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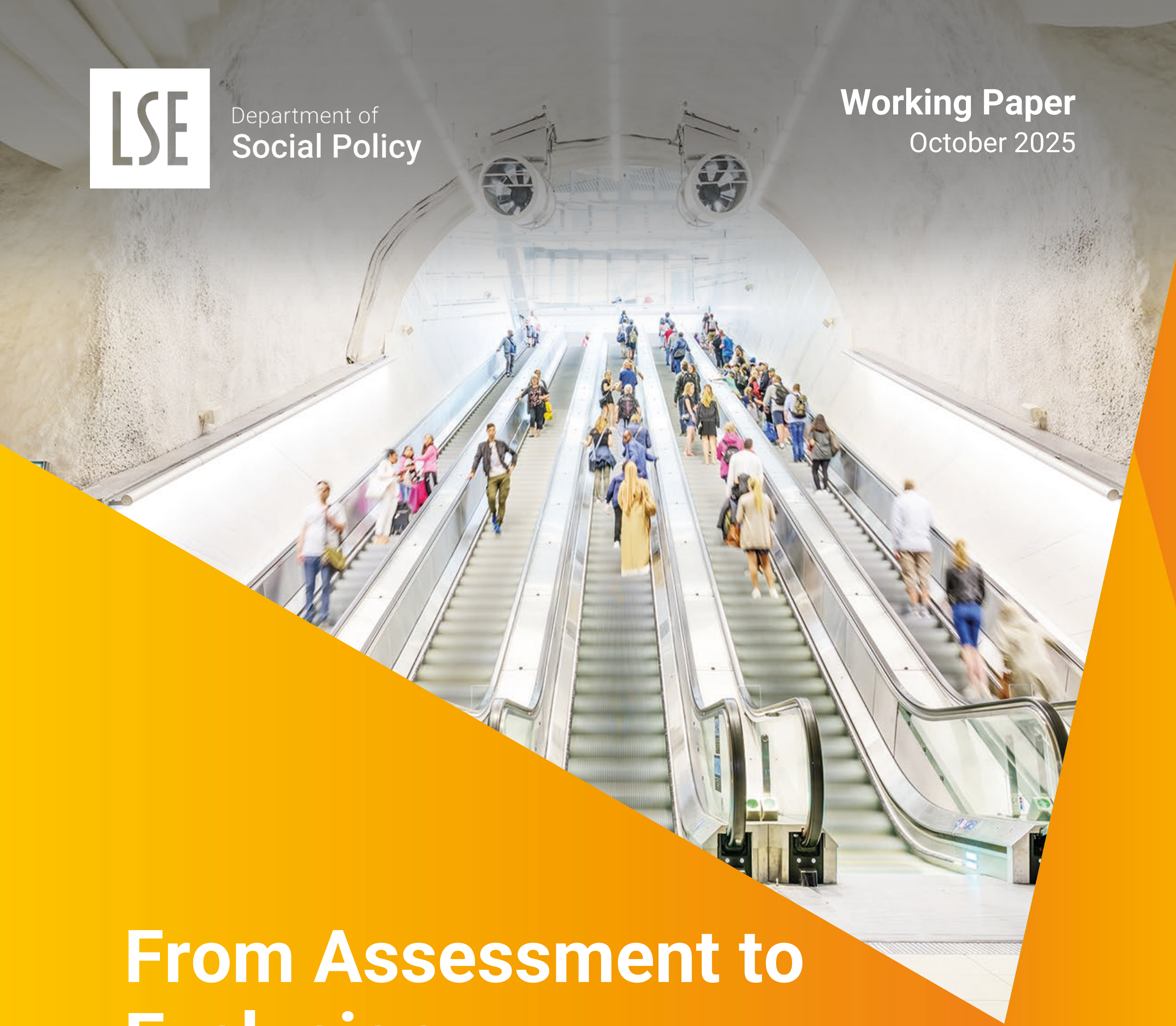

From Assessment to Exclusion:

Exploring the Role of Disability Hierarchies in PIP Claimant Experiences

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From Assessment to Exclusion: Exploring the Role of Disability Hierarchies in PIP Claimant Experiences

George Bowron[1]

Completed May 2024

Abstract

This study addresses the Personal Independence Payment application and assessment process, one which has been criticised extensively by claimants, disability rights groups, and international organisations. Motivated by personal experiences with disability and the PIP system, the research prioritises the voices of disabled individuals which are often sidelined in policy discussions. Employing a disability human rights lens and phenomenological approach, the study explores the subjective experiences of PIP claimants through in-depth, semi-structured interviews. By centring the narratives of claimants, the research aims to shed light on potential disparities across disability types, contributing to broader conversations about disability rights and welfare policy.

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[1] George Bowron died on 25th September 2025; and this working paper is published posthumously, in line with the author's wishes and his parents' agreement. It is published as it was completed in May 2024. Queries may be directed to Lucinda Platt: L.Platt@lse.ac.uk

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Introduction

Personal Independence Payment (PIP), a non-means tested benefit for disabled people of working age in the UK, administered by the Department for Work and Pensions (DWP), has frequently attracted criticism from those that go through its application and assessment process. The wider disability welfare system in which PIP sits has also been the subject of criticism from the UN Committee on the Rights of People with Disabilities (UNCRPD), which found ‘reliable evidence that the threshold of grave or systematic violations of the rights of persons with disabilities has been met’ in the UK (UNCRPD, 2016, p.20). Whilst some research has suggested that PIP claimants with psychosocial disabilities may be disadvantaged relative to claimants with other types of disabilities, little qualitative research spanning participants across multiple disability types exists to meaningfully examine this theory. This study, therefore, seeks to address this gap in the literature.

This study is motivated by my personal experiences of disability and with the PIP application and assessment process. Perhaps deriving from my position as a disabled person, it is of great importance to me to centre the narratives and lived experiences of disabled people in this research, voices which are too often ignored in policy formation processes. Therefore, I adopt a disability human rights and phenomenologically based approach to this study, drawing predominantly on semi-structured interviews conducted with PIP claimants to understand and compare their subjective experiences.

A note on language and terminology

Language in disability discourse is an issue of considerable importance. Far from being a matter of simple semantics, the language adopted by researchers has significant implications for perceptions and research directions (Vivanti, 2019, p.691; Bickenbach, 2012, p.xi). For the purposes of this dissertation, I generally adopt the convention of using identity-first language (e.g. “autistic person”, “disabled person”) in preference to person-first language (e.g. “person with autism”, “person with a disability”). As a disabled person myself, I believe that my disabilities represent a core facet of my identity and personhood, without which I would not be the person that I am; for this reason, I seek to centre disability rather than to create distance from it in my language choices. Such an approach to terminology has also been adopted by major UK disability rights organisation, including Scope, Disability Rights UK, and the Council for Disabled Children. Where there is common consensus amongst individuals with a particular type of disability or diagnosis to use person-first language, or where an individual participant prefers the use of person-first terminology, I endeavour to respect and apply this, hence the form of language used in this dissertation will vary.

For the purposes of my analysis in this dissertation, I draw upon the definition and classifications of disabilities presented in the *Convention on the Rights of Persons with Disabilities*, namely 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder [. . .] full and effective participation in society on an equal basis with others' (UN General Assembly, 2007). This definition, and its implication of four primary types of disability, is, however, imperfect. Many disabled individuals may experience impairments of multiple types, it is therefore often difficult to meaningfully classify an individual as having a disability which falls neatly into one category. This typology also does not distinguish between "visible" and "invisible" disabilities, thus potentially limiting analysis. I adopt the approach, based on the principles of disability self-advocacy, of classifying the type(s) of disability experienced by participants in accordance with how the participant identifies them.

Literature and background

Hierarchies of disability

Hierarchies of disability may be broadly constructed as the stratified treatment and perception of disabled people contingent on the type, presentation, and acquisition of their disability (e.g. Harpur, Connolly, and Blanck, 2017; Harpur, 2020; Deal, 2003). These hierarchies are highly fluid, with different contexts and actors producing differently structured hierarchies. Of particular importance in the context of this research, hierarchies of disability stand to exert a significant effect over legislation, social policy, and public policy (Harpur, 2020, p.14). This influence may manifest in how policy and legislation is constructed, with societal attitudes shaping what constitutes a 'real' disability (Platt, 2019, p.143) deserving of support from the state (Harpur, 2020, p.14). This has been exemplified recently with Prime Minister Sunak (2024), in a speech announcing a consultation on reforms to PIP, questioning whether ‘people with mental health conditions should get PIP in the same way [as people with other disabilities] through cash transfers’. Equally, this influence may manifest in the implementation of policies, for instance in the selection of physical sites through which services are accessed, which may disadvantage physically or sensorily disabled people.

The legislative and policy implications of hierarchies of impairment are perhaps most readily apparent when considering contemporary approaches to psychosocial and cognitive disabilities. The notion of ‘sanism’, defined by Perlin (1993, p.29) as ‘an irrational prejudice’ against individuals with ‘mental disabilities’ is illuminating in considering the position of cognitively and psychosocially disabled individuals within hierarchies of disability in healthcare. Whilst individuals with physical and sensory disabilities undeniably remain subject to ableism and to exclusion through inaccessibility, ‘it would not be legally or socially acceptable to drag [a] wheelchair user out of [a] building and detain them’, whereas individuals with psychosocial and cognitive disabilities may be detained and forcibly excluded from society at-large (Harpur, 2020, p.14). The issue of the exclusion of psychosocially or cognitively disabled people ‘is not implicit or covert, [...] but is explicit and legally legitimized’ with individuals with these types of disability often being subject to potentially indefinite involuntary detention (Rogers and Pilgrim, 2014, p.177). The prevalence and institutional entrenchment of sanist attitudes and policies raises the questions of whether these biases impact the experiences of psychosocially and cognitively disabled people in the PIP application and assessment process.

Whilst psychosocially and cognitively disabled individuals are especially impacted by legal disparities, it is important to emphasise that physically disabled, blind, and d/Deaf people are not inherently more advantaged by hierarchies of disability, with different settings, contexts, and situations producing different hierarchies, socially constructed both by disabled and non-disabled people.

Current research explicitly concerning hierarchies of disability focuses on three main, somewhat overlapping, domains: the labour market, social acceptance and preferences, and legal approaches to disability and accessibility. Education and welfare provision have also received research attention, though to a significantly lesser degree. Research pertaining to social security and benefits has tended to centre around the specific case of compensation for disablement arising from participation in the labour market (e.g. Açıksöz, 2017; Harpur, Connolly, and Blanck, 2017) as opposed to more general forms of disability benefits such as PIP.

Whilst research explicitly investigating experiences of hierarchies of disability in the UK's welfare system is lacking, findings from adjacent domains may be used to synthesise a framework through which to understand how hierarchies may present and be structured in this context. Research considering the labour market and workplaces has found, across various national contexts, that psychosocially disabled people are less likely to participate in the labour force than those with any other disability type (Olney and Devine, 2023, p.742; Harpur, 2020, p.9; Drew et al., 2011, p.1666). Stigmatisation and a poor understanding of psychosocial disabilities and how to accommodate these have been cited as key factors in driving low employment rates (Drew et al., 2011, p.1666; Harpur, 2020, p.147). The issues of stigmatisation and a poorer understanding of functional limitations associated with psychosocial disabilities relative to other disability types may have substantial implications for PIP's functional assessment process. Similarly, Harpur (2020, pp.83-85) argues that episodic or fluctuating disabilities, regardless of type, are disproportionately subject to disbelief and misunderstanding relative to stable disabilities.

Research on hierarchies of social acceptance of disabilities amongst the general public, predominantly based on the disability social distance scale (DSDS) devised by Tringo (1970), has demonstrated relatively stable attitudes to different types of disability over time, with invisible, generally less severe, physical disabilities and health conditions being rated as most acceptable, followed by sensory disabilities, then more severe physical disabilities, especially those which have a particularly visible phenotype such as dwarfism, and finally cognitive and psychosocial disabilities (Dear et al., 1997, p.465). Amongst disability professionals specifically, such a clear hierarchy by UNCRPD disability type is less evident, however, research amongst this group has found higher prestige is afforded to conditions which are most clearly and specifically defined in medical terms, such as heart attacks and cancer (Grue, Johannessen, and Rasmussen, 2015, p.183). This may have substantial implications for the structure of hierarchies in PIP assessment process. As psychosocial disabilities and physical disabilities characterised by symptoms that are difficult to localise or verify, particularly diagnoses of exclusion such as fibromyalgia or chronic fatigue syndrome, are afforded a lesser status by disability professionals (Grue, Johannessen, and Rasmussen, 2015, p.183), this may suggest that these attitudes are liable to be replicated in the PIP process.

Personal Independence Payments

PIP was introduced by the Welfare Reform Act 2012, replacing Disability Living Allowance (DLA) from June 2013 as the primary non-means tested disability benefit for people of working age in the United Kingdom (Gray, 2014, pp.13, 17, 21). Against the backdrop of austerity (Alldridge, 2019, p.448), PIP was introduced with the explicit goal of ‘reducing projected working-age expenditure by 20 per cent in 2015/16’ by ‘projected working-age expenditure to 2009/10 levels in real terms - £11.8bn’ (Department for Work and Pension, 2011, p.3).

Unlike DLA, in which disability was understood through medical assessment (Alldridge, 2019, p.449), PIP adopts a ‘functional’ form of disability assessment based on a claimant’s ability to complete ‘ten daily living activities and two mobility activities’ for each of which zero to twelve points are awarded depending on the degree of functional impairment (Gray, 2017, p.13). This process consists of two main stages, the PIP2 form and an assessment. The PIP2 form consists of fourteen questions over fifty pages requiring claimants to describe how they are impacted by their disability across the ten daily living and two mobility activities (DWP, 2013). After submission of the PIP2 form, assessments are broadly undertaken face-to-face, though video, telephone, and paper-based assessments are also used, being conducted by non-medical ‘Health Professionals’ (Gray, 2017, pp.13-14). The rate of PIP is then determined by the DWP on the basis of the assessors report; claimants may be awarded the ‘standard rate’, requiring eight to eleven points across the daily living component and/or mobility component activities, or ‘enhanced rate’, requiring twelve or more points in the relevant component, or given no award, for both the daily living component and the mobility component (Machin, 2017, p.438).

Where claimants dispute the DWP’s decision, there is a “mandatory reconsideration” process where a second DWP reviewer examines the original decision (Machin 2017, p.466). In the quarter ending January 2024, 26% of these reconsiderations resulted in a changed award, either granting an award that had previously been declined or increasing the rate in one or both components (DWP, 2024). The mandatory reconsideration process, however, has been criticised by claimants and tribunal judges for having ‘turned into an additional administrative barrier for claimants who wish to challenge their decision rather than a substantive re-examination of the evidence' (Gray, 2017, p.45). Where claimants remain unsatisfied with the DWP's decision, recourse to appeal lies with the Social Security and Child Support Tribunal, a judicial body independent of the DWP (Machin, 2017, p.466). Between October 2018 and September 2023, some 34% of mandatory reconsiderations progressed to an appeal to tribunal being lodged (DWP, 2024) with 70% of appeals heard at tribunal resulting in the DWP's decision being overturned in the claimant's favour (Ministry of Justice, 2024). This relatively high claimant success rate at appeal suggests that the PIP assessment process, as currently conducted by the DWP, fails in several cases to accurately assess entitlement in line with the criteria established by the Welfare Reform Act and subsequent judicial precedent. It is, unfortunately, not clear from data published by the Ministry of Justice whether particular disabilities or disability types are disproportionately affected by this inaccuracy.

Experiences of PIP

There are relatively few studies that seek to directly understand the experiences of PIP applicants. Those that do exist generally confine their analysis to claimants with a single condition or disability "type". Existing research overwhelmingly portrays claimant experiences as 'largely negative' regardless of financial outcomes (Davies et al., 2017, p.30; Gray, 2017, p.23), bringing about 'shame, humiliation, hopelessness, and social isolation' (Roberts et al., 2022, p.1), and increasing 'anxiety and uncertainty' (Machin and McCormack, 2021, p.1036). Difficulties communicating with the DWP and meaningfully conveying the impacts of disabilities via the PIP2 form; poor accessibility throughout the process; and a perceived dismissiveness, insensitivity, or lack of relevant knowledge amongst assessors consistently underscore applicants' experiences of the application and assessment process (Machin and McCormack, 2021, pp.1036-1041; Davies et al., 2017, pp.31-43).

Whilst research tends to emphasise the negative aspects of claimant experiences, some claimants report positive experiences and impacts, both in absolute terms and relative to other disability benefits. Perhaps most importantly, given the higher rate of absolute low income (22% vs. 16% after housing costs) and lower rate of employment (53.6% vs. 82.5%) amongst disabled people compared to non-disabled people (DWP, 2021; DWP, 2023), receipt of PIP represents a key element of ‘overall income’ and a means of ‘maintaining a reasonable standard of living’ for many (Machin and McCormack, 2021, p.1041). For those in receipt of the enhanced rate of the mobility component, this can act as a ‘passport to a range of wider disability supports’ (Roulstone, 2015, p.684), including the Motability vehicle leasing scheme through which disabled people receiving a qualifying benefit can access a vehicle or powered wheelchair, enhancing autonomy and mobility (Power, 2016, pp.280, 282). The challenging nature of the PIP process has also been credited for producing positive impacts on claimants and across the disability rights movement by promoting the development of solidarity and support networks amongst a community of people experiencing shared difficulties with social security benefits (Machin and McCormack, 2021, p.1043). Amongst claimants with experience of both PIP and Employment and Support Allowance (ESA), which use similar functional assessment processes, PIP was compared favourably against ESA (Gray, 2017, p.26), though this may reflect more negatively on ESA than positively on PIP.

Hierarchies of disability in PIP

Little direct research attention has been given to the salience of hierarchies of disability in the context of PIP. It has been suggested by many authors that claimants with psychosocial disabilities may be systemically disadvantaged in, and negatively impacted by, the PIP process (Akhtar, 2020; Barr et al., 2015; Gray, 2017; Machin, 2017; Machin and McCormack, 2021; Pybus et al., 2021; Roberts et al., 2022). This suggestion also appears to be reflected in quantitative studies concerning rates of claim disallowance, with Pybus et al. (2019, p.1) finding that individuals in receipt of DLA with a mental illness were 2.40 times more likely to lose their entitlement following a PIP eligibility assessment compared to claimants with musculoskeletal, neurological, or diabetic conditions.

Whilst functional assessments have been presented as more holistic and personalised than medical assessment, this appears to have failed to translate to practice. Pybus et al. (2021, pp.310-311) found that applicants with mental health conditions perceived the assessment process as ‘focussing overwhelmingly on physical health’, denying applicants the ability to ‘give a full representation of how they were affected by their mental health condition’. Similarly, possibly through the impacts of psychosocial disabilities often being less evident to outside observers, psychosocially disabled claimants frequently report feeling poorly understood and as though their experiences have been rejected or invalidated by the assessment process (Machin and McCormack, 2021, pp.1040-1041; Roberts et al., p.6). The UNCRPD (2016, p.16) found, in respect of UK disability benefit eligibility assessments that 'the needs, views and personal history of persons with disabilities, and particularly those requiring high levels of support such as persons with intellectual and/or psychosocial disabilities, were not properly taken into account or given appropriate weight in the decisions affecting them', furthering the notion that people in these groups are systemically disadvantaged in the PIP assessment process. Whilst claimants with physical and sensory disabilities may be relatively advantaged by the content of the assessment, it is important to note that the premises in which these assessments are conducted may pose significant accessibility challenges, disadvantaging members of these groups (Gray, 2017, p.24).

As identified by Gray (2017, p.35-36), claimants with psychosocial or hidden disabilities may be systemically disadvantaged through barriers to obtaining corroborating evidence, with many individuals with mental health conditions not seeking the level of support necessary to manage their condition or having their condition inappropriately managed exclusively in primary care services. Management of complex conditions in primary care services, often driven by financial pressures to discharge people from secondary care services (Reilly et al., 2021, p.1), acts as a significant barrier to claimants obtaining supporting evidence of the impact of their condition from a specialist (Pybus et al., 2021, p.311) with an estimated 31% of people with diagnosed Severe Mental Illnesses (SMIs) having no contact with secondary mental health services in a twelve-month period (Reilly et al., 2012, p.2). Additionally, some claimants, particularly those with psychosocial and cognitive disabilities, may experience difficulty understanding what evidence is required and how to obtain it (Gray, 2017, p.36), creating further systemic disadvantage.

Beyond potential disadvantage in the process, claimants with psychosocial disabilities appear likely to be more vulnerable to the adverse impacts of engaging in the PIP application and assessment process. Almost all existing research concerning the experiences of PIP claimants, regardless of disability type(s) considered, characterise participation in the PIP process as engendering 'fear, insecurity, and disempowerment' (Pybus et al., 2021, p.315), anticipatory anxiety concerning contact from the DWP and ‘the dreaded brown envelope’ (Roberts et al., 2022, p.9; Garthwaite, 2013), and pushing claimants to reflect negatively on their identity and capabilities (Davies et al., 2017, p.36). Evidence from the introduction of the Work Capability Assessment, a functional assessment of disability to determine benefit eligibility much like the PIP assessment, shows a correlation between (re)assessments and a significant increase in suicides, reported mental health conditions, and antidepressant prescriptions (Barr et al., 2015, p.341). It is reasonable to assume that psychosocially disabled claimants, given their pre-existing, or increased background risk of, anxiety, depression, self-harm, and suicidality, are likely to be differentially exposed to the adverse sequelae of engaging in the PIP process. For psychosocially disabled claimants with a background of trauma, experiences of PIP also appear to potentially be actively ‘re-traumatising’ (Roberts et al., 2022, p.12).

Research Design and Methodology

In seeking to centre and understand the perspectives of disabled people, the research design for this study drew from a social constructionist and phenomenological framework. As such, it collected qualitative primary data through in-depth, semi-structured interviews with the goal of understanding participants’ experiences of, and narratives about, their engagement in the PIP application and assessment process. By comparing these accounts, it was then possible to explore how they varied between participants with different types of disabilities, and to understand the salience and structure of hierarchies of disability in the PIP process.

As this research involved potentially vulnerable human participants, ethical approval was sought and received from the LSE Research Ethics Committee. To ensure all prospective participants were able to provide informed consent to participate, individuals currently subject to detention under the Mental Health Act 1983 or Deprivation of Liberty Safeguards under the Mental Capacity Act 2005 (MCA) were excluded from the study. Prospective participants were asked to confirm that they had capacity to provide informed consent when completing the consent form, in line with the principle set out in the MCA that all people aged over sixteen should be assumed to have capacity unless there is evidence to the contrary. This confirmation was accepted as true unless it became apparent during the course of an interview that a participant may lack capacity. No ad-hoc capacity assessments were necessary during the course of this research, however my professional training and experience in conducting capacity assessments ensured that it would have been possible to address capacity issues if these had arisen.

The use of pre-existing networks in recruitment as discussed below presented potential ethical challenges. This dynamic could have influenced participants' decision-making process by inducing participants to opt to participate where otherwise they would not. This is unlikely to be a significant concern, however, as participants opted in having seen a general recruitment post rather than being directly targeted for recruitment. To further mitigate this concern, explicit efforts were made to emphasise the voluntary nature of participation, assure confidentiality, and provide participants with opportunities to decline involvement without any negative consequences, including in the recruitment process, pre-interview, and post-interview.

With PIP claims often being a difficult experience, this raised ethical considerations about potential harms to participants' wellbeing arising from discussing these experiences. This was mitigated by offering participants the option to take a break or move to discussing a different topic, both pre-interview and as needed during the interview. My training as a Mental Health First Aider and awareness of local safeguarding procedures further ensured that provision was in place if wellbeing concerns arose.

Participant recruitment

All participants recruited to this study were individuals with experience of the Personal Independence Payment application and assessment process aged eighteen or older. The sample included five beneficiaries and one parent carer who completed the process on behalf of their adult child. The participants accessed by this research experienced a wide range of disabilities and long-term health conditions, encompassing the physical, psychosocial, and cognitive disability types. Unfortunately, no participants with sensory disabilities were recruited, thus limiting the ability of this research to access and compare accounts of individuals experiencing all four disability types. The sample was relatively demographically homogenous with all participants being of White British or Irish ethnicity and all participants but one being female. Given the small sample size, this homogeneity was advantageous, allowing for a more meaningful comparison of experiences dependent on disability type and reducing the possible confounding influence of demographic factors.

Table 1: Participant characteristics

Pseudonym	Gender	Self-identified disabilities or health conditions
James	Male	Epilepsy, autism
Mary	Female	Multiple sclerosis
Jennifer	Female	Multiple sclerosis
Linda	Female	Arthritis, fibromyalgia, anxiety
Jessica	Female	Inflammatory bowel disease, hypermobility, transient ischaemic attack, cardiac condition, anxiety
Sarah	Female	Carer of a person with a chromosomal deletion syndrome

Convenience and snowball sampling was employed to recruit participants. Recruitment was primarily conducted through online forums and social networks, notably the Scope forums and Facebook. Use of the Scope forums offered access to a wide range of disabled people as this forum is primarily concerned with disability-related issues and advocacy in the United Kingdom, with a substantial focus on disability benefits. Given that active users of the Scope forums publicly discuss disability, including sharing difficult experiences related to Personal Independence Payment, this channel served to alleviate potential ethical concerns by aiming to recruit those who have demonstrated a willingness to openly discuss challenging and personal experiences with unknown others.

The use of Facebook allowed access to the researcher's existing networks and "friends-of-friends". Conducting recruitment through Facebook offered significant practical advantages. Most notably, this channel resulted in a significantly higher response rate compared to that achieved attempting to recruit individuals who were previously unconnected to the researcher via the Scope forums. This can, possibly, be attributed to pre-existing familiarity evoking a sense of 'understanding, trust, respect, and comfort' (Irvine, 2012a, p.292) among the potential participants.

Prospective participants were given information about the research objectives and offered the opportunity to ask questions, ensuring a clear understanding of their potential involvement and the nature of the research, thus supporting informed consent. Given the nature of this research, participants were encouraged to inform the researcher of any accessibility requirements in order to support individuals with a broad range of needs to engage in this research.

Despite the limitations inherent to convenience sampling, such as potential selection bias, it was the most suitable method within the constraints of this research. The study focus was on exploring individual experiences and perspectives to reveal potential commonalities and differences in and between those with varying disability types through a pool of individuals with first-hand knowledge and experience of the Personal Independence Payment application and assessment process. It would be desirable to conduct future research with a significantly larger and more demographically representative sample in order to generate more generalisable findings.

Interviews and analysis

Semi-structured interviews, typically lasting 45-60 minutes (range 37-61), were used as the primary data collection method. These interviews, as is typical in semi-structured interviewing, followed an interview guide that was organised around key areas of interest (Irvine, 2012a, p.292). The interview guide encompassed various topics, including perceptions and emotions relating to the PIP process, experiences at each stage of the process, accessibility, understanding and perception of hierarchies of disability in the context of PIP, and perceptions of how the PIP process might be improved to address challenges or barriers identified by the participant. This approach ensured comprehensive exploration of the research question while allowing for flexibility to adapt to the flow of the participants' responses and to address topics raised by participants not covered by the guide (Irvine, 2012a, p.292).

Interviews were conducted using the Zoom video-calling platform. This provided enhanced flexibility for both the researcher and the participants, eliminating the need for travel, and thereby expanding the range of mutually agreeable interview times (Irvine, 2012b, p.298). Conducting interviews via Zoom, also offered further advantages. Firstly, it allowed for unobtrusive audio recording, ensuring accurate capturing of the interview data, and avoiding distraction through note-writing during the interview. As suggested by Oliffe et al. (2021, p.3), conducting interviews via

Zoom may have also fostered a sense of ease and comfort among participants, as they were able to engage in the interviews from the familiarity of their own surroundings. This potentially enhanced rapport building and facilitated participants' willingness to share personal accounts and is likely to have been a significant factor in supporting participants with psychosocial disabilities, notably autism and anxiety disorders, to engage. In the specific context of this research, the use of Zoom as opposed to in-person interviewing was particularly appropriate as a means of improving accessibility by facilitating access to assistive technologies, such as closed captioning, and protecting immunocompromised participants from avoidable exposure.

Interviews were audio recorded via Zoom and subsequently transcribed using the NVivo automated transcription service. The transcripts produced were then reviewed and manually edited to correct errors introduced during automatic transcription. In one case it was not possible to fully automatically or manually transcribe the interview due to a poor-quality audio recording in conjunction with the participant’s speech impediment, however the majority of the substantive content of the interview could still be transcribed.

I broadly adopted the analytical methodology presented by Green (2017) with a particular focus on ‘the *immersion / crystallization* analytic style’ (Crabtree and Miller, 1992, cited in Green, 2017, p.65, emphasis in original). This style of analysis, which ‘begins with immersion in the individual stories research participants tell’ represents a powerful means of centring the experiences and narratives presented by disabled people by seeking to answer the question ‘“what did she or he want us to hear about this experience as a whole?”’ (Green, 2017, pp. 6465).

Having developed an understanding of the ‘unique stor[ies]’ (Green, 2017, p. 67) presented by each participant, transcripts were coded, in the first cycle, in NVivo using ‘in vivo’ and ‘emotional’ coding techniques, drawing directly on participants’ own words to generate codes (Saldaña, 2021, pp.138, 160). In vivo coding, by generating codes directly from the language used by participants, assists in both developing an understanding of the experiences and emotions presented and in maintaining the voice of participants at the centre of the analytic process. Similarly, emotional coding is particularly appropriate in research ‘that explore[s] intrapersonal and interpersonal participant experiences and actions’ (Saldaña, 2021, p.160).

These coding techniques are, therefore, those most apt for addressing the research question within a theoretical framework which stresses the importance of understanding and valuing the voices of disabled people.

Following the initial coding of individual transcripts, the transcripts were cross-compared to identify commonalities and difference using an axial coding technique. This process enabled refinement and grouping of codes into higher-order themes. By classifying each participant in relation to disability type, award level, appeal experience, and gender it was then possible to compare the prevalence of themes and perceptions across participant characteristics.

Limitations to the research design and mitigations

The small sample size of six participants interviewed in this study presents a key limitation. This inherently constrains the range of narratives that could be gathered through this research, thus removing the possibility of directly comparing experiences between all four disability "types". It should be noted, though, that this limitation appears to be relatively prevalent in research concerning people's experiences of Personal Independence Payment (e.g. Machin and McCormack, 2021; Roberts et al., 2022). Similarly, this research is limited by the fact that those most significantly impacted by their disability are those least likely to be accessed by research (e.g. Harding, 2021; McDonald, Conroy, and Olick, 2016). This limited set of narratives, then, reduces the depth and breadth of analysis that may be meaningfully undertaken.

It is important to acknowledge the potential impacts of bias in recruitment and methodology on the findings of this research project. Selection bias may have influenced the composition of the pool of participants in this research, with those who elected to participate possibly having stronger, likely more negative, views on the Personal Independence Payment process. This appears to be borne out to some extent in this research, with all participants but one expressing some degree of negative sentiment about their experiences of the process. Further, social desirability bias may have influenced participants' interview responses, increasing their inclination to present their experiences of PIP negatively on the basis that a large proportion of public discussion of PIP is overwhelmingly negative. Whilst this characterisation may well be an accurate reflection of participants' experiences, it is possible that positive or neutral aspects were underreported to better accord with wider sentiments.

To mitigate the impacts of bias, efforts were made to create a non-judgmental environment during interviews to put participants at ease and encourage them to express their genuine thoughts and feelings in relation to their experiences. This approach appears to have been effective, with participants sharing highly personal, emotive accounts which, whilst predominantly negative in their characterisations of the PIP process, did highlight positive aspects. Questions, particularly those relating to the concept of hierarchies of disability, were constructed to mitigate social desirability bias by presenting a range of viewpoints, thus avoiding leading participants to assume any particular position to be more desirable. In conjunction, the researcher adopted a reflexive stance during interviews and data analysis, grounded in Green's (2017) framework, to reflect on and challenge possible sources of researcher bias. This strategy appears to have been successful with participants providing a variety of responses which do not appear to converge on any single perspective. Despite the apparent success of these mitigations, it is important to recognise that bias may be present to some extent and could have influenced data collection and interpretation.

Findings

This section presents the research findings, with four overarching themes:

1. Barriers in the PIP claims process
2. Negative psychological and physical impacts of claiming PIP
3. Isolated positive experiences and impacts of claiming PIP
4. Perceptions of better-known and visible disabilities as relatively advantaged

Barriers in the PIP claims process

The level of challenge faced by participants in bringing their claim for PIP varied significantly, though all participants were unified by some experience of adversity at some point in the application and assessment process.

Perhaps the most frequently noted barrier was difficulties in adequately capturing the impacts of a disability on day-to-day functioning in the PIP2 form and providing evidence to support this. This barrier was, however, mitigated by the use of guides such as those produced by *Cerebra* and *Benefits and Work*, though notably not the guide provided by the DWP with the PIP2 form, support from others, and by gaining experience with the process over time. Several participants noted that they required support from others to engage in the assessment process without which they would not have been able to access PIP.

> *"Trying to get my GP to print out 13 years worth of medical documents was impossible. They point-blank refused it multiple times"* – Jessica

> *"I think without the Benefits and Work website, I would have struggled more because the guides, because obviously they* [the DWP] *send you a guide, don't they, but their guide, I think, is not written in mind of you giving them your best."* – Mary

> *"It's difficult to evidence things that we don't do, that I don't do, because I don't do these things to give evidence because I don't do them anymore" – Jennifer*

> *"I went into it blind, I think, the first time, too blind, and I was trying to be positive, I think, whereas that's not, that's not the way to go about, you know, if you if you're in the mindset of this is what I can do, I'm feeling positive, I've walked up this hill, but, you know, it's, it's nearly killed me, but I managed it. I think I was, I was in the frame of, of, of trying to be too positive, I'd say, so I had no idea the first time around"* – Jennifer

> *"I had to do a lot of chasing up, well I say that, my mum had to do a lot of chasing up, and my sister helped as well, because I couldn't, I wasn't in a place mentally to be able to do that because the process, again, it does make me really unwell."* – Jessica

Several participants felt that they and their disability were not adequately understood or believed during the application, assessment, and in some cases reconsideration and tribunal, process. This lack of understanding, in the view of participants, posed a substantial barrier to accessing PIP and contributed to adverse effects.

> *“I was, I felt I wasn't believed at all in spite of having medical evidence and letters from my doctors and everything”* – Linda
>
> *“I was told by one of the DWP workers to j‘ust get over it’, that I was too young to be sick and that I should just I should just live my life and try to be positive” – Jessica*
>
> *“They look at a piece of paper and say, ‘No. You're not that sick. You're fine’, and it's, it's, soul destroying actually, it's really, really upsetting.”* – Jessica
>
> *“It was like he was subliminal, subliminally telling me that I was just being dramatic, and he was like, ‘Well, women get like this when they're unwell. Women get like this’”* – Jessica
>
> *“I think it* [request for reconsideration] *was, we were totally disregarded. It came back too quickly. They hadn't looked at it”* – Jennifer

Several participants commented on a perceived lack of expertise amongst PIP assessors. It was suggested that a lack of understanding of specific health conditions posed a barrier to the accurate assessment of the functional impact of disability, particularly in the case of fluctuating disabilities such as multiple sclerosis (MS).

> *“I think having actual doctors that know what they're talking about, that understand different things for different sectors, like to have a cardiologist, a neurologist, a gastroenterologist, physiologist, whatever.* [...] *I think that would make a lot of difference rather than having people that aren't medically trained, reading pieces of paper, say, saying ‘I think they sound okay.’ I think having actual doctors might make a difference.”* – Jessica
>
> *“I think the assessor needs to be somebody who has the condition themselves or knows more about the condition”* – Jennifer

> *“actually you're not qualified to check as far as I'm concerned, unless you are an MS specialist, I don't think you ha-, you're not qualified to make that judgment” – Mary*

Negative psychological and physical impacts of claiming PIP

Whilst all participants had unique, distinctive experiences of the application and assessment process, a unifying theme was that, for participants with a psychosocial element of their disability, the process caused substantial anxiety and, in some cases, marked exacerbations of physical disabilities and health conditions. This was also noted in some participants without a psychosocial disability, however the impacts of engaging in the PIP process were generally portrayed less negatively in this subset of participants.

Anticipatory anxiety, relating primarily to communication with the DWP and the lead-up to (re)assessment, was a recurrent theme. The ‘dreaded brown envelope’ (Roberts et al., 2022, p.9) phenomenon of intense anticipatory anxiety related to postal communication with and from the DWP was noted exclusively by participants with a psychosocial component of their disability. For some participants, this anxiety was also associated with flares of physical disabilities.

> *“You think oh god the letter's going to come* [...] *and the letter always seems to come like so many days later than what the date on the letter, and they want it back in by a certain time and, I'm still, like, somewhat terrified about it all the time”* – James

> *“I'm already stressing about 2026 already. I'm already anxious about it and I've still got two years to go. And I think you get that relief for the first month, maybe, when you're like, okay, it's over, it's done, like I won't have to do it again for years, and then it's, but it's going to come back around. It's going to come back.* [...] *I then spend 6 to 9 weeks in bed because of the stress where my heart goes and I get the sweats and my stomach goes and I end up flaring up and then I need steroids, and then my bones get worse because I'm on the steroids and then I break my ankle because the steroids*

> *have made my bones bad, and it's just this whole cycle of suffering."* – Jessica

Beyond purely anticipatory anxiety, elements of the application and assessment process were also noted to have significant psychological impacts on participants. These were particularly evident when considering participants' experiences of evidence submission and assessment.

> *"I had very bad like, post-traumatic stress from it almost, and I couldn't leave my house for weeks because every time I went out, I was like 'People are judging me. People are looking at me', like they saw my medical documents"* – Jessica

> *"I didn't really want that* [a home assessment] *very much, I was so scared, I didn't really want to see them and I was getting upset about them coming and stuff"* – James

> *"The face-to-face meeting in* [location omitted] *was very dehumanising. The man was very judgmental, um, not degrading, but I felt very demoralised."* – Jennifer

> *"I felt that they set you up for failure, uh, it felt very humiliating"* – Linda

Isolated positive experiences and impacts of PIP

Whilst participants all framed their experiences, as a whole, as neutral or negative, most participants spontaneously identified more positive aspects of their experience with or impacts of PIP. These primarily centred on positive interactions with specific members of staff and on the financial support provided by successfully claiming PIP.

> *"The lady that I spoke to over the phone was a lot more, a lot more compassionate, she, it felt as if she was trying to help me, I felt as if she was on my side a bit more the second time, she was a very nice lady."* – Jennifer

> *“Obviously it's beneficial. I get the higher rate or the enhanced mobility so they help me with my car which is a lifeline.* [...] *So if I didn't have that, it would make my life very difficult.* [...] *I wouldn't be able to afford to just pay for a car on my own. So that's extremely beneficial.”* – Jessica

Perceptions of better-known and visible disabilities as subject to fewer barriers

Most participants perceived better-known and/or visible disabilities as being subject to fewer barriers and more inviting of positive attitudes, both in the PIP application and assessment process and more widely, perhaps reflecting beliefs that assessors lack knowledge of less common conditions. This perception of the structure of hierarchies of disabilities that may operate within the PIP system appears broadly unchanged regardless of participants’ specific condition or disability type(s).

> *“I think physical disabilities are given preference, priority, because they're inarguable in a way. [...] So, I think that, so, physical visible first and then probably physical fluctuating second, I think neurodiversity comes way down the list, in term-, because it's harder for people to prove, because it's hard enough for people to get a diagnosis and sometimes that diagnosis can be a bit woolly and poorly understood by a lot of health professionals, never mind people who are assessing these things, who aren't really professionals and not that experienced”* – Mary

> *“The Down Syndrome Act is a little bit frustrating that it's one chromosome disorder and there are many similar ones, including 22Q, so I think that's a bit of a hierarchy and, and that frustrates me. [...] I'm wondering whether, like lesser-known conditions like EDS [Ehlers-Danlos Syndrome], they're not taken as seriously as those that are more known”* – Sarah

> *“I think having a visible disability, it's easier for the general population to respond in a positive way”* – Linda

> *“Because I don't have, I want to say a, like, known disability or I'm not in a wheelchair constantly or an amputee or have visible signs of being sick, I*

> *have been treated differently.* [...] *because I look healthy, because I don't have missing limbs or no hair or, you know, a feeding tube,* [...] *like it's, I'm not taken seriously ever when it comes to disabilities."* – Jessica

Discussion

The findings presented above accord broadly with existing literature considering claimant experiences, particularly those of Garthwaite (2013), Gray (2014; 2017), Machin and McCormack (2021), Pybus et al. (2021), and Roberts et al. (2022), suggesting good study reliability.

A hierarchy of disabilities in which psychosocially disabled claimants are disadvantaged and differentially subject to adverse impacts appears to emerge when comparing the experiences of participants. This finding, with psychosocially disabled participants appearing to both have more negatively perceived experiences and to subjectively experience more, and greater levels of, psychological harm through their participation in the PIP process, appears to support the view that PIP perpetuates a hierarchy of disabilities reflecting that present in the labour market. Similarly, participants with fluctuating or episodic disabilities, notably multiple sclerosis in this study, emphasised feeling misunderstood and disbelieved, according well with Harpur's (2020, p.83) findings in the context of the labour market. This raises questions as to validity of the construction of disability utilised in the PIP assessment process which tends to frame disability as a stable, predictable phenomenon. As suggested by participants, both the PIP2 form and assessment can be perceived as a "tick box exercise" which only provides "a snapshot of your life" (Jennifer), making it challenging for claimants to adequately capture the reality of their disability through PIP's highly standardised framework.

Several of the issues raised in Gray's independent reviews of the assessment process seemingly remain key features of claimants' negative experiences of PIP, despite some seven years having elapsed since recommendations for improvement were issued to the DWP. Particularly, this study demonstrates that claimants may still face substantial barriers and adverse impacts in collecting and providing supporting evidence, communicating with the DWP, relying on support outside the DWP, and, crucially, being and feeling understood in the assessment process. One issue identified by participants, and by Gray (2017, p.41), as having a significant impact on feelings of being misunderstood and distrusted in the assessment process, is that those conducting assessments ‘may be neither a specialist nor familiar with their health condition’. Whilst Gray (2017, p.41) concluded that, in principle, assessors’ lack of specialist knowledge should not interfere with their ability to conduct functional assessments, it seems that this remains a significant factor in leading participants to feel poorly understood in both this and other studies. This is potentially exacerbated further amongst claimants who have little or no access to specialist medical care outside of the PIP process, a population thought to disproportionately include those with hidden and psychosocial disabilities (Gray, 2017, p.35). As suggested by participants when asked to reflect on how their experiences of PIP might have been improved, it seems sensible, if not imperative, that the DWP further review the role of specialist medical practitioners in the assessment process, either as a means of providing advice and training to assessors on ‘condition-specific knowledge’ (Gray, 2017, p.41) or in directly conducting assessments, in order to improve the claimant experience and potentially thereby reduce adverse psychological impacts from feeling poorly understood or disbelieved.

Interestingly, this study may also suggest gendered and age-related dimensions to hierarchies of disability, both in the context of PIP and in functional or medical assessments more broadly. Jessica’s account of being dismissed, being told she “was too young to be sick” and that “women get like this when they're unwell”, whilst possibly an isolated experience, appears to closely reflect findings from studies in medical contexts that women, especially younger women with anxiety, are more likely to experience dismissal of symptoms or ‘medical gaslighting’ (e.g. Au et al., 2022; Sebring, 2021; Hoffmann, Fillingim and Veasley, 2022). Future research on claimant experiences of Personal Independence Payment ought to pay specific attention to the potential role played by gender and age-based biases in differentiating experiences between claimant groups as this dimension remains under-studied.

Conclusions

These findings support the notion that a hierarchy of disabilities, mirroring that found in the labour market, which disadvantages psychosocially disabled people may be propagated by the PIP application and assessment process. The generally negative perceptions of PIP expressed by participants in this study, particularly against the background of existing research which reports similar sentiments, underscores the need for further larger-scale, more representative research to produce a rigorous understanding of claimant experiences and how these may vary based on disability type and, as drawn out in the discussion, how this may be modulated by gender, age, and other factors. This also suggests that PIP, and disability welfare policy in the UK more generally, ought to be reviewed with the voices and needs of disabled people, rather than economic or ideological concerns, at the centre with a particular focus on the qualification of assessors, reducing barriers to obtaining evidence, and adoption of a trauma-informed approach.

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