welfare subject: Welfare reform in discourse,

policy and lived experience. *Policy & Politics*, *44*(2), 235–252.

https://doi.org/10.1332/030557314X13904856745154

Wright, S., Robertson, L., & Stewart, A. B. R. (2022). Universal Credit and the invalidation of

mental health problems: Claimant and Jobcentre Plus staff experiences. *Journal of

Poverty and Social Justice*, 1–20.

https://doi.org/10.1332/175982721X16437383460256

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2),

215-228.

Young, D., & Bates, G. (2022). Maximising the health impacts of free advice services in the

UK: A mixed methods systematic review. *Health & Social Care in the Community*,

30(5), 1713–1725. https://doi.org/10.1111/hsc.13777

Appendix A: Reflective Accounts

Reflection on interview method and data

Throughout this research I was aware of assumptions within research community that verbal interviews are superior for data quality; however, I was aware that verbal communication was not always a preferred communication mode for many autistic people. I became curious about how interviews could be adapted to the needs and preferences of the autistic community and read several papers that informed this study's method. I was aware throughout that the act of participating in a research interview may mirror participants' experiences of the PIP assessment, and I attempted to avoid recreating experiences of powerlessness by giving participants choice in how they participated in the study. Although the majority of women chose to verbally answer questions at their interview, many women chose to read the interview questions in advance and made notes to prompt themselves during our conversation. Several women described feeling thankful that they could choose how to participate in this study, and that having written notes and prompts allowed them to prepare their answers and process their thoughts. I noticed that having written answers allowed participants to feel that they had accurately conveyed their experiences to me and provided a scaffolding for further discussion of their experiences.

Interestingly, I noted that the quality of data was not necessarily dependent upon the interview mode. Some verbal interviews yielded less detailed descriptions of experiences, whilst written interviews allowed some women the time to process their thoughts and respond in detail. The quality of the data appeared to be determined by the participant's own comfort and the quality of prompts. For example, during a written interview with Jade, a specific prompt around imagery resulted in the metaphor of officials jumping on your head instead of offering a lifeline. On the other hand, Marie gave limited responses despite the interview being verbal. Similarly, Anna gave detailed responses in writing and gave less detailed responses when a technical error forced the interview to continue via speech instead of text. These experiences made me reflect on my own comfort with verbal communication and preference for seeing the participant so that I could see their

facial expressions and interpret their emotions. I initially felt uneasy with written interviews for this reason. I reflected that my discomfort may reflect autistic women's experiences in daily life and I practiced sitting with my own discomfort to prioritise my participants' comfort over my neurotypical communication preferences.

Reflection from interviewing:

First interview done! This one was an instant messaging one (at the participant's request), which meant that the process was quite long. Not being able to hear her voice or see her facial expressions was disconcerting → maybe this is my own uncertainty about the meaning of pauses in the interview. Was she thinking? Typing? Upset? Hesitant? I found it hard not being able to mentalise how she was feeling and then act according to my guess. Does this mirror how she finds social interactions? That sense of uncertainty seemed a theme in the process of PIP too. I wonder if this affected my ability to stay present with her answers. I noticed feeling much more 'certain' and feeling the 'flow' when we had to switch to audio (due to a technical hitch). But whose comfort is most important? I guess it is a balance I need to find ways to sit with my discomfort/the unknown to support my participants → this will free me up to be more attuned.

Reflections from meeting primary supervisor:

[…] We also reflected on the metaphors and ideas within X's transcript. We thought about our surprise that a text interview can show a good depth of data – N.B. our neurotypical assumptions about the superiority of verbal fluency?!- and actually how making these interview options available has offered people the opportunity to take part, who may not otherwise be able to.

Post-interview reflection:

Interestingly, I found it difficult to dig deeper into her experience of the process. I wonder whether this reflects my tiredness, worries about her being [profession] – what will she think of my skills?- but also her experiences seem 'good' and issue free. Plus it felt hard to go into issues around identity when she contests her diagnosis. Maybe I could have

explored this further... I was aware that I felt as though delving into it would frustrate her in some way. Or maybe it is the contrast with my own assumptions that feels uncomfortable? I.e. that an autism diagnosis is welcomed and accepted, or applying for PIP will elicit some meaning-making.

I could have picked up more on her point about identity not being defined by conditions → this sense of being able to distance herself from a disabled identity appears to have protected her from the anxiety and repercussions described by other women. Maybe as there was no risk of invalidation? [...] Interview technique note: Was I more tentative with my wording? Followed up with prompts enough? Spoke more to build a rapport? Did she feel invalidated by a lack of follow-up questions? Maybe my own lens/experiences have hindered me from considering how to explore more positive experiences.

Reflections from analysis A: Navigating neurotypicality:

I've been really stuck for the last week with analysis. Part of it has been the number of themes with each transcript, [...] part is my own struggle to get beyond the descriptive when formulating experiential statements. I wonder if part of the descriptive vs interpretative struggle is [...]

I'm so aware that I could misinterpret people as a neurotypical researcher. The level of hope and interest that the autistic community have shown in this research is simultaneously motivating and overwhelming. What's helped is reading examples of how other IPA studies have coded their data and the balance of closeness to the data and interpretation and coming back to the hermeneutic cycle. I have plunged myself into my participant's worlds, but maybe I am struggling to permit myself to come back around to my side.

[...] I am so aware that I could misrepresent or misunderstand these women's experiences and there's a reality that my voice is listened to and viewed as more trustworthy because of my profession [...] I find myself constantly going back to participant transcripts to make sure I'm not running away with my thoughts and replicating the epistemic injustices that I've read about in research and heard about from participants.

Reflections from analysis B: Navigating the emotional impact:

IPA analysis has felt like a slog at times, but I am starting to feel a shift now that I am coming to constructing Group Experiential Themes. I described it to Lizette as coming to a lookout point on a long and gruelling mountain trek. There is still a long way up, but it is nice to pause and enjoy the view and see the progress from the bottom of the climb. My reactions and feelings about the analysis have waxed and waned over time, and I'm embarrassed to say that I underestimated the emotional toll that immersion in the interview data would take on my mood. Constantly being surrounded by participants' experiences and reliving the interview through reading the transcript has felt exhausting and overwhelming at times. The practical steps of using IPA and learning how to waltz with the participant's words (dissecting each phrase and pause, wondering over what this all meant and circling back again) is tiring enough, but the effort of holding my own thoughts and weight of anger and despair has surprised me [...]

No wonder I have found myself avoiding plunging myself back into the transcripts and wanting to detach myself from that pain. People's pain. Copious cups of decaf coffee, hobnobs, going for a brief walk outside and coming back to my hopes for this research have been so central for staying afloat and being able to continue my journey through the transcripts.

Reflection on selecting quotes for the Results section:

It initially felt impossible to choose which quotes to include, and by definition, who's quotes would be excluded. I have tried to hold in mind the advice of my IPA textbooks – which quotes are illustrative and convey emotion to the reader – but I find myself drawn towards certain participant's quotes more than others. Dahlia and Sakura's quotes spring to mind quicker than some other women. Maybe because I felt connected to them during the interviews. We are a similar age. They showed vulnerability and eloquence, but I'm constructing a 'good participant' by awarding value to their communicative abilities. My neurotypical norms might be showing here. Does eloquence = better, more genuine? Some autistic women may have shown their emotions differently at interview. This reminds me to remain rooted in the words of the participants and keep an eye on who I am leaning

towards including. Otherwise, I am just echoing the communication catch-22 in this research.

**Reflection on heterogeneity within the sample:**

Participants were not excluded on the basis of employment status due to the possibility that autistic women in employment may face difficulties with daily living activities outside of a structured work environment. The inclusion of two participants who were in employment allowed an exploration of how this aspect of identity interacted with women's experiences of claiming PIP. For example, it highlighted differences in the impact upon wellbeing and personal identity. These contrasts between employed and unemployed women illuminated the experiences of the other participants, highlighting details and interpretations which may otherwise have been overlooked (e.g. the role of personal identification with being autistic) but also highlighting some commonalities (e.g. difficulties in communication within the PIP process)

Nevertheless, these differences in experiences presented a challenge in communicating the results of this study whilst including quotes which reflected the experiences of the unemployed majority and women in employment. I reflected upon how the accounts of un-employed participants appeared more emotive compared to those in employment, and how this focused my attention onto Marie's account and interpreting her seemingly calm reactions to the PIP process. This prompted me to return to the data and notice a pull to dedicate more space to interpreting Marie's account and how it differed to the other participants. Recognising this urge, I worked with the research team to ensure that I gave equal attention and coverage to each participant's account and highlighted divergent narratives throughout the analysis.

Appendix B: Summary of PIP Pathway

Figure 1

Summary of PIP Pathway
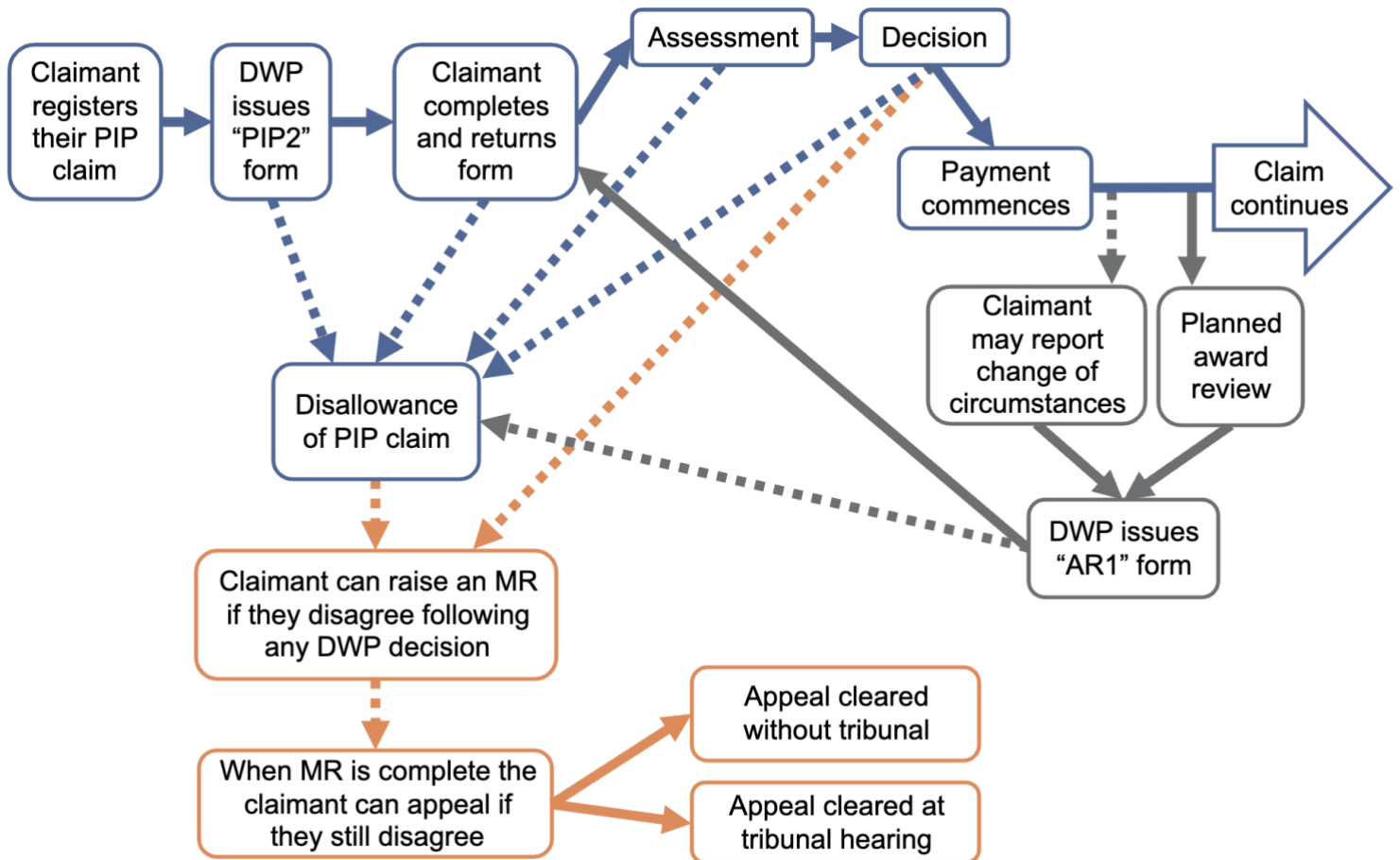
From "Guidance: PIP statistics: background quality and methodology report.", by Department for Work and Pensions, 2024. (https://www.gov.uk/government/publications/personal-independence-payment-statistics-background-and-methodology/pip-statistics-background-quality-and-methodology-report).

Appendix C: Overview of Studies Included in the Systematic Review

Table 14

Summary of Systematic Review Studies

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
Clifton et al. (2013)	The age of austerity: the impact of welfare reform on people in the North East of England	To explore what impact welfare reforms are having on people in the North East of England.	England	Data collection: questionnaire and focus group. Data analysis: Method not reported.	Fifteen mental health service users.	Not reported. Research introduction focuses on introduction of WCA and ESA.	Three themes were reported: -The current system is un-accessible and non-inclusive for us -The system makes us more ill -The system makes us poorer financially	+Collaboration between researchers and mental health services users. +Use of data triangulation by two methods of data collection. -A lack of detail on data analysis and data collection limits the credibility and transparency of this study. - No reflection on the impact of collaborative relationships between researchers and service users.
Dwyer et al. (2020)	Work, welfare, and wellbeing: The impacts of welfare conditionality on people with mental health impairments in the UK	To explore: 1. How do UK claimants with mental health issues experience the process of claiming and	England and Scotland	Data collection: Semi-structured interviews; repeated within three waves.	207 working-age benefit claimants who self-identified as having a mental health condition	Participants claiming ESA, JSA or UC dependent upon most recent WCA outcome	Report did not give an overarching theme structure. Participants experienced the	+ Repeated interview design elucidates longitudinal impacts. - Lack of clarity in analysis (i.e., description of methodology and reporting themes) undermines credibility of findings. -No discussion of managing

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
		maintaining social security benefits? 2. How does the conditionality inherent within the UK's benefit system impact on their mental health?[9]		Datal analysis: A "top–down" coding schema and framework matrix and "bottom–up" thematic analysis of a subset of transcripts.	(e.g. depression, anxiety, schizophrenia, OCD, psychosis and PTSD).		WCA as an "uncaring and insensitive process that appeared to lead to inappropriate decisions" regarding fitness to work. Participants who attended a WCA described assessors questioning the nature and impact of mental health difficulties. Participants described increased mental distress triggered by attending assessment, appeals and an ever-present	participant distress, which is referenced in the paper.

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[9] Only data pertinent to the first aim was included within the SLR.

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
							threat of a sanction exacerbates existing anxieties and illness, undermining mental health support.	
Greener and Moth (2020)	From shame to blame: institutionalising oppression through the moralisation of mental distress in austerity England	To examine the shifting institutional arrangements which assign sick roles, incapacity and benefits/services for those living with mental distress in austerity Britain.	England	Data collection: Semi-structured interviews and focus groups Data analysis: Thematic analysis	13 participants: six focus groups and three individual interviews. All participants had longer term contact (more than 4 years) with mental health services.	Participants were claimants of employment or disability benefits (DLA, PIP or ESA).	Three main themes were reported: - Delegitimisation of mental distress - Self-help and self-management - Punitive conditionality	+Reflection on rich data provided by repeated focus group design. + Provides a clear discussion of results and links to systemic implications. - Lack of rationale and clarity in analysis undermines credibility of results. - No reflection on low uptake of interviews and who chose to participate via focus group.
Hansford et al. (2019)	The impact of the Work Capability Assessment on mental health: claimants' lived experiences and GP	To explore how the WCA process, and moral narratives surrounding its	South West England	Data collection: Focus groups and semi-	16 focus groups (n=97; 18-65 years old; 36 men and 61 women	Participants who discussed the WCA and subsequent	Four themes were reported: - Assessors' understanding of mental health	+Triangulation of data across primary sources (claimants and GPs). + Thoughtful recruitment pathways and inclusion of

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
	perspectives in low-income communities	implementation, impact the mental wellbeing of claimants		structured interviews Data analysis: Grounded theory	experiencing 'poverty-related distress'.) Semi-structured interviews (n=57; 18-65 years old; 26 men and 31 women) with experience of mental distress. Interviews with GPs (n=10).	impact within interviews (22/57 interview participants) and focus groups (7/16 focus groups).	conditions and the suitability of assessment - Conflict between WCA decisions and the advice of other healthcare professionals - Needing support to comply with process - Re-traumatization, shame, and alienation from support.	project advisory board and member checking increase credibility of findings. - Lack of discussion of wider ethical considerations (i.e., informed consent and reducing potential distress).
Lowe and DeVerteuil (2020)	Austerity Britain, poverty management and the missing geographies of mental health	To explore 'missing geographies' that welfare restructuring may create, and the impacts upon mental well-being.	London, UK	Data collection: Semi-structured interviews Data analysis: No description	25 participants: 15 below pension age 11 men and 14 women who self-identified as having a 'mental illness'	Of those below pension age: ESA/IB (=13) JSA (n=2) DLA/PIP (n=18)	Two themes were reported: - Benefits reform as re-assessment: Service users' experiences of well-being	+ Gathered data from multiple perspectives (claimants and welfare advisors). +Longitudinal design allows depth and temporality to findings. - Findings credibility undermined by lack of

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
					21 participants had engaged with mental health services and received a formal diagnosis. Interviews with mental health service providers (n=5).		- The missing geographies of benefits reform: Impositions and dismissals	description of analysis and no discussion of impact of fewer interviews. - Unclear whether participants were in process of claims, and how this may have impacted management of potential distress.
Machin and McCormack (2021)	The impact of the transition to Personal Independence Payment on claimants with mental health problems	To explore the impact of the transition from DLA to PIP on claimants with mental health problems	West Midlands, England	Data collection: Semi-structured interviews Data analysis: Thematic analysis	Twelve participants (7 men; 5 women) who self-identified as having mental health problems. All White British and over 35 years old.	All participants had migrated from DLA to PIP. None had award removed during transition from DLA to PIP.	Three themes were reported: - Problems with the Personal Independence Payment claims process - Problems conveying mental health problems during the assessment process - Positive experiences associated with	+ Clarity in method description and considers impact of recruitment pathways and participant demographics on results. + Clarity in analysis description and credibility from cross-checking by research team. - No description of researcher reflexivity - Missing description of interview schedule -Unclear how soon after migration data was collected

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
							the transition to Personal Independence Payment	and implications for client distress
Mattheys et al. (2018)	"Treading in sand": A qualitative study of the impact of austerity on inequalities in mental health	To explore the effects of austerity measures since 2010 on inequalities in mental health in Northeast of England (including personal experiences of the benefits system).	North-East England	Data collection: Semi-structured interviews Data analysis: Thematic analysis	Twenty-eight participants: 17 claimants with self-reported longstanding mental health problems (10 women and 7 men). Five participants were recruited from the most and seven from the least deprived areas of locality. Five participants recruited from Citizen's	Benefits: JSA = 3 ESA/IB = 6 DLA/PIP = 4 In paid employment or retired = 8.	. Two themes were reported: -The Daily Struggle? Financial (in)security and the impact on mental health - Keeping people in distress: the disproportionat e impact of austerity	+ Design allows for comparison of how relative deprivation interacts with welfare reform to undermine mental health. - Lack of detail about analysis undermines credibility of findings.

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
					Advice benefits clinic. And eleven stakeholders from community organisations			
Ploetner et al. (2019)	Understanding and improving the experience of claiming social security for mental health problems in the west of Scotland: A participatory social welfare study	To examine the extent to which the austerity ailments conceptual framework (McGrath et al., 2015) extent to captures the experiences of people with mental health problems who are currently claiming benefits.	Scotland	Data collection: Focus groups Data analysis: Framework analysis in comparison to austerity ailments framework (McGrath et al., 2015).	Twenty-three participants (11 women; 12 men).	All participants had 'claimed social security benefits for a mental health problem'.	Five themes were reported: -Humiliation and shame -Fear and distrust -Instability and insecurity -Isolation and loneliness -Powerlessness and being trapped -Need for support -Experiences of social stigma -Suggestions for improvement	+Participatory design and reflection on researcher relationship +Clarity of design and multiple coders lend credibility to findings - No reflection on who may have declined to take part and the possible impact on results.

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
Porter et al. (2021)	Evidence, objectivity and welfare reform: a qualitative study of disability benefit assessments	To examine the impact of reforms made to UK disability benefits assessments in the name of objectivity, both for disabled people accessing benefits, and in terms of the trustworthiness of assessments.	United Kingdom	Data collection: Semi-structured interviews Data analysis: Thematic analysis	Fifty participants (25 women; 25 men). Six British Asians, 42 White Britis, one mixed race participant and one White non-British participant. Aged 21-65 years old. Mixed sample of participants with physical, mental health, sensory impairments or learning disabilities.	All participants had applied for disability benefits (ESA/UC or PIP) within the previous 3 years.	Four themes were reported: -Claim forms: standardised efficiency over health and selfhood - Face-to-face assessments and the human cost of disinterestednes s - Personalised medical evidence marginalised - Procedural objectivity: barrier to trustworthy assessments and a lever of inequality	+Considers intersectionality and social resources within claimant sample. + Multiple coders and use of quotations increases credibility of findings. -Minimal detail reported in relation to wider ethical implications and no reflexivity on researcher-participant relationship.
Pybus et al. (2021)	Functional assessments in the UK social security system: the experiences of claimants with mental health conditions	To explore the experience and the impact of functional eligibility assessments on	England	Data collection: Semi-structured interviews	Eighteen participants (10 men; 8 women) with self-reported mental health	Claimants currently in receipt of ESA, UC and/or PIP	Three themes reported: -Claimant journeys -Assessing eligibility	+ Specific view of health assessments. + Highlighted specific risk to MH claimants as process exacerbates existing difficulties

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
		claimants with mental health conditions.		Data analysis: Thematic analysis	conditions (e.g. anxiety, depression, psychosis and PTSD.	Eleven participants had been turned down for one or more benefits	-Support	and low access to specialist supporting info. +Careful consideration of recruitment within the community. - The ethics and potential impact of conducting interviews in a public settings not discussed. - Recruitment within community support organisations, and given that most participants received benefit, may not reflect experiences of those not in contact with organisations or those with severe MH difficulties.
Roberts et al. (2022)	'It's Like the Sword of Damocles'–A Trauma-Informed Framework Analysis of Individuals' Experiences of Assessment for the Personal Independence Payment Benefit in the UK	To understand to what extent participants' experiences of PIP assessment fit the principles of trauma informed care principals as outlined by NHS Education for	Scotland	Data collection: Semi-structured interviews Data analysis: Framework analysis in comparison to the Scottish	Twelve participants (4 men; 8 women) receiving psychological therapy, for post-traumatic difficulties, from community	Participants had been assessed for PIP within the preceding three years.	Five core themes reported (subthemes in italics): -Harm: *Anxiety, distress, adverse impact on mental health, humiliation.*	+Clear comparison established trauma informed care framework to explore claimants' experiences of traumatization. - Lack of detail on interviews (guide, use of trauma-informed principals and managing potential distress). -The vast number of subthemes leads to thin descriptions and

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
		Scotland (NES, 2019).		Psychological Trauma Training Plan (NHS Education for Scotland, 2019) and thematic analysis.	mental health services. Aged 20-62 years old.		-Distrust: *Lack of transparency, not feeling believed, distrust of other claimants, distrust of system, distrust of assessor.* -Rigidity: *Inaccessibility, inflexibility, tick-box exercise, robotic assessor.* -Intimidation: *Threat, surveillance, the dreaded brown envelope, austere environment, feeling on trial, hostile dynamic with assessor.* -Powerlessness: *Lack of control, rigged game, dehumanisation, intrusive*	limited quotes throughout the paper.

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
							questions, getting help from professionals.	
Scullion and Curchin (2022)	Examining Veterans' Interactions with the UK Social Security System through a Trauma-Informed Lens	To explore veterans' experiences of social security, with specific reference to the Work Capability Assessment (WCA) and conditionality within the UK benefits system.	England	Data collection: Two waves of semi-structured interviews with veterans; focus groups with stakeholders. Data analysis: Thematic analysis	Forty-seven veterans with self-reported mental health difficulties (Male 46; Female 1)	Claiming either: ESA (27) UC (15) or JSA (2).	Two themes reported: - Re-traumatisation? Veterans' experiences of the Work Capability Assessment - Trauma-blind? Conditionality, the Claimant Commitment and interactions with Jobcentre staff	+First study to relate the principals of trauma focused care theory to welfare system. +Data collection designed to increase credibility through longitudinal data collection with participants and triangulation with stakeholder accounts. - A lack of detailed description of the analysis undermines the study's rigour and credibility of results.
Shefer et al. (2016)	Only Making Things Worse: A Qualitative Study of the Impact of Wrongly Removing Disability Benefits from People with Mental Illness	To investigate the impact of removal or reduction of disability benefits on disability benefit	London, England	Data collection: Semi-structured interviews as part of larger mixed	Seventeen people (Female: 10; male: 7). Reported ethnicity (10 White British;	Recipients of benefits advice support from local branch of Mind due to removal	Three main themes were reported: - The impact of reduced income -The stress involved with	+Clear description of methodology, participants and data analysis increases the credibility of results.

Author (year)	Title	Study purpose	Setting	Methodology	Participants	Benefits status	Key Findings	Strengths and limitations
		recipients (whose disability was related to mental health) and won their appeal.		methods study (only qualitative reported in paper). Data analysis: Thematic analysis	2 Black British; 1 Black Carribean; 2 South Asian; 1 Polish)	of existing ESA/IB or appeal following a new assessment. All participants had their ESA or IB reinstated at appeal.	being trapped in cycle of assessments, rejections, and appeals -The invisibility of disability and the anger about being mistrusted.	+First paper to specifically explore the impact of benefit removal -No discussion of who opted to participate and any impact on the results. -No reflection on credibility or strengths of study.

Appendix D: Summary of Critical Appraisal Skills Programme evaluation of systematic

review papers

Papers were evaluated based on CASP guidance (CASP, 2018) and scoring descriptors

provided by Long et al. (2020). 'Yes' was selected when sufficient information was provided

to fufil CASP criteria. 'Can't tell' was selected when a conclusion could not be reached

between 'yes' and 'no' due to insufficient information (i.e. a reporting issue). 'Somewhat'

was used when there was information that highlighted both strengths and limitations (i.e.

methodological issue

Table 15

Summary of CASP outcomes for Systematic Review Studies

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Clifton et al. (2013)	Y	Y	Y	Y	Can't tell	N	Somewhat	Can't tell	Y	Illustrates collaborative research between researchers and mental health services users. Some limitations.
Dwyer et al. (2020)	Y	Y	Y	Y	Y	Can't tell	Somewhat	Can't tell	Somewhat	Contributes to literature on the impact of WCA, subsequent conditions placed upon claimants and demonstrates impact over several years.

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Greener and Moth (2020)	Y	Y	Y	Y	Can't tell	Can't tell	Can't tell	Can't tell	Somewhat	Provides novel insight into dynamics within mental health and welfare systems: delegitimisation of distress; increasing punitive and conditional assessment and new models of self-management.
Hansford et al. (2019)	Y	Y	Y	Y	Y	Can't tell	Can't tell	Y	Y	Provides detail and insight into lived experience of WCA and mechanisms of how this leads to increased mental distress. Unique finding: hopelessness and shame linked to WCA resulted in people retreating

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
										from other healthcare and support services (e.g. GP). Insight from GP perspectives around increasing role to minimise negative consequences of benefit system reforms.
Lowe and DeVerteuil (2020)	Y	Y	Y	Y	Y	Can't tell	Can't tell	Can't tell	Somewhat	Combines insight from claimants across time and welfare rights advisors. Specifically focused on re-assessment period and draws on concept of 'missing geographies' of

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Machin and McCormack (2021)	Y	Y	Y	Y	Y	Can't tell	Y	Y	Y	daily living and coping. Transition to PIP specific. Reclassification of disability and impact on claimants' identity.
Mattheys et al. (2018)	Y	Y	Y	Y	Y	Can't tell	Y	Somewhat	Somewhat	Comparison o impact of austerity and welfare reform between people with MH needs in most and least deprived areas.how factors related to deprivation impact alongside welfare reform impact people with pre-existing MH.

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Ploetner et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Participatory design. Explored validity of Austerity ailments framework and builds upon it. By highlighting relevance of social stigma and need for support navigating the benefits system.
Porter et al. (2021)	Y	Y	Y	Y	Y	Can't tell	Can't tell	Y	Y	Explicitly discusses impact of social and financial resources on claims. Questions epistemological assumptions underpinning benefit reform. Welfare reform made in the name of procedural

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Pybus et al. (2021)	Y	Y	Y	Y	Y	Somewhat	Somewhat	Y	Y	objectivity appear to increase inequality with claimants with fewer resources (social/economic) least likely to succeed. Eligibility assessment specific. Limited opportunity to discuss impact of MH on functioning and asked to recount traumatic experiences as evidence. Highlighted role of healthcare professional support to manage claim and impact on MH.

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Roberts et al. (2022)	Y	Y	Y	Somewhat	Can't tell	Can't tell	Y	Somewhat	Y	Contributes directly to clinicians work with traumatised individuals and gives framework for reforming systems.
Scullion and Curchin (2022)	Y	Y	Y	Y	Y	Can't tell	Somewhat	Somewhat	Somewhat	Identifies impact of 'trauma blind' system in retraumatising
Shefer et al. (2016)	Y	Y	Y	Y	Y	Can't tell	Can't tell	Somewhat	Y	First study to specifically focus on claimants with MH difficulties experiences of benefits being withheld.

Appendix E: Evolution of the Research Question

Stage	Process
Moving from General Disability Benefits to PIP	The initial research question focused on autistic people's experiences of applying for Personal Independence Payments (PIP). The research team decided to concentrate on autistic people's experiences of Personal Independence Payment (PIP) instead of a variety of disability-related benefits, after considering the homogeneity of sampling within the broader benefits literature and the possibility of excluding people in employment if the focus was on Employment and Support Allowance.
Moving from Autistic People to Late-Diagnosed Autistic Women	We considered narrowing the inclusion and exclusion criteria to sample along gender or age at diagnosis, given the potential impact of these on both the experiences of autistic people and autistic identity development. However, Heselton et al. (2021) noted tensions between conducting IPA research and engaging the autistic community, as attempting to achieve a homogenous sample through limiting recruitment to people diagnosed in adulthood led to the autistic community feeling rejected. Moreover, the researchers described no substantial differences in the experiences of participants diagnosed as children and those diagnosed in adulthood. Similarly, Corden et al. (2021) noted that the number of years since diagnosis (not age at diagnosis) was associated with people's level of dis/satisfaction with being autistic. Following discussion, the research team decided against narrowing inclusion criteria and agreed that sampling based upon a specific phenomenon (i.e. applying for PIP) would be sufficiently homogenous for the needs of Interpretative Phenomenological Analysis. Regardless of the broad inclusion criteria, all participants in this research were autistic women who received their diagnosis in adulthood. Therefore, the research question was altered to reflect the homogeneity of the available participant sample.

Appendix F: Ethical Approval and Ethics Amendment[10]

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Georgina Turff
CC	Dr Lizette Nolte
FROM	Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair
DATE	31/05/2022

Protocol number: **LMS/PGR/UH/04977**

Title of study: Autistic adults' experiences of applying for Personal Independence Payment

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Nina Viljoen (external secondary supervisor) – UH visiting lecturer

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 31/05/2022

To: 30/08/2022

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[10] Ethical amendment to extend data collection timeframe.

University of Hertfordshire **UH**

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Georgina Turff
CC	Dr Lizette Nolte
FROM	Dr Rebecca Knight, Health, Science, Engineering 7 Technology ECDA Vice Chair
DATE	06/10/2022

Protocol number: **acLMS/PGR/UH/04977(1)**

Title of study: Autistic adults' experiences of applying for Personal Independence Payment

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Nina Viljoen (external secondary supervisor) – UH visiting lecturer

Modification: Detailed in EC2.

Conditions of approval specific to your study:

Ethics approval has been granted subject to the following conditions being seen and approved by the supervisor as addressed prior to recruitment and data collection:

- ☐ Please include the protocol number on the advert.
- ☐ Permissions to use external sites (e.g. Reddit) need to be sought before advertising on them.

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

<u>Original protocol</u>**:** Any conditions relating to the original protocol approval remain and must be complied with.

<u>Permissions</u>: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

<u>External communications</u>: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Appendix G: Participant Information Sheet

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC6: PARTICIPANT INFORMATION SHEET

Autistic adults' experiences of applying for Personal Independence Payment

Dear XXXX,

Thank you for your interest in participating in this study. This sheet is to give you the information about the study and what your involvement would include. Please take the time to read the following information carefully and take your time to decide whether you would like to take part. Do not hesitate to contact me via email if anything that is not clear or for any further information you would like to help you make your decision.

The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:
https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation).

What is the purpose of this study?
My name is Georgina Turff; I am a third year Trainee Clinical Psychologist at the University of Hertfordshire. As part of my training, I am completing a research project. My professional and personal experiences have made me interested in the experiences of autistic people within the benefits system, such as applying for Personal Independence Payment (PIP).

There is a growing collection of research examining how changes to the benefits system affect people's emotional wellbeing and sense of identity. Many of these studies have interviewed people with 'invisible' conditions which affect their lives; however, there is little research into the experiences of neurodiverse people. This research aims to better understand the experience of autistic people who have applied for PIP. I am hoping to interview 6-8 people to explore what the experience of PIP has been like, including the impact on people's wellbeing.

This study has no links to the Department of Work and Pensions.

Why have I been invited?
You have been invited as you are an autistic person, who has had experience of applying for PIP within the last 3 years. You may have expressed interest after speaking to someone you know or saw a post on social media advertising the study. You responded to the contact details provided and as such have been sent this information sheet.

University of Hertfordshire **UH** Ethics Committee

Do I have to take part?

No, it is completely up to you whether or not you decide to take part in this study. If you choose to participate, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a specific reason. A decision to withdraw at any time, or a decision not to take part at all, will not disadvantage you in any way.

Once the interview has been completed you can withdraw your interview up to four weeks after our meeting, this is because once I begin analysing the data it becomes difficult to identify and extract specific interviews. All identifying information will be anonymised. Once the research is written up there may be direct quotes, but these will not be identifiable to others.

Are there any age or other restrictions that may prevent me from participating?

You must be over 18 years old and have a diagnosis of Autistic Spectrum Condition/Asperger's to take part. You will be asked confirm this diagnosis via providing a photograph or scan of the front page of the diagnostic report (if possible). It is OK if you cannot find your diagnostic report – please let me know and we can decide together the best way to confirm these details.

You must have applied for PIP within the last 3 years and discussed Autistic Spectrum Condition as part of your application process. I understand that the application process can be distressing and difficult to talk about, therefore ask that you are not currently in the process of applying when taking part in this research.

How long will my part in the study take?

If you decide to take part in this study, I will invite you to an interview. This will take approximately 60 minutes. It may be longer or shorter depending upon how much you want to talk.

What will happen to me if I take part?

☐ If you would like to participate in this study after reading this information sheet, you need to contact me. I will send you a participant consent form to complete.

☐ I will also ask you to complete a basic demographics form about yourself, including gender, age, any relevant diagnoses, preferred contact method and anything that will make it easier for you to participate in the interview (e.g. taking regular breaks).

☐ I will ask you to send a photo or scan of the front page of your diagnostic report. I will keep your information safe by deleting the file immediately after I have read it.

☐ I will contact you via your preferred contact method and arrange an interview with you. The interview could be via telephone, instant messenger or videocall (i.e. Skype) with video or just audio. You will need a either phone, laptop, iPad and Wi-Fi to take part.

☐ An outline of the interview questions could be sent to you before the interview if that would help you.

☐ During the interview, I will ask questions about your experience of applying for PIP, your thoughts and feelings about the process and its impact on you.

☐ It is possible to conduct the interview over more than one session if the interview time is too long for you.

University of Hertfordshire UH Ethics Committee

- After the interview I will ask you whether you would like to be contacted to comment on the research findings or to be involved in any creative projects to share the study findings with other people.
- I will contact you a week after the interview to check if you have any further comments to add.
- I will offer you the option to review the themes from the interview after I have analysed the data. This would help the study team to know whether the analysis reflects your experiences. You can decide whether you want to provide this feedback or not. This would entail a final meeting or email contact several weeks after the initial interview.

What are the possible disadvantages to taking part?

You will be asked to take part in a relatively long interview and asked to share and reflect life experiences that are personal to you. This can be distressing for some people. It is important that you find a quiet place to have our conversation so that you feel as comfortable as possible.

Although it is very helpful to hear about some of these difficult life experiences for this study, you have the choice to decide not to talk about anything that you find too difficult to share or reflect on. There will be time at the end of our conversation to talk about how you have found talking about your experiences and I will be happy to speak to you about where to seek support if you do feel distressed.

What are the possible benefits of taking part?

There are no direct benefits of taking part in this project; however, it might allow you to think and talk about your experiences. Given the lack of research on this topic, it is hoped that the findings contribute to current understanding and have a positive impact upon wider policy and support for autistic applicants.

How will my taking part in this study be kept confidential?

The following precautions will be in place to keep your information and participation in this study confidential:

- All person-identifiable (i.e. names, specific service names and geographical references) will be changed in agreement with you, to ensure your confidentiality. All data will be anonymised with numbered IDs, which will subsequently be replace by a pseudonym of your choice for write up and future publications.
- I would like to audio-record interviews with your permission so that they can be typed up and analysed. We will be looking at themes within the interviews. Audio-recordings will be password protected and deleted after transcription. Only I will have access to these files. The interviews will be kept strictly confidential.
- It is possible that I may be required to use an approved transcription service to transcribe your interview if there is not time for me to transcribe it myself. Recordings will be labelled to protect your identity and the service will be required to sign a non-disclosure confidentiality agreement.
- Storing all identifiable data (including consent forms, demographics forms and interview data) securely in password protected files on the University of Hertfordshire OneDrive. This will be stored separately from any interview recordings.
- As part of the research process, some data collected may be looked at by authorised individuals from the University of Hertfordshire, this may include the sharing of anonymised transcripts with other trainee clinical psychologists conducting research at the University of Hertfordshire. To ensure the quality of the research, anonymised sections of the data might be viewed by academic and professional assessment bodies. Any

University of
Hertfordshire **UH** Ethics
Committee

individuals who have access to this anonymised data will have a duty of confidentiality to yourself as a research participant.

What will happen to the data collected within this study?
The data collected will be stored electronically, in a password-protected environment, for 10 years, after which time it will be destroyed under secure conditions. We will analyse themes within the interview data and present these in a doctoral thesis. The findings may also be published in an academic journal. This may include some direct, anonymized quotes from participants.

Will the data be required for use in further studies?
You can decide whether your interview data can be used again in future studies. Anonymised transcripts from this study may be re-analysed as part of future research at the University of Hertfordshire. You can indicate on the consent form whether you want your data to be used in this way.

Who has reviewed this study?
The University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee with Delegated Authority. The UH protocol number is LMS/PGR/UH/04977

Factors that might put others at risk
Please note that if, during the study, you disclose any information that makes me believe that you or others are at immediate risk, I may need to share this information with relevant organisations. In some cases, this may mean that you would be withdrawn from the study. I will always share my actions and decisions with you where possible.

Who can I contact if I have any questions?
If you would like further information or would like to discuss any details personally, please get in touch with me by email:
Georgina Turff: g.turff2@herts.ac.uk

If you do not feel comfortable contacting me, then please contact my supervisor on the details below.

What next?
If you are interested in participating in the study, please complete the reply slip provided below and return to me (Georgina Turff) by email (g.turff2@herts.ac.uk).

Thanks again for taking the time to read this information.

Best wishes,
Georgina Turff
Trainee Clinical Psychologist

Supervisor: Dr Lizette Nolte
Clinical Psychologist
L.Nolte@herts.ac.uk

Form EC6, 12 February 2020

Appendix H: Participant Consent Form

University of Hertfordshire UH Ethics Committee

Informed consent form for participants of project:

Autistic adults' experiences of applying for Personal Independence Payment

Please read the information sheet before completing this consent form.

Please retain a copy of both the information sheet and this completed consent form for future reference.

Study Title:
Autistic adults' experiences of applying for Personal Independence Payment.

Department:
School of Life and Medical Sciences, Doctorate of Clinical Psychology, University of Hertfordshire.

Name and Contact Details of Principal Researcher:
Georgina Turff, Trainee Clinical Psychologist, University of Hertfordshire
g.turff2@herts.ac.uk

Details of Researchers involved:
Dr Lizette Nolte, Research Lead for Doctorate of Clinical Psychology, University of Hertfordshire

Dr Nina Viljoen, Clinical Psychologist, Hertfordshire Partnership University NHS Foundation Trust

Approval for research:
This research is approved by UH Research Ethics Committee.
Ethics Approval Number: LMS/PGR/UH/04977

		Tick Box
1.	I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.	

Form EC3 – 26 May 2021

University of Hertfordshire UH Ethics Committee

2.	I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.	
3.	In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place and I have been informed of how this recording will be transmitted.	
4.	I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to myself. In signing this consent form I accept that support might be sought for me, should circumstances require this.	
5.	I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.	
6.	I understand that my participation in this study may reveal findings that could indicate that I may require medical or mental health advice. In that event, I will be informed and advised to consult relevant third parties such as my GP.	
7.	I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.	
8.	I have been told that I may at some time in the future be contacted again in connection with this or another study.	
9.	I understand that anonymised transcripts may be used for future research. Please tick if you consent to your data being used in this way.	

I, the undersigned *[please give your name here]*

……..

of *[please give contact details here (e.g. email address or phone number]*

……

hereby freely agree to take part in the study entitled
Autistic adults' experiences of applying for Personal Independence Payment. (UH Protocol number: LMS/PGR/UH/04977)

Signature of participant……………………………………...…   Date…………………………

Signature of (principal) investigator………………………   Date…………………………

Name of (principal) investigator….…………………………………

Form EC3 – 26 May 2021

Appendix I: Transcriber Confidentiality Agreement

Non-Disclosure Agreement with Transcription Company

This non-disclosure agreement is in reference to the following parties:

Georgina Turff (discloser)

and

Kate MacFarlane (transcriber)

- The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.
- If the recipient is able to identify and knows the participant in the recording, the recipient agrees to cease transcription, inform the disclosure and destroy any copies of the recording.
- The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.
- The recipient agrees to return and/or destroy any copies of the recordings they were able to access provided by the discloser.

TRANSCRIBER TO COMPLETE:

SIGNED: *Kate MacFar*

NAME: KATE MACFARLANE

DATE: 17 JULY 2022

University of Hertfordshire **UH** Ethics Committee

This is an official notification by student of the University of Hertfordshire in respect of a study involving human participants.

Title of study: **Autistic adults' experiences of applying for Personal Independence Payment**
Protocol Number: LMS/PGR/UH/04977
Approving Committee: Health, Science, Engineering & Technology ECDA

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

If you have any queries concerning this document, please contact me: Georgina Turff, Trainee Clinical Psychologist, mobile: 07925371822, email: g.turff2@herts.ac.uk or my supervisor. Dr Lizette Nolte, Research Lead, email: L.Nolte@herts.ac.uk

Appendix J: Pre-Interview Survey

Pre-interview survey

1. What is your name?
   _____

2. Which terms do you prefer to use in relation to autism?
   e.g. autistic, person on the spectrum, person with autism, neurodiverse or a
   different term.

   _____

3. This study is looking at the experiences of people with an autism diagnosis. Please
   indicate when you received your diagnosis and which service or clinician you saw for
   assessment:

   _____

4. We are interested in hearing the experiences of people who have applied for PIP.
   Please indicate (approximately) when you last went through the application and
   assessment process for PIP:

   _____

5. If you decide to participate in this study, which of the following is the best way to
   meet to ask you about your experiences?
   i)   Video-call (e.g. MS teams, Skype) interview (you can choose video or just audio
        call). Please indicate your preference: a) video and audio   b) audio only
   ii) Telephone interview
   iii) Online messaging (e.g. using chat feature on Zoom with no video or audio)

6. If you choose to take part in an interview, what would be helpful to make it
   comfortable?
   a) Reviewing the interview questions in writing ahead of time
   b) Reviewing the interview questions via audio recording ahead of time
   c) Having the questions available in writing at the interview
   d) Multiple shorter interviews
   e) Regular breaks
   f) A 15-minute "getting to know you" pre-interview conversation via phone or
      video-call
   g) Other: _____

7. If you chose to take part, what is the best time of day to speak to you?
   (a) Morning
   (b) Afternoon
   (c) Evening
   (d) No preference

8. If you chose to take part, is there a better time during the week to speak with you?
   a) Yes, on these days: _____
   b) No, I can be flexible.

9. Is there anything else that I can do to make participation more comfortable and accessible for you?
   _____

10. What is the best way to contact you to arrange an interview?
    Please provide details below:
    _____

Appendix K: Interview Schedule

Title of study:
Exploring autistic adults' experiences of applying for Personal Independence Payment

Pre-questions introduction:
- Introduction to me as researcher and my motivations for the research.
- How are you feeling about the interview?
- Interview topics covered: your experience of applying for benefits, how you felt, the impact on your life and how you feel about yourself.
- Will ask questions but will also be led by what feels important to them to discuss.
- No right or wrong answers – interested in their experience and views.
- Interview like a one-sided conversation. I will say little and some Qs seem self-evident but useful in understanding how you see things.
- Take time to think and respond.
- Not obliged to answer if uncomfortable.
- Length approx.. 60-80 minutes.
- Breaks in interview at any time. How will I know if they need a break?
- I will take responsibility for managing time
- Right to withdraw
- Recording consent
- Confidentiality/storage of recording

Introductory questions:

1. **Can you tell me a little about yourself and any conditions/disability you live with?**
   Prompt:
   I wonder whether there was a particular reason why you wanted to
   take part in this research?

2. **What does [autism term] mean to you?**
   Prompt:
   How do you define it?
   Do you see yourself as autistic, having ASD, a condition or neurodivergent?

3. **Can you tell me when you applied for PIP and why did you apply?**
   Prompt:
   What was happening in your life before you applied for PIP?
   Were there things in your life that you were struggling with?
   Had you applied to any disability benefits in the past?

4. **What was your experience during the application process?**
   a. Of the forms?

    b. Of the interview process?
    c. What was the outcome?
    d. Did you go to Mandatory Reconsiderations, Appeal or Tribunal?

Prompts:
How did you feel? [refer to feelings wheel]
Why?
What did you think?
Sometimes people say they feel: Sad, Angry, Happy, Numb, Excited, Tired, Anxious
Some people might think: This is taking for ever, this is really hard, that was easy,
why do I have to go through this process…
Is this right or is it something else?
How did your body feel?
How did you feel about yourself?

5. **How do you think being autistic impact on your experience of applying for PIP?**
    Prompts:
    Where there any parts that felt particularly stressful/not stressful?
    Why?

6. **To what extent did COVID-19 impact on your experiences?**

7. **How were you with the outcome after you had received it?**
    Prompts:
    What did you think about the outcome?
    How did you feel about yourself?
    How did you feel (emotionally, mentally)?
    Why?
    What did you do?

Questions about wellbeing and identity:

8. **How did the application process affect your everyday life?**
    Prompts:
    practical / daily functioning
    physical health and mental health,
    relationships with friends and family,
    socialising / hobbies,
    ability to engage in local community,
    ability to work/ study/ volunteer,

    Anything else?
    Can you give an example of that?

9. **How would you describe yourself as a person?**
    Prompts:

What sort of person are you?
What would you say are your main characteristics?

10. Did the PIP process affect/change how you see yourself?
    Prompt:
    If so, how do you see yourself now as different from before the application?

11. Did going through the application process change how you feel about [preferred ASD term]?
    Prompt:
    How did you feel before?
    How has it changed?
    How did it change/ or not change?

12. Did the benefits process change how other people feel about you?
    Prompts:
    Friends, family, people who don't know you /society, media (TV, radio, social media).
    How?
    Can you give an example of that?

General prompts:
    How did you understand that?
    How do you make sense of that now?
    And what did you think about that? At the time and now?
    Can you tell me a little more about that?
    Can you give me an example of that?

Appendix L: Annotated Transcript

Original transcript	Exploratory notes	Experiential statements
I: Goodness, can you tell me more about the worry. What was the impact? P: Well it just made me more anxious than I already am all the time anyway. And that made it more difficult for me to fill in the form, and to do other life tasks. It just reduces my capacity in general. I: So you were facing worry about the form, which then impacted your ability to complete the form. What sort of impact did it have on those other life tasks? P: It made my executive functioning skills even worse. So it's lucky I didn't have anything to go to at the time (because of coronavirus), as I wouldn't have been able to organise my normal life tasks as well. But even daily household tasks, such as washing up; it felt like there was no room in my brain to even do things like that,	Worries increased anxiety on top of background of anxiety. Anxiety reduced capacity to fill in the form – cyclical nature of lack of adaptation reducing capacity to do task. [Mental image of Ouroboros – the snake that eats itself] [Worry] made my executive functioning skills even worse. 'lucky' that during covid as I wouldn't have been able to organise my normal life – lucky that responsibilities lessened but ?also removed coping/distractions? 'it felt like there was no room in my brain even to do things' – trapped, overwhelmed?	The increasing weight of worry impacts filling in the form The struggle of daily life: no room in my brain

P: Well I find uncertainty very difficult. So it's not just now that the outcome is still uncertain. But also how long it will take to resolve. And this is hanging over me all the time, again interfering with my daily life. P: I don't mean now, now. I meant at that time, now. I: You told me a bit about how the form impacted daily life, how did the impact after the interview compare?	Uncertainty; very difficult. Initial uncertainty of outcome is added to uncertainty of how long until a resolution. Shift to present tense in language – part stuck in that time and feeling? Never ending? 'Hanging over me all the time' – Looming, inescapable feeling of doom [Sword of Damocles metaphor from recent paper]	The perpetual uncertainty hanging over me
P: Well similar I suppose. As then I had to write an MR letter, and organise asking for one from the [local organisation] woman too, and sending it. But at least this time I had details of why they had refused it in the letter, so I could respond to those points specifically. So maybe not quite as bad an impact as the form itself. But then it had been dragging on for quite a while by then, so the impact was cumulative as well.	Details of why refused allowed more structured response. 'at least' – feeling of improvement from no communication before, increased specificity 'Dragging on' – a never ending/drawn out process. [dragging a weight? like Sisyphus and his boulder?]	Specificity of letter gave a second chance to express needs

I: Through all this process, how were you feeling about yourself? P: Like I wasn't worth anything to these people. Like they value getting paid their wages and jumping through the hoops more than who is on the other end of the forms.	I wasn't worth anything to these people. These people – the amorphous/disembodied faceless government system. Jumping through the hoops – [conjuring images of agility shows]. Feels superficial and unfeeling. Mechanistic/trained element to it. Who is on the other end of the forms – reasserting personhood through use of "who" and emphasis that a claimant is a person not just a form/application number. Feeling dehumanised by a mechanical like system?	Devalued and dehumanised by the process
P: I think autistic people are considered very low value to society. I mean there's a reason only 22% of us are in employment (only 16% full-time), and it's not that we are lazy.	Jumps from personal to membership of wider community. Comforting not being alone? Contribution and value of a human in society? – speaks to work statistics [value as 'productivity' work?]. [DWP doing work of society? All neurotypical]	Society views autistic people 'not worthy'
P: So regardless of what the law says about equality, it's not put into practice.	Society vs autistic people. Strengths and personhood overlooked? Felt not worth supporting/low potential? 'It's not that we are lazy' – pulls on societal assumption of individual fault, narrative of 'lazy benefit claimant' evoked and distanced from autistic community [a call to eligibility/ontology of difficulties?].	DWP mirroring society's disregard for autistic people

Appendix M: Personal Experiential Theme Development Process

NVIVO List of Experiential Statements

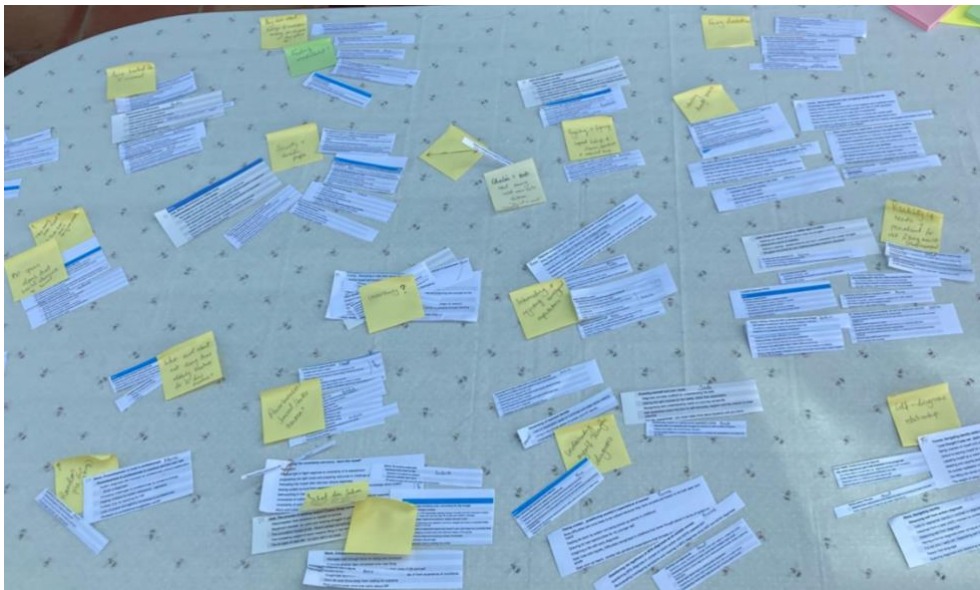**Manual Revising and Grouping of Experiential Statements**
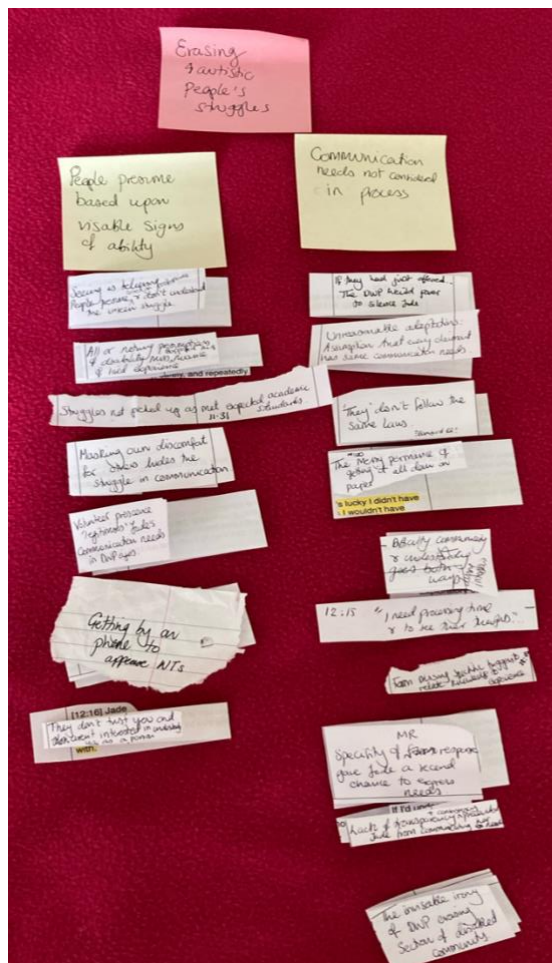
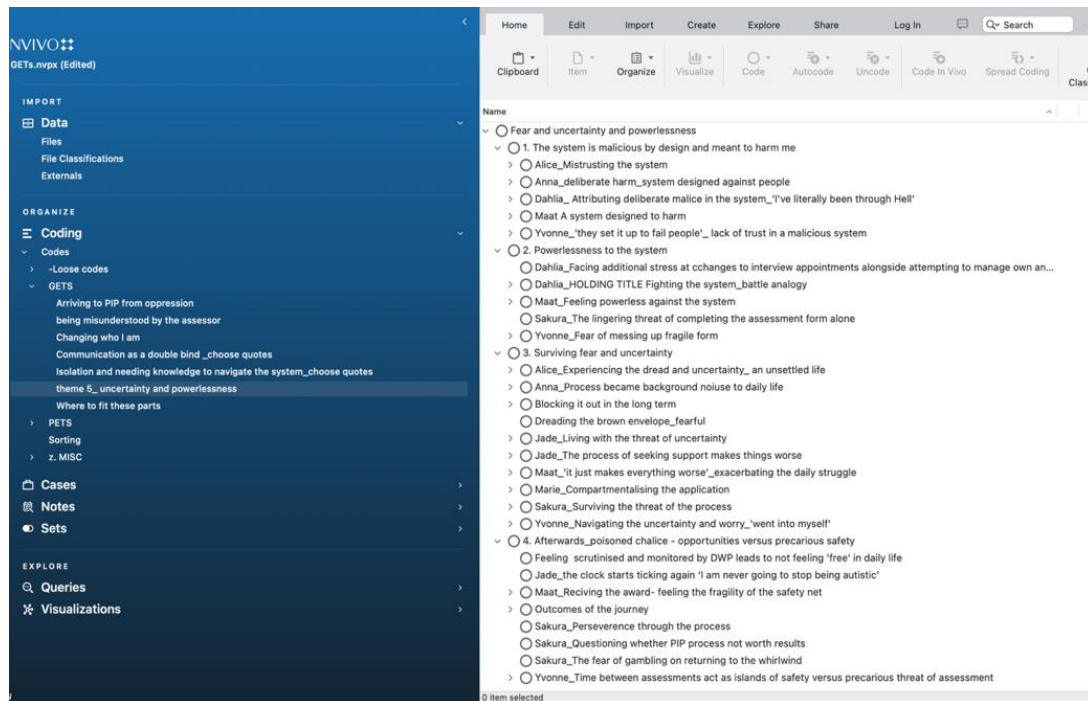**NVIVO grouping of Personal Experiential Theme**
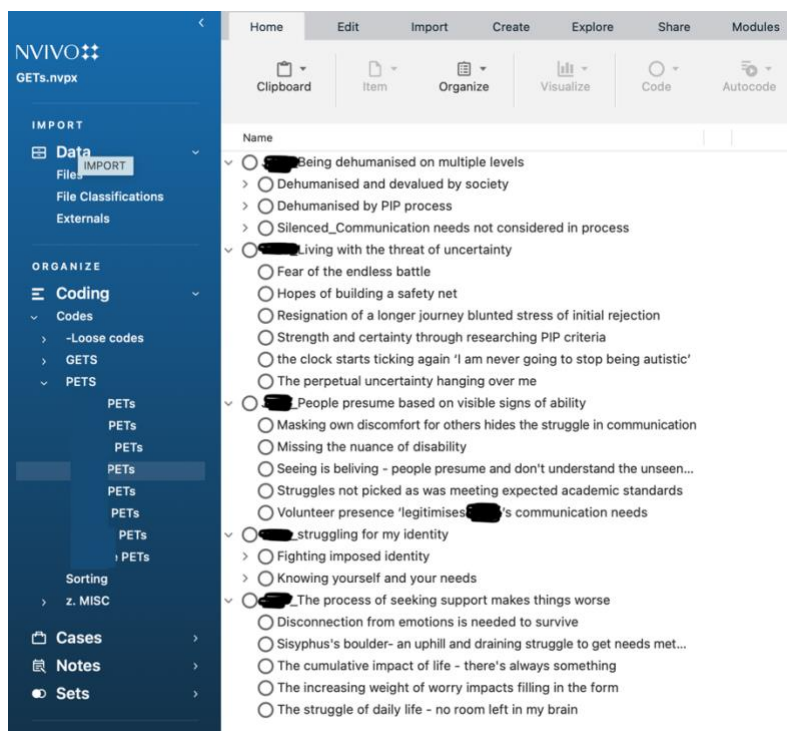
Appendix N: Group Experiential Theme Process

Manual Clustering

NVIVO Clustering: Inside a Group Experiential Theme

NVIVO Clustering: Group Experiential Themes

Appendix O: Identification of Group Experiential Theme (GET) across Participants

Table 16

Summary of GET Prevalence across Participants' Accounts

GET	Subtheme	Anna	Alice	Dahlia	Jade	Maat	Marie	Sakura	Yvonne
Powerlessness and Threat	"They've got you under their thumb": Feeling Powerless	✔	✔	✔		✔		✔	✔
	"it just makes everything worse": Responding To Threat And Uncertainty	✔	✔	✔	✔	✔	✔	✔	✔
	A Poisoned Chalice: Opportunities and Threat		✔		✔	✔	✔	✔	✔
Communication: Caught in a Catch-22	-	✔		✔	✔	✔	✔	✔	✔
Distance and Dependence: "It's really hard to know who to turn to"	Needing Knowledge to Navigate the System		✔		✔	✔		✔	✔
	Feeling Isolated from Loved Ones		✔	✔		✔	✔	✔	✔
Being Misunderstood by the Assessor	"They don't see the struggle"	✔	✔	✔	✔	✔		✔	✔
	Facing an Inhuman(e) System		✔	✔	✔	✔	✔	✔	✔
	"It just brings all back": Reliving Past Invalidation	✔	✔	✔				✔	
Changing Who I Am	"I really am the most useless person in the whole world"		✔	✔			✔	✔	✔
	Resisting the Imposition			✔	✔	✔		✔	✔