“They don’t understand people with learning disabilities”: Exploring the experiences of people with intellectual disabilities who undergo welfare assessments.

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Thesis Overview

Individuals with intellectual disabilities are eligible for out of work and disability benefits within the United Kingdom (UK) welfare system. Research suggests that the welfare system causes psychological harm (Arie, 2018), which has been linked to work capability assessments (WCA; Barr *et al.,* 2016). Existing studies on people who claim benefits (e.g. Allen *et al*., 2016) have not focussed on the experiences of people with intellectual disabilities. The aim of this project is to explore the experiences of people with intellectual disabilities who undergo WCA and provide insight into potential interventions to reduce any psychological distress related to claiming benefits.

Stigma is experienced by people who claim benefits (Baumberg *et al.*, 2016) and people with intellectual disabilities (Scior, 2016). Stigma has been linked to psychological distress in people with intellectual disabilities (Ali *et al*., 2015) and people who claim benefits (Thompson, in press). Self-stigma may be particularly harmful (Boyd *et al.,* 2014). It has been suggested that self-compassion may act as a buffer between self-stigma and distress (Wong *et al*., 2019). Therefore, Chapter One of the thesis comprises a systematic review of literature examining the relationship between self-stigma and self-compassion. The synthesis of twenty quantitative papers demonstrated consistent, inverse associations between self-compassion and self-stigma scores, suggesting that self-compassion could have potential benefits for reducing the impact of self-stigma.

Chapter Two is an empirical paper exploring the lived experiences of eight people with intellectual disabilities in the UK, who were interviewed about their experiences of being assessed for welfare eligibility. Interpretative phenomenological analysis (IPA) suggested five closely related themes; *living in fear; marginalisation; relationship with the assessor; others as a safe base;* and *finding value*. The findings captured the distressing nature of the benefit assessment process for people with intellectual disabilities. Although this was an exploratory study, findings suggest that future research and interventions might be usefully targeted towards improving the experience of the assessment process, as well as clinically treating individual's responses to the assessment process. Recommendations for change across individual, systemic and policy levels are included.

Chapter Two was prepared with consideration to journal submission (Journal of Applied Research in Intellectual Disability), however the thesis version exceeds the journal word count requirements to reflect the level of detail required for thesis submission.

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Chapter I: Examining the relationship between self-stigma and self-compassion.

Abstract

Objectives: Self-stigma is thought to negatively impact on self-esteem and wellbeing. Self-stigma has been found in some individuals with stigmatised identities, but not everyone who experiences public stigma internalises stigma. Self-compassion has been hypothesised to reduce the risk of self-stigma and the negative outcomes associated with it. This review examined the nature of the relationship between self-compassion and self-stigma and explored the evidence for Wong *et al.'s* (2019) model: *Hacking Stigma by Loving Yourself.* **Method:** A systematic review of published studies that reported the correlational relationship between self-compassion and self-stigma, using univariate or multivariate methods. **Results:** Twenty papers were included, with 21 data-sets that investigated self-stigma related to: weight, mental health, sexual minority status, help-seeking, affiliate stigma, and HIV. Self-stigma scores showed consistent, inverse associations with self-compassion scores in univariate analyses (r= -.12 to r= -.68). Significant, inverse relationships were maintained with multivariate analyses (β= -.20 to β= -.43), although only a small number of studies utilised this approach. **Conclusions:** Findings suggest that self-stigma and self-compassion are inversely associated, which could have potential utility for improving the impact of self-stigma. The relationship is observed across all types of self-stigma investigated in the included papers. The included mental health self-stigma evidence was relatively more limited due to methodological limitations of the studies. More research is needed to investigate self-compassion as a mediator between self-stigma and wellbeing before interventions are developed and evaluated.

Introduction

Stigma

Goffman (1963) adopted the term ‘stigma’ from the Greek language, indicating an observable mark that infers something bad about an individual. He conceptualised social stigma as the shame an individual experiences when society discredits a personal attribute of theirs. Stigma research has spanned across different groups, such as such as those with mental health diagnoses (Livingstone and Boyd, 2010), those with intellectual disabilities (Ali *et al.*, 2012) and those considered overweight (Puhl & Heuer, 2009). The definition of stigma varies widely, reflecting the wide application of the concept to different groups and individuals (Link and Phelan, 2001). Current conceptualisations of stigma consider individual cognitive processes such as labelling, attribution and stereotyping and pay increasing attention to social forces that sustain stigma, such as power and discrimination (Corrigan 2000; Corrigan *et al.,* 2003; Herek, 2007, 2009; Link and Phelan, 2001).

Stigma literature suggests there are four main stigma domains (Livingstone & Boyd, 2010; Corrigan *et al.,* 2005; Herek 2009). Public stigma refers to behavioural manifestations of negative stereotypes, such as discrimination or prejudice, observed in the wider societal group. Perceived (or felt) stigma refers to the stigma an individual experiences or expects towards them from the public. Structural stigma refers to the policies and procedures that restrict the opportunities of those who are stigmatised. Internalised stigma (or self-stigma) is thought to be experienced at the individual level; stigma is accepted and applied by a stigmatised individual to themselves and others who share the attribute. This review focuses on self-stigma, which is thought to be the most harmful stigma domain (Ritsher & Phelan, 2004).

Self-stigma

Self-stigma is thought to occur when a stigmatised individual applies stigmatising stereotypes to themselves, incorporating society’s negative evaluation of them into their own values and self-view (Corrigan *et al.,* 2006; Corrigan and Rao, 2012; Corrigan & Watson, 2002; Livingstone & Boyd, 2010). Link (1982, 1987) proposed that stigma is internalised through modified labelling, where stigmatised labels are learnt in early life and then applied to the self when one becomes part of a stigmatised group. This suggests that all of those who are stigmatised will automatically internalise stigma once they become aware of their stigmatised identity. However, research suggests that this is not the case; some who are stigmatised reject their stigmatised status, becoming angry, rather than accepting of stigma (Corrigan & Watson, 2002).

Therefore, it is likely that there are mediating processes that affect whether stigma is internalised or rejected by those who are stigmatised. Cognitive processes, such as appraisal of stigmatised stereotypes, are theorised to be an important step between becoming aware of stigma and applying stigma to the self (Corrigan & Watson, 2002; Crocker & Major, 1989; Sheehan & Ali, 2016). Within these social-cognitive perspectives it is recognised that the experience of public stigma does not always lead to self-stigma (Corrigan *et al*., 2006; Watson *et al.,* 2007; Vogel *et al*., 2013).

When individuals do internalise stigma it can have a profound impact. Boyd *et al*. (2014) described self-stigma as the "psychological point of impact of societal stigma" (p.17). Research has indicated that self-stigma mediates the impact of public stigma on psychological distress (Feinstein *et al.,* 2012), negative social outcomes (Munoz *et al.,* 2011), and poor physical health (Livingstone & Boyd, 2010); in these studies, the presence of self-stigma was linked to higher levels of these deleterious outcomes.

Mechanisms Associated with Self-stigma

Considering the negative impact self-stigma appears to have, several researchers have sought to uncover mechanisms associated with self-stigma. For example, Hatzenbeuhler *et al.* (2009) attempted to explain why some individuals who identify as sexual minorities internalise stigma and experience negative effects; their model highlighted the mediating role of emotional regulation. They suggested that experiences of stigma-related prejudice can lead to elevated emotional dysregulation, social difficulties, and cognitive risk factors that in turn trigger the internalisation of stigma. This theory recognises that while self-stigma may in part be a reaction to experiences of public stigma, there are likely to be other psychological processes involved. The model was based on sexual minority stigma literature; therefore, it may be less applicable to self-stigma more broadly.

Other research has focused on investigating the mechanisms associated with self-stigma related to experiencing mental health difficulties. Hassaon-Ohayon *et al.* (2012) observed shame as a mediating factor between a person's insight into their mental health difficulties and self-stigma; higher shame-proneness was associated with increased self-stigma. Shame has also been observed as the main emotional component of stigma in people with substance dependencies (Luoma *et al.,* 2012). The role of shame in self-stigma is unsurprising considering the association between shame and beliefs that one is defective or flawed (Tangney *et al.,* 2007), the latter being a hallmark of self-stigma.

Self-esteem may also play an important role in self-stigma; in their 'why try' model of self-stigma, Corrigan *et al.* (2009) suggested that self-esteem and self-efficacy mediate the impact of self-stigma on reduced goal-related behaviour in those with mental health difficulties.. Link & Phelan (2001) found evidence to support the 'why try' model, demonstrating an association between higher self-stigma and lower self-esteem and self-efficacy. However, this relationship was correlational, therefore it is unclear whether low self-esteem leads to an increased risk of internalising stigma or whether self-stigma has a negative impact on self-esteem.

For people who attract a diagnosis of psychosis, social anxiety was found to be associated with self-stigma (Lysaker *et al.,* 2010). Birchwood *et al.* (2007) proposed that stigmatising experiences lead to the social devaluation of people experiencing psychosis, which in turn manifests in shame and social anxiety. These findings support Cassano *et al.* (1998), who proposed that internalised stigma may lead those with severe mental health difficulties to avoid social situations.

Self-stigma Reduction Interventions

Reducing public stigma remains integral to improving the wellbeing of those who are stigmatised (Wood *et al.,* 2017). A systemic approach to public stigma reduction should emphasise the role of power, with an anti-oppression approach that draws upon social justice and the intersectionality of stigma (Corrigan *et al*., 2005; Holley *et al*., 2012). However, while public stigma reduction strategies should undoubtedly continue to be explored and implemented, it is recognised that they often take an extended period to facilitate change (Rusch *et al*., 2005). Therefore, researchers have turned to reducing self-stigma and its impact on individuals who are stigmatised (Yanos *et al.,* 2015).

Self-stigma reduction interventions have focused on either altering an individual's stigmatised beliefs and attitudes or developing acceptance and coping skills (Mittal *et al.,* 2012). One such intervention is Acceptance and Commitment Therapy (ACT), a third-wave cognitive-behavioural therapy that conceptualises suffering as an inevitable part of human experience, rooted in Eastern philosophy, such as Buddhism (Hayes, 2005). From this perspective, distress arises when one attempts to escape uncomfortable inner experiences with behaviours that lead to an inconsistency between actions and values (Tirch *et al.,* 2014). Therefore, ACT aims to facilitate the development of acceptance towards unwanted inner experiences (Hulbert-Williams *et al.,* 2015).

Limited empirical research has demonstrated the potential value of ACT in reducing the self-stigma for people who use substances (Luoma *et al.,* 2008) and those who experience self-stigma due to their weight (Griffiths *et al*., 2018). Luoma and Platt (2015) suggested that self-compassion may be the active variable in ACT and could also enhance the impact of ACT in reducing self-stigma and associated negative outcomes. Indeed, self-compassion has been found to be associated with better wellbeing in those who are stigmatised, including overweight individuals (Hilbert *et al.,* 2015), people with HIV (Brion *et al.,* 2014) and people with eating disorders (Kelly & Tasca, 2016).

Self-compassion

Self-compassion describes a healthy, compassionate way of relating to oneself, including the desire to heal oneself from suffering with kindness (Neff, 2003). There are different models of self-compassion that may relate to self-stigma differently. Neff (2003) conceptualised self-compassion as an interaction of three dimensions: 1) self-kindness, as opposed to self-judgement or self-criticism; 2) common humanity, the acknowledgement of suffering as universal as a human experience and a way in which we are connected to each other; and 3) mindfulness, the ability to accept suffering as inevitable while not over-identifying with it. When an individual is high in self-compassion, they are considered to have the ability to accept and integrate negative experiences (Neff & Dahm, 2015). This model is primarily concerned with defining self-compassion and this definition has been used in further research where a framework to identify different elements of self-compassion is required (e.g. Wong *et al*., 2019).

Gilbert (2014) developed a model of self-compassion more concerned with the relationship between self-compassion and emotional distress, developing thinking around the clinical utility of self-compassion in improving wellbeing. To do so, Gilbert (2009, 20014) drew upon neuroscientific evidence to develop an evolutionary model, based upon the recognition that historically evolved emotional and social processes may impact current experiences of emotional distress. For example, the environment in which the human brain evolved has led to a vulnerability to unhelpful cognitive biases, such as self-criticism (Baumeister *et al.,* 2001). Furthermore, the relationship one has to the self seems to be a significant factor in the development of distress, with evidence to suggest that shame and self-criticism underlie mental health difficulties (Gilbert & Irons, 2005). Gilbert (2014) outlines three affective systems conceptualised as ancient, evolved mechanisms: the threat-protection system, the drive or motivation system and the soothing system. Emotional distress is thought to be an outcome of imbalance between these systems and subsequent difficulties being self-compassionate (Gilbert, 2009).

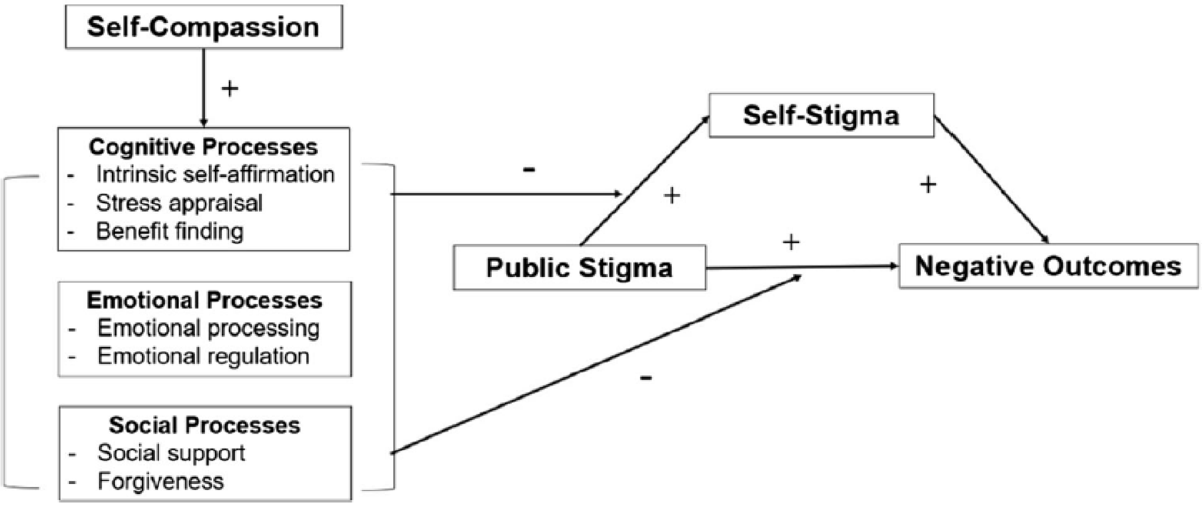
A wealth of research links self-compassion with wellbeing; meta-analyses have found that self-compassion is significantly associated with better psychological and cognitive wellbeing and lower levels of psychiatric diagnoses (MacBeth & Gumley, 2012; Zessin *et al*., 2015). Self-compassion has been associated with; better physical health (Allen *et al*., 2012; Hall *et al*., 2013), the ability to cope with major life stressors (Vettese *et al.,* 2011) and the effective management of chronic pain (Costa & Pinto-Gouveia, 2011). This has led to the clinical application of self-compassion enhancement within psychological interventions.

Hacking Stigma by Loving Yourself (Wong et al. 2019)

Wong *et al*. (2019) suggested that self-compassion might protect against the negative effects of self-stigma by allowing stigmatised individuals to accept their stigmatised identity and develop a more balanced view of the self. The authors developed their model (*Hacking Stigma by Loving Yourself*) by drawing upon thinking from Hatzenbeuhler *et al.* (2009), who suggested that the link between self-stigma and negative outcomes is rooted in the emotional, social, and cognitive difficulties that arise following experiences of prejudice. Therefore, the model outlines how self-compassion might be beneficial in each of these domains, protecting against cognitive biases, emotional dysregulation, and social difficulties (see Figure 1.1). The assumption that higher self-compassion is associated with less self-stigma is a key aspect of the model.

Figure 1.1

Wong et al.'s (2019) Model: Hacking Stigma by Loving Yourself



Wong *et al.'s* (2019) model is supported by literature that suggests self-compassion is an adaptive emotion regulation strategy due to its association with less rumination and enhanced emotion regulation capacity (e.g. Vettese *et al.,* 2011). However, Wong *et al.,* (2019) noted that although the theoretical foundation is strong, more empirical research is needed to provide further evidence for their model of self-stigma and self-compassion.

Aims

The current review aims to provide empirical evidence pertaining to Wong *et al's.* (2019) model, *Hacking Stigma by Loving Yourself,* specifically the assumption that there is an inverse relationship between self-compassion and self-stigma (e.g., higher self-compassion is associated with less self-stigma). This review aims to systematically identify and synthesise the published, quantitative data that examines the relationship between self-stigma and self-compassion. If an association is observed, the overall direction and strength of the relationship will be discussed in the context of clinical implications.

Methods

Systematic Methodology

Systematic methodology encourages the objective synthesis of data from a group of primary studies, by aiming to minimise bias (Greenhalgh, 1997). Transparent and reproducible methods are achieved by reporting pre-determined parameters, such as inclusion criteria and quality assessment tools. This allows the review to be reliably replicated and accurately appraised by readers. The Centre for Reviews and Dissemination (Khan *et al.,* 2008) outlined specific advantages of utilising systematic methods, including improved reliability and accuracy of conclusions, the provision of comprehensive overviews of specific areas and the assimilation of large volumes of information.

Due to considerable heterogeneity across the methodology and outcome measures used in the eligible studies, meta-analyses will not be conducted. Popay *et al.* (2006) suggests that narrative synthesis aims to 'tell the story' of the data from studies included in the review. There is no standardised methodology for this approach to synthesis, however the current review will utilise the Economics and Social Research Council guidance (Popay *et al*., 2006).

Search Strategy

To reduce the potential for selection bias, a systematic search strategy was developed. A circular process was undertaken, whereby terms were informed by reviewing the literature and the research question was modified accordingly (Khan *et al*., 2008). This culminated in the following search terms:

(1) "*self compassion*" OR *self-compassion* OR *compassion**

(2) *stigma* OR *stigma** OR *self-stigma* OR *"self stigma"*

The terms were combined using the Boolean 'AND' function across five databases: PsycINFO, CINAHL, PubMed, Scopus and Web of Science. The search took place in October 2020 and was limited to peer-reviewed articles and those written in English.

Inclusion and Exclusion Criteria

Pre-determined inclusion and exclusion criteria were utilised to allow systematic decisions regarding the inclusion of papers. The following criteria were applied:

1) Primary research papers that collected quantitative data (no limit on publication date).
2) Participants were aged 18 or over.
3) Included measures of self-stigma and self-compassion.
4) Bivariate or multivariate analyses examined the relationship between the two variables.
5) Published in peer-review journals, thus excluding unpublished thesis and other grey literature.

Single case designs were excluded to ensure comparability between studies and increase the robustness of the findings. Papers where an English version was not available were excluded due to the language limitations of the research team.

Study Selection

Following the implementation of the above search strategy, the referencing software 'EndNote' was utilised to store all the references the search returned. Titles and abstracts of the studies were screened against the inclusion and exclusion criteria and categorised as either 'exclude' or 'review full text'. A 10% sample of the initial records were also screened by an independent researcher, to cross check the screening process, which confirmed that the inclusion criteria were robust.

The papers for full text review were read thoroughly by the lead researcher and included or excluded based upon the inclusion and exclusion strategy. The reference lists of included studies were also reviewed by hand, to identify any other papers that were eligible for inclusion. Included studies were examined and relevant data was extracted and tabulated.

Assessing Quality

To assess quality and the risk of bias within each of the included study, the Joanna-Briggs Institute (JBI) critical appraisal checklist for analytical cross-sectional studies was utilised (see Appendix A). The JBI tool reflected the context of the included papers and effectively captured the cross-sectional nature of the studies. The lead researcher valued the concise items that considered the key areas of potential bias in cross-sectional studies. Furthermore, the JBI is recommended compared to the other tools that are designed to assess cross-sectional studies and is the most used in cross-sectional studies (Ma *et al.*, 2020). A bespoke guidance tool (see appendix B) was developed to ensure a standardised approach to the quality assessment as some items seemed somewhat vague and subjective. The guidance tool also allowed a scoring system to quantify the methodological quality of the studies which allowed variations in methodological quality to be considered in the synthesis.

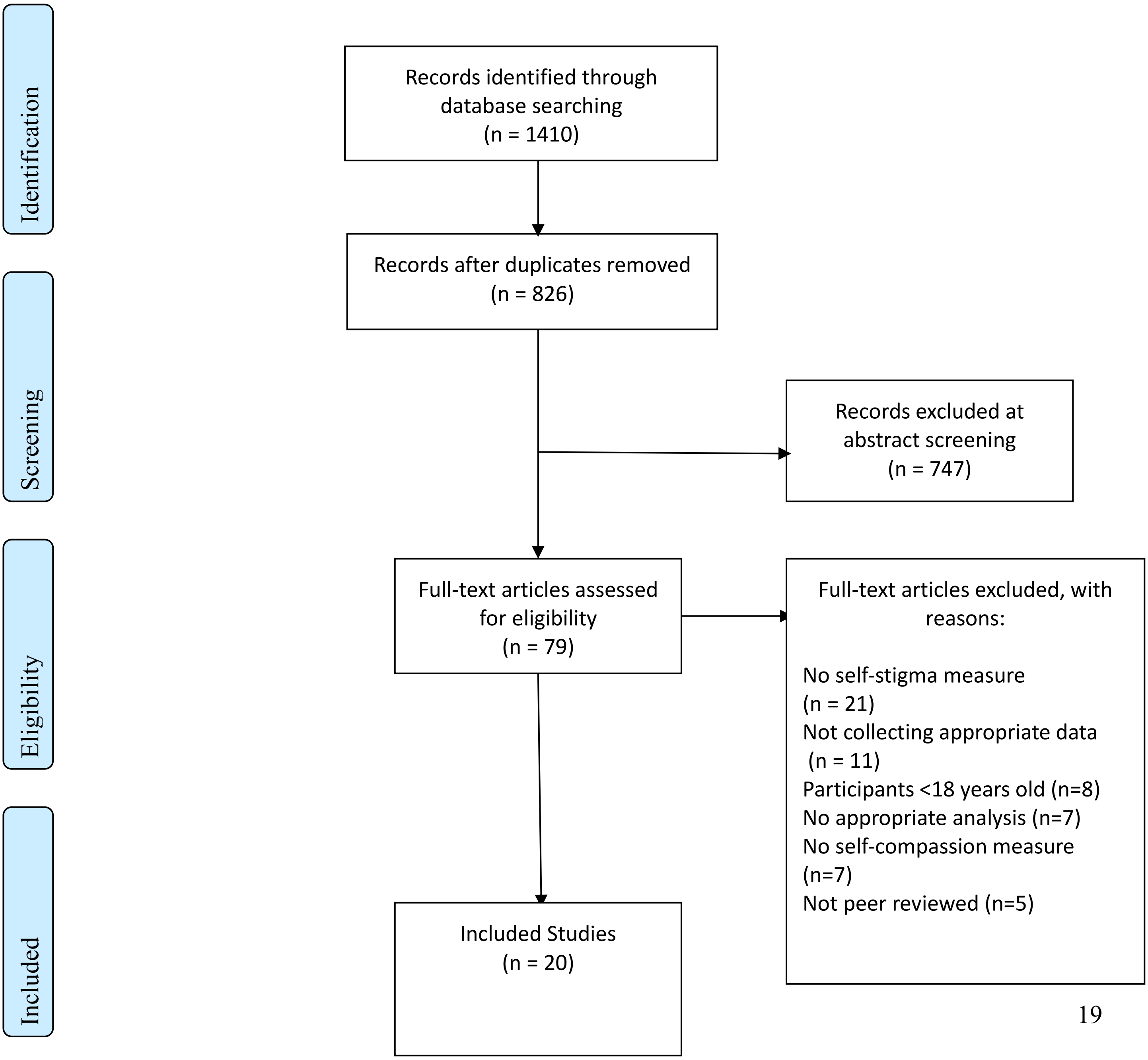
Results

Study Selection

Figure 1.2 summarises the study selection process. 1410 records were identified in the initial search and 826 unique citations remained following the removal of duplicates. After screening the titles and abstracts of these records against the inclusion and exclusion criteria, 79 potentially eligible papers remained. 20 papers were included in the current review.

Figure 1.2

PRISMA 2009 Flow Diagram



Study Characteristics

Table 1.1 summarises the main characteristics of the 20 included studies. The studies were published between 2015 and 2020 and conducted in various countries. 5953 participants were included, and mean ages ranged from 19.3 to 53.6. All but one of the studies were of cross-sectional design, with one utilising a naturalistic case control design (Dossing *et al.*, 2015). The studies investigated a variety of self-stigma types and sampled a range of target populations.

Five studies investigated internalised stigma relating to sexuality, recruiting either self-identifying gay men (Beard *et al.*, 2017), gay men living with HIV (Skinta *et al.*, 2018) or sexual minorities more generally (Chan *et al.*, 2020; Fredrick *et al.*, 2019; Petrocchi *et al.*, 2020).

Of the five studies that focused on internalised weight bias, two studies sampled students (Huelleman & Calogero, 2020; Webb & Hardin, 2016), two recruited clinically obese and overweight people (Forbes and Donovon, 2019; Hilbert, 2015) and one sampled bariatric surgery candidates (Braun *et al.*, 2020).

Four studies investigated internalised stigma related to seeking psychological help, such as counselling. These studies all sampled student populations (Booth *et al.*, 2019; Heath *et al.*, 2017; Heath *et al.*, 2018; Hilliard *et al.*, 2019).

Four studies looked at self-stigma related to the experiences of mental health difficulties and recruited participants with either current or remitted mental health difficulties (Chan *et al.*, 2018; Collett *et al.*, 2016; Dossing *et al.*, 2015; Yang and Mak, 2017).

Two studies sampled parents of children with ASD to investigate affiliate stigma (internalised associated stigma); one recruited from China (Wong *et al.*, 2016) and the other from Australia (Torbet *et al.*, 2019). One study investigated internalised HIV stigma, recruiting individuals living with HIV (Yang & Mak, 2017). Yang and Mak (2017) investigated two types of self-stigma with two corresponding samples, therefore 21 samples and datasets are synthesised.

Table 1.1

Summary of Participant Demographics & Study Design

Authors (year), country	Target population	Type of Stigma	Design	Sampling method	Sample size (n)	Age Mean (SD)	Female N (%)	Ethnicity N (%)
Beard, Eames & Withers (2017), UK	Self-identifying gay men	Homophobia	Cross-sectional	Self-selecting via community spaces (online and physical)	139	38.3 (N/R)	0%	Black or Black British Africa (0.72%) Other (5.04%) White British (84.2%) White Irish (3.56%) White European (6.47%)
Booth et al. (2019),USA	Male university students	Help-seeking	Cross-sectional	Self-selecting via targeted emails	777	24.1 (N/R)	0%	African-American Indian or Other or did not respond (3.5%) Alaskan Native (0.1%), American/Black (5.5%), Asian or Asian-American (15.5%) Hispanic/Latino (6.4%) Multiracial (5.7%) White (63.3%),
Braun et al. (2020), USA	Bariatric surgery candidates	Weight	Cross-sectional	Purposive sampling via sample pool of a prospective trial	213	42.78 (12.0)	82.8%	Asian (1%) Black/African American (18.3%) Native American/Alaska Native (1%) Multiracial (6.6%) Other/undisclosed (8.5%) White (64.8%)

Authors (year), country	**Target population**	**Type of Stigma**	**Design**	**Sampling method**	**Sample size (n)**	**Age Mean (SD)**	**Female N (%)**	**Ethnicity N (%)**
Chan, Lee & Mak (2018), China	Individuals with psychiatric diagnoses	Mental Health	Cross-sectional	Self-selecting via community mental health centres	311	43.61 (9.52)	65.9%	N/R
Chan, Yung & Nie (2020), China	Sexual minority (lesbian, gay or bisexual) individuals	Homophobia	Cross-sectional	Self-selecting via community spaces (online and physical)	401	27.48 (6.5)	N/R	N/R
Collett *et al.* (2016), UK	Individuals experiencing persecutory delusions	Mental Health	Cross-sectional	Recruited from clinical teams in an NHS trust	21	45.6 (12.1)	52%	N/R
Dossing *et al.* (2015), Denmark	'Remitted' bi-polar disorder' patients	Mental Health	Naturalistic case control	Purposive recruitment via a Mood Disorder Clinic in Denmark	30	N/R	N/R	N/R
Fredrick *et al.* (2019), USA	Self-identifying sexual minorities	Homophobia		Self-selecting via social media sites	213	25.15 (8.86)	55.5% cisgender female .3% transgender female	White (89.5%)

Authors (year), country	**Target population**	**Type of Stigma**	**Design**	**Sampling method**	**Sample size (n)**	**Age Mean (SD)**	**Female N (%)**	**Ethnicity N (%)**
Forbes & Donovan (2019), Australia	Overweight and obese females	Weight	Cross-sectional	Self-selecting	147	30.74 (8.91)	100%	N/R
Heath *et al.* (2017), USA	Male undergraduate students	Help-seeking	Cross-sectional	Self-selecting via university research pool	284	19.68 (1.67)	0%	African American (4.2%) Asian American/Pacific Islander (9.2%) European American (80.3%), Latino (2.8%), Multiracial (2.1%) Other (1.4%).
Heath *et al.* (2018), USA	Undergraduate students	Help-seeking	Cross-sectional	Self-selecting	369	19.3 (1.7)	51.5%	African American (1.9%) Asian American or Pacific Islander (5.4%) European American (81.0%) Latino/Latina American (5.4%) Multiracial American (1.9%) Other or no response (4.4%)

Authors (year), country	**Target population**	**Type of Stigma**	**Design**	**Sampling method**	**Sample size (n)**	**Age Mean (SD)**	**Female N (%)**	**Ethnicity N (%)**
Hilbert *et al.* (2015), Germany	Overweight and obese men	Weight	Cross-sectional	Random-route-assisted sampling from 2012 population survey	1158	53.56 (16.22)	0%	N/R
Hilliard *et al.* (2019), USA	College student athletes	Help-seeking	Cross-sectional	Self-selecting targeted via email	243	19.38 (1.25)	39.91%	Asian (2%) Black/African American (8%) Biracial (2%) Hispanic/Latino (4%) Native American (1%) Pacific Islander (3%) White/Caucasian (82%)
Huelleman & Calogero (2020), Canada	Undergraduate females	Weight	Cross-sectional	Self-selecting targeted via university participant pool	177	19.3 (1.44)	100%	Aboriginal (0.6%) Black (1.1%) Chinese (21.5%) Eastern (4.0%) Filipino (0.6%) Korean (1.1%) Latin (1.7%) Middle Multi-racial (5.6%) Other (2.3%) South Asian (13.0%) Southeast Asian (1.1%) White (47.5%)

Authors (year), country	**Target population**	**Type of Stigma**	**Design**	**Sampling method**	**Sample size (n)**	**Age Mean (SD)**	**Female N (%)**	**Ethnicity N (%)**
Petrocchi *et al*. (2020), Italy	Italian people self-deined as gay, lesbian or bisexual.	Sexuality	Cross-sectional	Self-selecting via lesbian, gay and bisexual spaces and mailing lists	327	Lesbians:25.7, (4.5); Gay men: 27.8, (5.7); Bisexual women: 25.2, (4.2) Bisexual men: 27.1, (6.9).	50.5	N/R
Skinta *et al.* (2019), USA	Self-defining gay men living with HIV	Sexuality	Cross-sectional	Self-selecting via LGB spaces (physical and online)	195	43.5 (11.7)	100%	White 54.4 Black 31.2 Hispanic 12.2 Asian 1.1 Native Hawaiian/Pacific Islander 1.1
Torbet *et al*. (2019), Australia	Parents of children with ASD	Affiliate	Cross-sectional	Targeted self-selecting via autism specific services	237	39.97 (7.12)	96.2	Caucasian 90.3 Indigenous or Torres Strait Islander 2.1 Asian 2.5 Other 2 5.1
Webb & Hardin (2016), USA	Weight diverse college women	Weight	Cross-sectional	Self-selecting via University research participant pool	362	19.4 (1.53)	100%	20.2% Black/African American, 63.0% White/European American, 5.6% Hispanic or Latina American, 4.0% Asian or Asian American, 5.9% Multi-ethnic or racial, and 1.2% identified as Other.

Authors (year), country	**Target population**	**Type of Stigma**	**Design**	**Sampling method**	**Sample size (n)**	**Age Mean (SD)**	**Female N (%)**	**Ethnicity N (%)**
Wong *et al.* (2016), China	Chinese parents of children with autism diagnoses	Affiliate	Cross-sectional	Targeted self-selecting	180	42.31 (7.20)	84.2%	N/R
Yang & Mak (2017). China	People with mental health dx	Mental Health	Cross-sectional	Targeted self-selecting	169	42.7((10.2)	47.4%	N/R
	People living with HIV	HIV	Cross-sectional		291	41.8 (11.1)	5.2%	

Assessment of Self-stigma and Self-compassion

As shown in Table 1.2, self-compassion was measured using the Self-Compassion Scale (SCS; Neff, 2003) in all but one study. Fourteen studies used the original 26-item version of the measure, while six used the adapted 12-item version (Raes *et al*., 2011). One study used the Forms of Self-Criticizing and Self-Reassuring Scale (FSCRS; Gilbert *et al*., 2004) to measure self-compassion. The scale is comprised of three subscales: inadequate self, hated self, and reassured self.

Self-stigma was assessed with a range of measures, reflecting the diversity in the types of self-stigma being investigated. The studies that measured internalised sexual stigma each utilised a different scale. One study measured self-stigma content and process separately with two different scales (Chan *et al*., 2020). Similarly, each study measuring mental health self-stigma used a different scale, with two studies assessing self-stigma content and process separately (Chan *et al.,* 2018; Yang & Mak (2016).

Two studies investigating internalised weight stigma used the 11-item Weight Bias Internalization Scale (WBIS; Durso & Latner, 2008) while three used the 9-item WBIS-Modified (WBIS-M; Pearl & Ruhl, 2014). The studies examining internalised help-seeking stigma all used the Self-Stigma of Seeking Help Scale (SSOSH; Vogel *et al*., 2006). The two studies assessing affiliate stigma both used the Affiliate Stigma Scale (Mak and Cheung, 2008). HIV self-stigma was investigated in terms of both content (the cognitive subscale of the Self-Stigma Scale, SSS; Mak and Cheung, 2010) and process (Self-stigmatizing Thinking's Automaticity and Repetition Scale, STARS; Chan and Mak, 2017).

Table 1.2
Summary of Assessment and Results

Authors	**SC Measure**	**SS Measure**	**Bivariate Analyses Outcome**	**Multivariate Analyses**	
				Control Variables	**Outcome**
Beard *et al*. (2017)	SCS	IHI	r = -.456, p<.001	N/A	N/A
Booth *et al.* (2019)	SCS	SSOSH	r = −.31, p<.001**	N/A	N/A
Braun *et al.* (2020)	SCS	WBIS	r = -0.54, p<0.01**	N/A	N/A
Chan, Lee & Mak (2018)	SCS-SF	Subscale of the ISMIS	Content: r = −.48, p<.001**	N/A	N/A
		STARS	Process: r = −.59, p<.001**		
Chan, Yung & Nie (2020)	SCS	SSS-SF (content)	r= −.38, p <.001**	Stigma stress	β = −0.20, p <.001**
		STARS (process)	Process: r = −.53, p < .001**	Stigma stress	β = −0.43, p<.001**
Collett *et al.* (2016)	SCS	SSMIS	r = −.27	N/A	N/A
Dossing *et al*. (2015)	SCS	ISMI-10	r = −.28	N/A	N/A

Authors	SC Measure	SS Measure	Bivariate Analyses Outcome	Multivariate Analyses	
				Control Variables	Outcome
Fredrick *et al*. (2019)	SCS-SF	PSS	*r* = -.28, p < .001**	N/A	N/A
Forbes & Donovan (2019)	SCS	WBIS	*r* = −.68, p<.01**	N/A	N/A
Heath *et al.* (2017)	SCS	SSOSH	*r* = −0.24, p<.001**	Emotional Control Self-reliance Disclosure risks	β = -0.23,p < .001**
Heath *et al.* (2018)	SCS	SSOSH	*r* = −0.30, p< .001**	N/A	N/A
Hilbert *et al.* (2015)	SCS	WBIS	*r* = −0.31, p<0.001**	N/A	N/A
Hilliard *et al*. (2019)	SCS-SF	SSOSH	*r* = −.06	N/A	N/A
Huelleman & Calogero (2020)	SCS-SF	WBIS-M	*r* = −0.43, p<0.001**	N/A	N/A
Petrocchi *et al. (*2020)	FSCRS	MISS-SF	*r* = −0.12, p<.05**	N/A	N/A

Authors	**SC Measure**	**SS Measure**	**Bivariate Analyses Outcome**	**Multivariate Analyses**	
				Control Variables	**Outcome**
Skinta *et al.* (2019)	SCS-SF	IHS	*r* = −0.37, p<0.001**	N/A	N/A
Torbet *et al.* (2019)	SCS	ASS	*r* = −0.47. p<0.01**	N/A	N/A
Webb & Hardin (2016)	SCS	WBIS-M	*r* = −.45, p=<0.001**	N/A	N/A
Wong *et al.* (2016)	SCS	ASS	*r* = −.49, p=<0.01**	N/A	N/A
Yang & Mak (2017)	SCS-SF	Content - SSS (cognitive subscale) Process-STARS	*Sample 1 (PMI)* Content: *r* =−0.32, *p*<0.01** Process: *r* = −0.41, p < 0.01**	N/A	N/A
			Sample 2 (PLHIV) Content: *r* =−0.31, *p*<0.01** Process: *r* = −0.26, p < 0.01**	N/A	N/A

SCS = Self-Compassion Scale; IHI – Internalised Homonegativity Inventory; SSOSH = Self-Stigma of Seeking Help Scale; SCS-SF = Self-Compassion Scale (Short Form); ISMIS STARS = Self-stigmatizing Thinking's Automaticity and Repetition Scale; SSS-SF = Self Stigma Scale (Short Form); SSMIS ISMI-10 PSS WBIS = Weight Bias Internalization Scale; WBIS-M= Weight Bias Internalization Scale (Modified); FSCRS = Forms of Self-Criticizing and Self-Reassuring Scale; MISS-SF= Measure of Internalized Sexual Stigma for Lesbians, Gay, and Bisexual People—short version; HIS = Internalised homophobia Scale; ASS= Affiliate Stigma Scale; SSS= Self Stigma Scale; PMI= People with mental illness; PLHIV= People living with HIV.

Critical Appraisal of Studies

Table 1.3 summarises the critical appraisal, undertaken prior to data extraction. All studies were deemed of reasonable methodological robustness to be included in the review, demonstrated by their overall appraisal scores being over half of the total possible score (8). Appraisal scores ranged from 4.5 (Dossing *et al.*, 2015; Chan *et al.*, 2020; Forbes & Donovan, 2019; Yang & Mak, 2017) to 7.5 (Huelleman, 2020). Average risk of bias scores across each self-stigma type were calculated, falling between 4.5 (HIV stigma) and 6.2 (weight stigma), where the highest possible score was 8.

The further impact of the critical appraisal on the narrative synthesis is included in the discussion section.

The most common methodological limitation across the studies was not reporting the sample size calculation; only five studies reported this (Beard *et al.,* 2017; Collett *et al.*, 2016; Heath *et al.*, 2017; Huelleman & Calogero, 2020; Webb & Hardin, 2016). Lack of these calculations means readers cannot discern if sample sizes are adequate to allow results to be generalised across the target population, therefore reducing the overall validity of the studies. The included studies are mostly cross-sectional in design and analysed correlational data. This means that causality cannot be inferred as there were no indicators of temporality. Therefore, the reader cannot assume the direction of the relationship between the constructs; more self-compassion may lead to lower self-stigma, however lower self-stigma may lead to higher levels of self-compassion.

There was limited reporting and exploration of missing data, with just six studies clearly reporting missing data and how it was explored (Booth *et al.*, 2019; Braun *et al.*, 2020; Heath *et al.*, 2017; Hilliard *et al.*, 2019; Huelleman & Calogero, 2020; Webb & Hardin, 2016). A further three studies reported missing data but did not explore it (Petrocchi *et al.*, 2020; Skinta *et al*,. 2019; Wong *et al.,* 2016). Two studies appeared to not have any missing data, as they reported corresponding figures of the number of participants and the amount of full data sets they analysed (Chan *et al.*, 2018; Collett *et al.*, 2016) The remaining studies did not clearly indicate incidents of missing data.

Six studies sampled student populations (Booth *et al*., 2019; Heath *et al*., 2017; Heath *et al*., 2018; Hilliard *et al*., 2019; Huelleman & Calogero, 2020; Webb & Hardin, 2016). Concerns have been raised about the use of student samples in psychological research due to not being representative of a target population and varying from the general-public, thus impacting generalisability and the ability compare results (Heinrich *et al.,* 2010; Hanel & Vione, 2016). This suggests the validity of these studies may be negatively affected by this sampling method.

Table 1.3

Critical Appraisal and Risk of Bias Summary

Authors (year)	**Defined participant eligibility criteria?**	**Sample demographics adequately described?**	**Recruitment setting adequately described?**	**Sample size calculation reported?**	**Valid and reliable measures?**	**Missing data reported and explored?**	**Confounding factors considered in the analyses?**	**Statistical methods appropriate?**	**Total Score**
Affiliate stigma									
Torbet *et al.* (2019)	Yes	Yes	Yes	No	Yes	No	Yes	Yes	6
Wong *et al.* (2016)	Yes	Partial	Partial	No	Yes	Partial	Yes	Yes	5.5
							Total Average Score		5.75
Help-seeking stigma									
Booth *et al.* (2019)	Yes	Yes	Partial	No	Yes	Yes	No	Yes	5.5
Heath *et al.* (2017)	Yes	Yes	Partial	Yes	Yes	Yes	No	Yes	6.5
Heath *et al.* (2018)	Yes	Yes	Partial	No	Yes	No	No	Yes	4.5
Hilliard *et al.* (2019)	Yes	Yes	Partial	No	Yes	Yes	Partial	Yes	5.5
							Total Average Score		5.5
HIV stigma									
Yang & Mak (2017)	Yes	Partial	Partial	No	Yes	No	Partial	Yes	4.5

Authors (year)	Defined participant eligibility criteria?	Sample demographics adequately described?	Recruitment setting adequately described?	Sample size calculation reported?	Valid and reliable measures?	Missing data reported and explored?	Confounding factors considered in the analyses?	Statistical methods appropriate?	Total Score
Mental health stigma									
Chan *et al*. (2018)	Yes	Partial	Partial	No	Yes	Yes	No	Yes	5
Collett *et al.* (2016)	Yes	Partial	Partial	Yes	Yes	Yes	Partial	Yes	6.5
Dossing *et al.* (2015)	Yes	Partial	Partial	No	Yes	No	Partial	Yes	4.5
Yang & Mak (2017)	Yes	Partial	Partial	No	Yes	No	Partial	Yes	4.5
								Total Average Score	5.13
Minority sexuality stigma									
Beard *et al.* (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	7
Chan *et al*. (2020)	Yes	Partial	Partial	No	Yes	No	Partial	Yes	4.5
Fredrick *et al.* (2019)	Yes	Partial	Yes	No	Yes	No	Partial	Yes	5
Petrocchi *et al.* (2020)	Yes	Partial	Partial	No	Yes	Partial	Yes	Yes	5.5
Skinta *et al.* (2019)	Yes	Yes	Yes	No	Yes	Partial	Yes	Yes	6.5
								Total Average Score	5.7

Authors (year)	Defined participant eligibility criteria?	Sample demographics adequately described?	Recruitment setting adequately described?	Sample size calculation reported?	Valid and reliable measures?	Missing data reported and explored?	Confounding factors considered in the analyses?	Statistical methods appropriate?	Total Score
Weight stigma									
Braun *et al*. (2020)	Yes	Yes	Yes	No	Yes	Yes	Partial	Yes	6.5
Forbes & Donovan (2019)	Yes	Partial	Partial	No	Yes	No	Partial	Yes	4.5
Hilbert *et al.* (2015)	Yes	Partial	Yes	No	Yes	No	Yes	Yes	5.5
Huelleman (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Partial	Yes	7.5
Webb & Hardin (2016)	Yes	Yes	Partial	Yes	Yes	Yes	Partial	Yes	7
							Total Average Score		6.2

Main Findings

The included studies examined associations between self-compassion and self-stigma using univariate analyses. 18 studies found significant negative correlations, with Pearson r correlation values ranging from -0.12 to -0.68. Using Cohen's (1988) parameters, these can be considered small to large effect sizes. Three studies observed a non-significant relationship (Collett et al., 2016; Dossing et al., 2015; Hilliard et al., 2019).

All five studies investigating the relationship between internalised sexual stigma and self-compassion found a significant relationship, with small to large effect sizes; values ranged from -0.12 to -0.53. In terms of internalised weight stigma, all five studies found a significant relationship, with effect size values ranging from medium (-0.31) to large (-0.68).

Three studies investigating self-stigma related to seeking help found significant correlations, with small to medium effect sizes; values ranged from -0.24 to -0.31. One help-seeking study did not find a significant relationship (Hilliard *et al.,* 2019).

Of the four studies examining internalised mental health stigma, two found positive correlations with medium to large effect sizes, where values ranged from -0.32 to -0,59. Two studies did not observe a significant relationship between mental health self-stigma and self-compassion (Collett *et al*., 2016; Dossing *et al*., 2015).

Both studies investigating affiliate stigma found significant large effect correlations with self-compassion, ranging from -0.47 to -0.49. The study examining HIV self-stigma also observed a significant relationship, with a medium effect size.

Two studies examined the relationship between self-stigma and self-compassion using multivariate analyses. After controlling for potential covariates, both Chan *et al*. (2020) and Heath *et al*. (2017) found significant inverse relationships between the variables. Chan *et al.* (2020) found that self-compassion was more strongly related to self-stigma process ($\beta = -0.43$) than self-stigma content ($\beta = -0.20$).

Discussion

This review identified bivariate and multivariate relationships between self-stigma and self-compassion in the existing literature. Across a range of self-stigma types, most studies found a significant, inverse, bivariate relationship between the variables. Observed effect sizes ranged from small to large but the majority were within the medium to large parameters (Cohen, 1988). When multivariate analyses controlled for potential covariates, significant relationships were maintained. These findings offer support to Wong *et al's*. (2019) *Hacking Stigma by Loving Yourself* model, which suggested that self-compassion may buffer the negative effects of self-stigma, by confirming that there does appear to be an inverse relationship between self-compassion and self-stigma, across a range of stigmatised groups.

The average critical appraisal scores across the studies grouped by self-stigma typed were varied. The most methodologically robust group was the internalised weight stigma studies, followed by the affiliate stigma group and then the internalised sexual stigma group. Less robust were the studies in the internalised HIV, mental health, and help-seeking stigma groups. In the context of the correlation ranges, this suggests that the medium to large effect sizes observed in the weight self-stigma group are relatively robust. In comparison, the medium effect size observed in the HIV self-stigma groups group may be less reliable.

Of the three studies that did not find a significant relationship, two investigated mental health self-stigma (Collett *et al.,* 2016; Dossing *et al.,* 2015). Collett *et al.* (2016) was one of the few studies to report a sample size power calculation, however the sample size (n=21) reported did not meet this figure (n=26). Dossing *et al.* (2015) also reported a relatively low sample size (n=30). These sample sizes are low in comparison to the mean sample size of the included studies (n=297) and may have reduced the likelihood of finding a significant relationship between the variables.

The other study that did not observe a significant relationship investigated internalised help-seeking stigma (Hilliard *et al.,* 2015). Of the four studies investigating help-seeking self-stigma, Hilliard *et al.* (2015) was the only study to utilise the short form version of the Self-Compassion scale (SCS; Raes *et al*., 2011); the other studies used the original version SCS (Neff, 2003). There is a possibility that if the original SCS was used it may have been more sensitive and thus more likely to demonstrate a significant relationship.

One study demonstrated a significant, but notably lower effect size in the analyses (Petrocchi, 2020). This was the only study to utilise The Forms of Self-Criticizing and Self-Reassuring Scale (FSCRS; Gilbert *et al.,* 2004) rather than a variation of the SCS. Gilbert and colleagues initially developed and validated the FSCRS in relation to depressive symptoms in a sample of female undergraduate students; the final measure included scales related to the 'inadequate-self', the 'hated-self' and the 'reassured-self' (Gilbert *et al.,* 2004). The reassured-self subscale was extracted in the current review as a measure of self-compassion and demonstrated the lowest effect size across the significant relationships observed. This may be due to the measure not measuring the same range of elements of self-compassion as the SCS and its short form version.

While there was support for the assumption that more self-compassion is associated with less self-stigma, as asserted in Wong *et al.*'s (2019) model, we cannot conclusively infer that self-compassion leads to a reduction in self-stigma from the reviewed data. However, this is a feasible hypothesis in relation to some theories of self-compassion. For example, Gilbert & Proctor (2006) suggest that self-compassion deactivates the threat system (associated with autonomic arousal, feeling unsafe and the fight or flight response) and activates the soothing system (associated with parasympathetic responses, safety, and connection). As the literature suggests that stigma is a social threat, self-compassion may play a role in mediating an individual's experience of stigma by facilitating both less threat activation and increased soothing activation. This may foster an emotional resilience to stigma and reduce the risk of public stigma being internalised.

Limitations

This review reflects a general shift from sociological to psychological research in the field of stigma, focusing on individual experiences and underlying cognitive processes (Holley *et al.*, 2012). However, the review does not consider the wider context of stigma, such as power and social justice. It has been argued that these key constructs in stigma research have been underexplored (Corrigan, 2005; Link & Phelan, 2001) and further examination would improve our understanding of the structural processes that perpetuate inequalities and contribute to stigma.

The included studies focused on single aspects of participants' identities that the researchers considered stigmatised. This may have excluded important complex interactions between social categories and how they relate to the experience and internalisation of stigma. Intersectionality is an increasingly helpful framework for understanding how systems of oppression, such as race, class and gender, interlock and interact to contribute to discrimination (Simien, 2007). Stigma research has begun to apply these ideas. For example, Himmelstein *et al.* (2017) proposed an intersectional model that accounted for the findings that women reported more weight self-stigma than men, however black men and women reported less weight self-stigma than white men and women.

The included studies spanned a range of target populations and investigated several different types of self-stigma. While this might suggest that the inverse relationship between self-stigma and self-compassion is robust enough to be demonstrated across groups, there is the potential that variations in the relationship within specific populations are lost in this review. It is highly likely that these constructs interact differently across different groups. Furthermore, the range of types of self-stigma meant that there were many different measures of self-stigma utilised across the studies. This may impact the comparability of the data and while population specific measures may increase the validity of self-stigma as a construct, it also has the potential to reduce the likelihood of reliably measuring self-stigma across different populations.

A major limitation of the studies included in the review is that they only demonstrate cross-sectional, correlational data. This means that causality cannot be inferred as there are no indicators of temporality. Subsequently, there is no evidence to suggest that increasing self-compassion would reduce self-stigma. Some of the included studies do go on to look at self-compassion as a mediator or moderator variable within the inverse relationship between self-stigma and wellbeing, however these analyses were beyond the scope of the current review and research question.

Research Implications

While the current review demonstrates a potential relationship between self-compassion and self-stigma across groups, some of the studies' methodological robustness suggests more research is needed before firm conclusion are drawn. In particular, the relationship between HIV, mental health and help-seeking self-stigma requires more robust research to conclude the relationships with self-compassion currently observed are in fact reliable.

The current review cannot determine the temporal direction of the inverse relationship between self-stigma and self-compassion; while it supports an existing theoretical model that asserts increasing self-compassion might lead to reduced self-stigma (Wong *et al.,* 2019), future research should explore this relationship empirically and determine the direction of the relationship between the variables by utilising prospective and experimental designs.

Furthermore, none of the included studies examined which factors might mediate the relationship between self-stigma and self-compassion; this would highlight the specific elements within the constructs that contribute to the associations observed.

Additionally, more research examining self-compassion as a mediator or moderator to the relationship between self-stigma and wellbeing would increase our understanding of how the observed relationship can be utilised. Understanding these relationships would strengthen the rationale for designing and evaluating interventions that utilise self-compassion to reduce the detrimental effects of self-stigma evident in some stigmatised individuals. Qualitative research may also be valuable to further our understanding of how people experience self-compassion and self-stigma, which is likely to be a rich and multi-faceted relationship that varies between people.

While self-compassion appears to play some role in self-stigma, other mechanisms that might reduce the likelihood of stigma being internalised should continue to be explored. For example, self-esteem and self-efficacy may be important constructs associated with self-stigma (Livingstone & Boyd, 2010). Furthermore, other elements of ACT and self-compassion warrant further investigation, such as mindfulness and psychological flexibility.

Clinical Implications

It is important to continue to consider ways in which the damaging outcomes associated with self-stigma can be reduced. The current review demonstrated an association between self-stigma and self-compassion that warrants consideration in this context. Figure 1.3 summarises multiple levels of intervention where the relationship between self-compassion and self-stigma may have some clinical utility in improving wellbeing in those who self-stigmatise. The ‘gold-standard’ for reducing the negative impact of self-stigma would be reducing or eradicating public stigma. In Wong *et al*’s., (2019) model, self-stigma and the negative outcomes associated with it would decrease if public stigma was to decrease.

However, large-scale public stigma reduction strategies can take a long time to facilitate any change (Corrigan *et al.,* 2005). Furthermore, theorists are beginning to suggest that interventions to reduce a specific type of public stigma (e.g., mental health) are only meaningful if they improve attitudes towards everyone within the group, even if individuals belong to other stigmatised social groups (e.g., those who are homeless or use substances), in line with intersectional frameworks (Oexle *et al.,* 2018).Therefore, other levels of intervention are needed to support the wellbeing of those who self-stigmatise, while work on public stigma reduction continues.

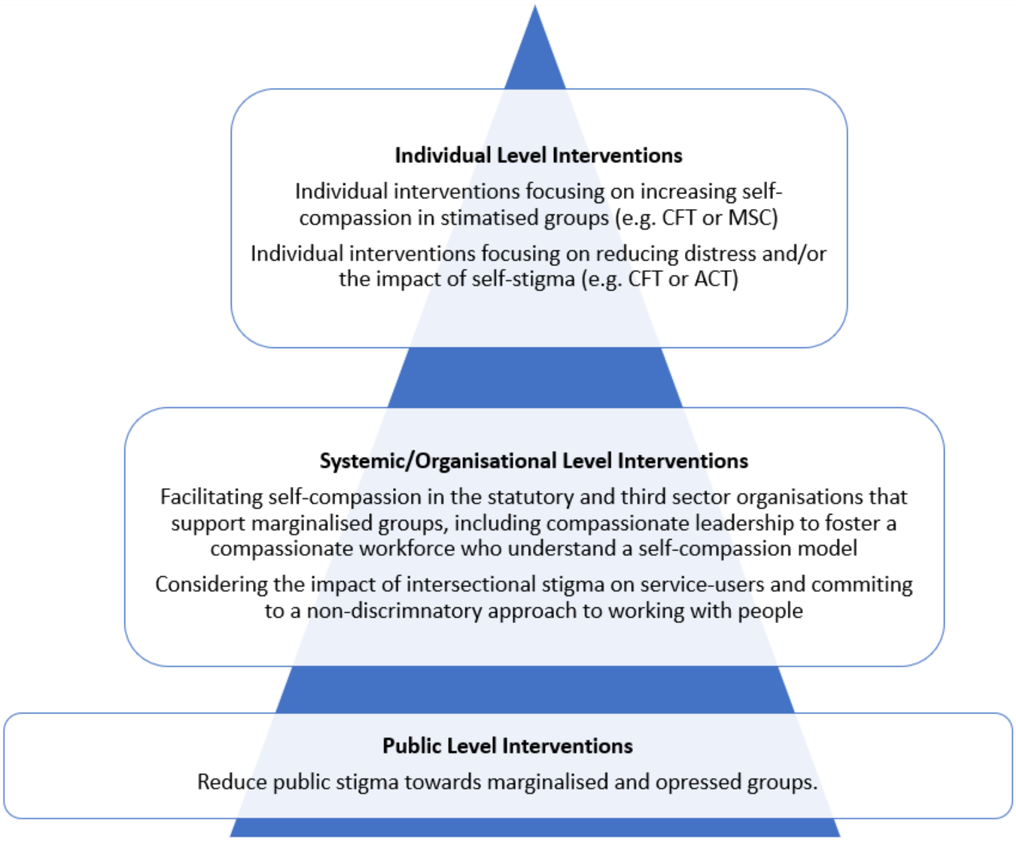
The next level of intervention outlined in Figure 1.3 refers to systemic and organisational interventions. Gilbert and Woodyatt (2017) suggested that compassion is inherently social, so thinking beyond individual interventions may be beneficial when exploring a self-compassion intervention for self-stigma. For example, taking these ideas out of the therapy room and into the communities of stigmatised groups. Many stigmatised groups are already supported by national and local third sector organisations who aim to reduce stigma and promote social inclusion (e.g. The Royal Mencap Society for people with intellectual disabilities, Rethink Mental Illness for those experiencing emotional distress and Stonewall for members of the LGTBQ+ community). Staff involved in these types of organisations are likely to have direct contact with stigmatised individuals and thus may benefit from understanding the link between self-stigma and self-compassion. This could be facilitated by compassionate leadership, creating an ethos of self-compassion.

If these organisations can provide a relationship and environment that facilitates self-compassion, it might go some way to reducing either the negative impact of self-stigma, or the likelihood of stigma being internalised at all. This would also be in line with Wong *et al.* (2019), whose model proposed that one of the ways self-compassion might buffer against self-stigma is through social processes, such as social support.

There are also potential interventions at the individual level, as outlined in Figure 1.3. The studies in these groups comprise of subclinical populations of marginalised groups, suggesting that they may not need, or have access to, specific psychological therapy such as Compassion Focused Therapy (CFT; Gilbert, 2009) which is focused on individuals with clinical needs. Mindful Self-Compassion (MSC; Neff & Germer, 2013) is more focused on improving skills in the general population, however the 8-week workshop requires attendees to pay for the intervention. Furthermore, it is important to note that applying specific therapies to negative outcomes associated with self-stigma holds some tension. It could be argued that employing individual interventions suggests that the onus is upon the stigmatised person to change their cognitive, emotional, and social processes to build resilience against internalising self-stigma or the impact of self-stigma. Instead, a systemic approach is more able to locate the problem in the system, as opposed to the individual.

Figure 1.3

Potential multi-level interventions to reduce self-stigma



Individual Level Interventions

Individual interventions focusing on increasing self-compassion in stimatised groups (e.g. CFT or MSC)

Individual interventions focusing on reducing distress and/or the impact of self-stigma (e.g. CFT or ACT)

Systemic/Organisational Level Interventions

Facilitating self-compassion in the statutory and third sector organisations that support marginalised groups, including compassionate leadership to foster a compassionate workforce who understand a self-compassion model

Considering the impact of intersectional stigma on service-users and commiting to a non-discrimnatory approach to working with people

Public Level Interventions

Reduce public stigma towards marginalised and opressed groups.

Conclusion

The current review explores the relationship between self-stigma and self-compassion across a range of diverse samples. Findings suggest that higher levels of self-compassion are associated with lower levels of self-stigma. While there is potential clinical utility for applying self-compassionate approaches to work with stigmatised groups, more research is needed with prospective designs and multivariate analyses. Furthermore, the role of self-compassion as a mediator between self-stigma and well-being is an important area for future research.

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CHAPTER II

“They don’t understand people with learning disabilities”: Exploring the experiences of people with intellectual disabilities who undergo welfare assessments.

This article is prepared with consideration to submission to the Journal of Applied Research in Intellectual Disability. Please see Appendix C for author guidelines.

Abstract

Many people with intellectual disabilities in the UK are in receipt of welfare benefits. The UK Welfare Reform Act (2012) has been criticised for causing harm to welfare claimants, particularly regarding work capability assessment processes. The unique experiences of those with intellectual disabilities who undergo these assessments is not well-researched. Qualitative interviews were conducted with eight participants with intellectual disabilities, aiming to explore their experiences of the welfare assessment process. Interpretative phenomenological analysis suggested five superordinate themes in the participants accounts: ‘living in fear’; ‘marginalisation’; ‘relationship with assessor’; ‘others as a safe base’; and ‘coping’. Interventions to improve the experience at individual, structural and policy levels are discussed.

Introduction

It is estimated that 2.16% of adults in the UK have an intellectual disability (Office for National Statistics, 2019) and around 95% are unemployed (Hatton, 2019). Those who are unemployed are likely to rely on financial support from family or state welfare benefits. The modern welfare state is rooted in the Beveridge Report (1942), which aimed to tackle the social consequences of the 1930s economic depression and the Second World War, such as unemployment and sickness (Deeming, 2019). The 'Beveridgean' welfare model was based on fixed tax contributions and designed to meet the welfare needs of the poorest people, through a universal offer (Titmuss, 1974). However, the financial crises of the 1970's put strain upon the welfare state, as Conservative leadership heralded a new period of austerity, where levels of payments for sickness and unemployment continued to increase (Deeming, 2019; Gregg, 2008).

In the 1990's, 'New' Labour governments tackled high rates of welfare payments with their 'New Deal' scheme, aiming to reduce welfare dependency by conceptualising welfare as an incentive to work (Deeming, 2019). Welfare reform became more radical as Conservative leadership introduced austerity measures in response to the budget deficit, including reduced welfare spending (Page, 2015).

The evolution of the welfare state highlights some important differences between the initial aims and current operationalisation of the welfare system. While welfare was intended to support the poorest and sickest, the current neoliberal political agenda seems to have sought to justify the removal of the welfare state, by stigmatising the claiming of welfare benefits (Baumberg et al., 2016; Garthwaite, 2015).

The current impact of claiming welfare benefits is an emerging area of interest following the most recent UK Welfare Reform Act (2012), which included increased conditions that must be met for benefits to be received (Department for Work and Pensions;

DWP, 2010). Increased conditionality has been criticised for causing harm to claimants (Arie, 2018), including increasing psychological distress (Wickham *et al.,* 2020) and exacerbating mental health conditions (Cheetham *et al.,* 2018). Moth *et al.* (2020) argued that welfare reform has heralded a punitive approach to welfare that should be seen as a form of social harm.

A key change following welfare reform was the introduction of work capability assessments (WCA), aiming to assess an individual's ability to work (DWP, 2010). Baumberg *et al.* (2015) argued that WCA fail to consider opportunities for work or the support individuals might require in employment. WCA have been associated with increased suicides, mental health symptoms and antidepressant prescribing (Barr *et al*., 2016). Claimants report exacerbation of existing health issues (Dwyer *et al*., 2016) and deterioration in mental health, including thoughts of suicide (Marks *et al*., 2017). Distress has been linked to completing forms, errors in reports and lack of assessor expertise (House of Commons, 2018).

Researchers have explored the potential mechanisms underlying the link between welfare reform and distress. Cheetham *et al.* (2018) suggest WCA negatively impact self-esteem and evoke feelings of helplessness and despair. Moth & Lavalette (2017) explored the experiences of people with mental health difficulties who underwent WCA and found an exacerbation of psychological distress; a summary of mechanisms their data suggested might underlie this is provided in Table 2.1.

Table 2.1

Summary of Mechanisms Underlying Exacerbation of Mental Health Difficulties Related to Claiming Benefits (Moth & Lavalette, 2017)

Mechanism	**Description**
Re-traumatisation	Disclosing intensely personal and sensitive experiences was as highly distressing. Some participants felt forced to disclose and relive traumatic experiences and were not offered specialist or therapeutic support.
Invalidation	Participant's felt their experiences were disregarded and undermined in the assessment. The credibility of their experiences was questioned.
Fear	Participants described fear triggered by invitation to assessment and fear of sanctions (e.g. benefits being stopped if not meeting eligibility conditions).
Mistrust	Participants felt that the assessment process was designed to trip them up and trap them through misrepresentation of their experiences, which led to not trusting the system.
Double Binds	A type of 'trap' experiences by participant's characterised by contradictory injunctions and conflicting messages (e.g. requested to travel for WCA but presentation at location cited as invalidation for their claim to be incapacitated due to ability to travel).
Shaming and Blaming	Participant's described experiences of shame directly linked to welfare policy. They felt they were stigmatised as useless compared to working people.

Those with disabilities are thought to be disproportionately impacted by welfare reform (McGrath *et al*., 2016; Garthwaite, 2014). High levels of uncertainty and anxiety have been found in the experiences of those claiming disability benefits (Baumberg, 2014) which may be linked to feelings of powerlessness around the outcome of the assessment (de Wolfe, 2012; Ploetner *et al.,* 2019).

For people with intellectual disabilities, Redley (2009) argued that WCA did not acknowledge restricted opportunities for employment and failed to address the lack of services that support their self-development. Therefore, people with intellectual disabilities are at risk of being socially excluded, being unable to fulfil the responsibility of employment that constitutes mainstream citizenship within neoliberal politics (Hall, 2010; Goodley, 2016).

In 2012 the Disability Living Allowance (DLA) was replaced with Personal Independence Payment (PIP), including the addition of a WCA conducted by private companies (DWP, 2016). Multiple inquiries have raised concerns after finding PIP claimants did not feel listened to or understood during the assessment (Gray, 2014; United Nations, 2016; Gray 2017). The British Psychological Society (BPS, 2016) suggested the PIP assessment failed to recognise the highly individualised nature of people's experiences, reflected in PIP claimant's experiences of WCA as dehumanising, difficult to understand, and complex (Allen *et al*., 2016). Furthermore, disabled claimants report experiences of humiliation and shame in relation to claiming welfare (Garthwaite, 2014; Ploetner *et al.,* 2019). While there are no identified sources that provide the specific questions asked within a PIP assessment, Appendix D outlines the general assessment and dispute process, as well the details of eligibility and payment processes.

People with brain injuries have also reported that undergoing WCA to claim PIP was a negative experience; they felt assessors did not consider the hidden impact of their injuries and lacked empathy and patience (Headway, 2018). There are currently few suggested interventions or approaches to support claimants; the main source of accessible advice and support currently comes from activist and pressure groups such as Disabled People against Cuts (DPAC, 2017), Recovery in the Bin (Recovery in the Bin, 2019) and Mencap (nd).

Stigma

Benefit stigma is an emerging field, as researchers attempt to understand the mechanisms that underlie the impact of welfare reform. Stigma refers to widely endorsed negative stereotypes held by those with social power, resulting in discrimination and loss of status for specific groups (Link and Phelan, 2001). Evidence suggests claiming benefits is stigmatising (Baumberg *et al*., 2016; Garthwaite, 2015). Saffer *et al.* (2018) argued that the media promotes a discourse of 'benefit scroungers', including televisions shows such as 'Benefits Street' (Channel 4) where receiving benefits is characterised as a lifestyle choice. Claimants have reported verbal abuse related to a 'scrounging' narrative (Pemberton *et al.,* 2016) and feeling looking down on by others (Garthwaite, 2015). The stigma of claiming benefits has been linked to a negative impact on self-esteem (Pemberton *et al.,* 2016), shame and social withdrawal (Garthwaite, 2015), and psychological distress (Patrick, 2016).

As the welfare system exists within a political context, some argue that unemployment has been positioned as an individual and personal failure, rather than a product of socio-economic factors, to better serve current dominant neoliberal approaches (Friedli and Stern, 2015). This is maintained by behavioural approaches such as surveillance, deterrence, sanctions, and stigma (Wacquant, 2009, as cited in Moth *et al*., 2020). Scambler (2018) coined the term 'weaponising stigma' to describe how this narrative of unemployment as an individual failure, has been used as a political tool to justify the limitations of the welfare state to the public.

People with intellectual disabilities are already a highly stigmatised group (Scior & Werner, 2016; Redley, 2009). Research suggests that those with intellectual disabilities are perceived as severely cognitively and socially impaired and childlike (McCaughey & Strohmer, 2005; Gilmore *et al*., 2003). Roth *et al.* (2016) found that people with intellectual disabilities felt ridiculed by others, often not understanding why they are treated differently to others. People with intellectual disabilities' perception of stigma has been linked to low self-esteem (Paterson *et al*., 2012) and psychological distress (Ali *et al*., 2015; Dagnan & Waring, 2004).

Low rates of paid employment for people with intellectual disabilities in the UK (5.9%; Hatton, 2019) may be in part due to stigma; Shaw *et al*. (2004) found evidence that the public believe people with intellectual disabilities to be mostly unemployable. Unemployment may also perpetuate stigma, due to current neoliberal ideologies that emphasise an individual's responsibility to work to gain citizenship and eligibility for rights (Redley, 2009; Goodley, 2016). This serves to exclude people with intellectual disabilities from employment and means many people with an intellectual disability in the UK rely on the welfare system.

There is emerging evidence suggesting welfare reform such as WCA have a negative impact on claimants. However, our current understanding of the impact of welfare assessments for people with intellectual disabilities is under-researched and the unique intersections of having an intellectual disability and claiming benefits remains to be explored. Accordingly, the current study will explore how people with intellectual disabilities make sense of their experience of welfare assessments.

Method

Design

Semi-structured virtual interviews were conducted. Data analysis was conducted in line with interpretative phenomenological analysis (IPA; Smith, 1996; Smith & Osborn, 2003; Smith *et al.,* 2009).

IPA

IPA aligns with the researcher's epistemological stance (see Appendix E) as it seeks subjective and unique understanding, rather than objective reality (Flowers *et al*., 1999; Smith & Osborn, 2003) and represents both the participant's experience and the researcher's position (Smith & Osborn, 2003). Rose *et al*. (2019) concluded that IPA is appropriate for research concerning the experience of people with an intellectual disability. Furthermore, the research area is novel and complex, for which IPA is considered particularly useful (Smith & Osborn, 2008).

Participants

Eight participants chose pseudonyms to maintain anonymity. Participants included four males and four females and ages ranged from 28-54. All participants lived in the community. Table 2.2 summarises participant demographics.

Procedure

Ethics. Liverpool University ethical approval was granted prior to recruitment and data collection (see Appendix F).

Recruitment. Participants were recruited in the North-West via two independent Mencap charities who both promote equality for people with intellectual disabilities. Staff distributed information to Mencap members who satisfied the participant inclusion criteria (see Table 2.3). Those who expressed interest were invited to a pre-meeting via online video-conference platform ‘Zoom’ to learn more. Eight people attended a pre-meeting with a Mencap staff member and all decided to take part.

Informed consent. An accessible participant information sheet (PIS) and consent form (see Appendix G and H) were developed based on guidance from the Department of Health and National Research Ethics Service (DH, 2010; NRES, 2011) and consultation with people with intellectual disabilities. During the pre-meeting, the PIS was shared via Zoom’s screen-share function and read through by the researcher, who answered any further questions. Six participants agreed to participate during the pre-meeting, while two contacted Mencap staff the following week to confirm participation. Consent was audio-recorded following review of the consent form at the beginning of each interview.

Table 2.2

Summary of Participant Demographics

Pseudonym	Conditions	Current Welfare Benefits	Current Employment	Length of Interview
AJ	Intellectual disability; autism	PIP	Employed part-time	45 mins
Bob	ID	PIP, ESA	None	52 mins
Dave	ID	PIP, ESA	None	57 mins
Jonathan	Intellectual disability; autism	PIP	Volunteer	38 mins
Louise	ID	PIP, ESA	Volunteer	47 mins
Miss Moneypenny	ID	PIP, ESA	Employed part-time	34 mins
Natasha	ID & autism	ESA	Employed part-time	55 mins
Sue	ID	PIP	None	47 mins

Interviews. Due to COVID-19 restrictions all interviews took place virtually via Zoom, between February and April 2021. They lasted between 34 and 57 minutes. Participants were interviewed once, and seven people opted to have a Mencap staff member present (on Zoom) for the interview. An interview schedule was developed in consultation with research supervisors to ensure it was congruent with IPA, with revisions made following a pilot interview with a person with an intellectual disability (see Appendix I). As varying levels of communication were expected within the sample, prompts were devised. Questions were generally open-ended and exploratory, and the schedule was intended as a guide only. Following consultation with people with intellectual disabilities, an easy read interview schedule was produced for those who required visual aids (see Appendix J). This was offered to participants but none felt they required it.

Table 2.3

Summary of Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
• Self-reported intellectual disability • Aged 18+ • Capacity to consent (if concerns flagged by Mencap staff or researcher) • Experience of a welfare eligibility assessment in the last 30 months. • Communication skills required for participating in an interview. • English as first language	• High distress levels as indicated by self-report, information from staff or carers or observation of the researcher.

Participant wellbeing. Mencap staff who had an ongoing relationship with the participants were available through their virtual presence at the research interviews. For the one person who did not require support of Mencap staff, a member of staff agreed to be contacted if the researcher had concerns regarding the participant's wellbeing. The researcher had a list of local services that offer wellbeing support and welfare advice. Interviews ended by asking participants about their immediate wellbeing. One participant showed signs of distress and was offered information about wellbeing services, however opted instead to arrange a follow-up call with Mencap staff, during which they reported no further distress related to the interview.

Reflexivity in IPA. Heidegger (1994) asserted that we are never free from our assumptions. In IPA, the researcher collects and interprets data with awareness of their own experiences, pre-conceptions, and prejudices. This contributes to the double hermeneutic element of IPA, which refers to the researcher making sense of and interpreting the participant's sense-making (Smith *et al*., 2009). An examination of the researcher's personal, professional, and political identity is provided to contextualise the data analysis (see Appendix E). The statement was drafted prior to the commencement of any interviews, allowing reflection on potential preconceptions. Reflexivity in IPA is argued to be dynamic, complex, and interactional (Engward & Goldspink, 2020); therefore, the researcher kept a reflective diary to record their responses to the research process and the impact of personal, societal, and cultural events, relevant to the research (see Appendix K for excerpts).

Data analysis. IPA does not prescribe a single method of data analysis (Smith *et al.,* 2009); the current analysis was informed by Smith *et al*. (2009) and Smith & Osborn (2008). The transcripts were re-read while listening to the audio recordings before in-depth line by line coding took place; descriptive, linguistic and conceptual features were noted, which informed emerging themes (see Appendix L for sample coding). Qualitative data analysis software NVivo was used to store emerging themes and quotes. For each participant emerging themes were re-organised into relevant clusters, until each participant had a list of themes stored in NVivo (case by case analysis; see Appendix M). The themes were then considered together iteratively, to explore patterns within the data set (cross-case analysis), producing a set of superordinate themes and subthemes. Analysis was circular and dynamic, exploring different patterns in different ways (see Appendix N) before completion.

Quality Assurance. An audit trail (see Appendices L, M, and N) ensured analysis could be traced to the original data as suggested by Yin (1989). The researcher considered their own position in relation to the analysis, evidenced in the position statement (see Appendix E) and reflective journal (see Appendix K). The analysis was grounded in the data, as encouraged by Smith (2011) to ensure credibility; all themes were evidenced by direct quotes and themes required representation from at least half of the sample (see Table 2.4). As suggested by Elliot *et al.* (1999) credibility checks were maintained through frequent discussions with supervisors.

Results

Data analysis resulted in five closely related superordinate themes: 'living in fear'; 'marginalisation'; 'relationship with assessor'; 'others as a safe base'; and 'coping'. Each theme had several subthemes. Table 2.4 lists the themes and their occurrences across participants; each theme occurred in at least half of the participant's analyses. Each theme is described below, supported with direct participant quotes. Quotes are rich but quite short, which is not unusual for an IPA focussing on people with intellectual disabilities (Rose *et al.,* 2019).

Living in Fear: 'I was nervous and scared'

A strong, visceral sense of fear was dominant across seven of the participant's accounts, expressed in two main subthemes described below.

Fear of the Assessment: 'I just couldn't wait to get out of there'. Seven participants described feeling scared and anxious about the assessment. Their fear responses ranged from acute panic ('*Very scared and panicky*' Jonathan) to stress ('*I was almost pulling my hair out at times with the stress*' Bob), and anxiety ('*I was anxious and all*' AJ).

Interpretation of participant's language supported this theme. For example, Sue described the assessment as '*horrible*' throughout her interview; the etymology of the word *horror* is from the Latin word *horrere*, meaning to shudder and tremble in fear. Therefore, Sue’s language suggested fear or dread:

> ‘*That's my experience and... (pause) and horrible experience actually*’ (Sue).

Jonathan described an embodied experience of anxiety during the assessment; he ‘*couldn’t sit still*’ and felt like he had ‘*run a marathon*’, interpreted as a physical fear response. Sue’s language suggested she was angry during the assessment (‘*pissed me off’*), potentially indicating a ‘fight’ response to fear. Analysis suggested Dave wanted to escape the assessment, interpreted as a ‘flight’ response to fear (*‘I just couldn't wait to get out of there’).* Louise’s response to assessment was severe and upsetting:

> *‘I do have meltdowns, when I go to [welfare] appointments’* (Louise).

The unpredictability of the assessments was interpretated as contributing to fear and anxiety:

> ‘*I think it just makes me nervous: you don't know what they're gonna ask you, who you're gonna see, how long your appointment's gonna be*’ (Natasha).

There was also fear related to getting the questions wrong:

> ‘*Like things where you don't know the answer to, don't know how to say, things that make you feel nervous makes and you wanna leave the room’* (Jonathan).

Table 2.4

Occurrence of Themes Across Participants

Themes		Participants							
Superordinate Theme	**Subtheme**	**AJ**	**Sue**	**Natasha**	**Louise**	**Bob**	**Jonathon**	**MMP**	**Dave**
Living in Fear	*Assessment*	x	x	x	x	x	x	-	-
	Financial survival	x	x	-	x	x	x	-	-
The System Is Marginalising	*Learning Disability Stigma*	x	x	x	x	x	x	x	x
	Benefit Stigma	-	-	-	x	-	x	x	x
	Disempowerment	x	x	x	x	x	x	x	x
Relationship with Assessor	*Humiliation and Dismissal*	x	x	x	x	x	x	x	x
	Not Understanding Me	-	x	x	x	-	-	x	x
Others as Safe Base	*Support from Others*	x	x	x	x	x	x	x	x
	Degrees of Independence	-	x	x	x	x		x	x
Coping	*Finding Value*	-	x	-	x	x	-	x	-
	Resistance	-	x	x	x	-	-	-	x

Fear related to financial survival: ‘How am I gonna live?’. Five participants discussed fear in the context of survival, including the fear of losing their benefits and thus their ability to meet their basic human needs:

> ‘*How am I gonna live? How I'm gonna feed and clothe myself’* (Bob).

Jonathan named his biggest fear as becoming homeless, which suggested that financial security felt fragile and fleeting:

> ‘*I always saw like a homeless person on the street and I was just had a massive fear that I don't wanna end up like that’.*

Bob described how the stress of financial insecurity impeded his ability to live his life:

> *‘If you're struggling with money and, like I have been, you, you can't really have a life, cos you're stressing about everything else’.*

Analysis suggested that Bob’s mood was significantly impacted, leading to depression:

> *‘I've felt depressed because things weren't going the way I had hoped or having to go through [the assessment process] all over again’.*

The Process is Marginalising: ‘Other people are better than me’

Analysis suggested that the welfare assessment process was experienced as marginalising by all participants. This included the assessment process reinforcing stigma and disempowering participants by removing their sense of agency.

Reinforcing intellectual disability stigma: ‘I feel stupid’. Across all participants’ accounts, the assessment process appeared to reinforce a stigmatised view that people with intellectual disabilities are inadequate. Inaccessible DWP correspondence highlighted cognitive difficulties related to the participant's intellectual disabilities:

> '*It's horrible. And especially when you got, get letters from benefits and you don't know what the hell they're talking about*' (Sue).

Dave felt hurt to be reminded of his perceived inadequacies, which seemed to be linked to how he understood the assessor to feel about him. Here, a shaming, accusatory voice is attributed by Dave to the assessor, who is inviting an imagined other to join in the humiliation of him when Dave's difficulties with reading become apparent:

> '*It was horrible… oh you can't read or write, look at him, you know… it hurt me a lot…It does hurt me a lot now*'.

Miss Moneypenny described a sense of shame grounded in comparison of herself with others when she was unable to understand DWP letters, which suggested she had internalised the stigma related to having an intellectual disability:

> '*It feels horrible, cus really, God, erm, I feel stupid because other people are better than me, because they've gone through school and done better than me, so I feel terrible*'.

AJ and Bob understood that they had lost their benefits due to performing well and focusing on their strengths in the assessment, which was interpreted as a 'lose-lose' situation where rejecting the stigma of inadequacy could lead to loss of welfare:

> '*I still didn't get [benefits] because the woman said I answered every question without difficulty*' (Bob)

Reinforcing benefit stigma: 'Pretending to be disabled'. Four accounts suggested the system reinforced benefit stigma in a variety of ways. Louise described proving her entitlement to benefits during the hostile questioning of the assessment:

> '*This is why I've come, because I've got learning disabilities, I've got health conditions as well… why do they have to interrogate people?*'.

Dave described not being believed about his health condition during his assessment, interpretated as perceiving the assessor as stigmatising by questioning the legitimacy of his benefit claim:

> *'She said, can you move it? I said yeah, I can move it. Well it's not sore is it? So you've lied about that and everything.*'

It is important to note that this is reported speech, therefore we cannot be certain of the conversation between Dave and his assessor. However, interpretation of this quote suggests that Dave experienced the conversation as invalidating and accusatory, even if the assessor was not as leading as this reported speech suggests.

Miss Moneypenny appeared to justify the scrutiny and judgement of the assessor, suggesting she may have internalised negative stereotypes linked to benefits:

> '*They gotta ask those questions and make sure that the person is not doing wrong and pretending to be disabled.*'

Disempowerment: 'You've got to do it though'. Analysis suggested that all participants experienced powerlessness. Agency appeared tied to the risk of losing welfare:

> '*You've got to do it though, it's important or they'll cancel your benefits*' (AJ)

Passivity was interpreted as powerlessness:

> '*They sort of sort it out for me they sort all me money out'* (Miss Moneypenny).

Personalised attributions framed the assessor as powerful within the assessment, with them specifically being referred to as the decision maker by Louise:

> *'Then might give you money, might not give you money. We have to do whatever they say*'

AJ appeared to feel forced to answer personal questions during the assessment, suggesting a sense of powerlessness in this situation:

> *'It's quite scary and worrying… I didn't wanna answer them'*

Relationship with the Assessor: 'His attitude fucking stunk'

All participants discussed their relationship with the assessor during their assessments. The analysis suggested that it reflected the fear and marginalisation of the assessment process. The relational consequences of these mechanisms are discussed here.

Humiliation and dismissal. 'I felt humiliated in front of her'. Analysis suggested all participants experienced the assessor as humiliating and felt socially inferior during interactions with the assessor *('He spoke to me like shit'* Sue; *'I thought she was a bit of a snob*' Miss Moneypenny*)*. Miss Moneypenny clearly stated she felt humiliated and how this negatively affected her mood:

> '*I felt humiliated in front of her… I got a bit down in the dumps over it really cus to be asked those kinds of questions, it's not nice.'*

The participants descriptions of the assessor being impersonal were interpretated as being dismissive of the potential emotional impact of the assessment:

> '*They'll just go through the questions and they'll be like can you do this, can you do that… they're that busy asking the questions they're not seeing how like you're reacting*' (Natasha).

Louise described how her assessor did not stop when she became distressed and requested a break, interpreted as dismissal of emotional experience ('*the lady who's interviewing me she was like no we're just best to carry on').*

Only Jonathan described a helpful interaction with an assessor, who he felt attempted to be friendly by '*trying to be like, act like my buddy*' and help his understanding ('*dumb the questions down for me')*. However, Jonathan's language was interpreted to suggest a stigmatised, rather than reasonable, adjustment. Jonathan's perception of this as helpful may imply internalised stigma.

Not understanding me: 'They don't understand me'. Analysis suggested five participants felt their needs were not understood by assessors ('*They don't understand me*' Louise). There was a sense that assessors didn't understand people with intellectual disabilities more generally:

> '*They don't really understand people with learning disabilities'* (Natasha).

Furthermore, analysis suggested that assessors did not explore what it meant to have an intellectual disability:

> *'But I can't remember them asking me how I actually deal with my disability*' (Bob).

Others as a Safe Base: 'Someone there that you know, and you trust'

All participants discussed the supportive role of others in relation to the benefit process. This was expressed in a sub-theme related to different types of support and a sub-theme highlighting different levels of independence.

Support from others: 'I just love what they done for me'. All participants discussed helpful support from the 3rd sector ('*MENCAP was supporting me'* AJ) and family ('*Mum and my auntie… was always there to help me*' Jonathan). Multifaceted support included filling in forms ('*She do'ed the sign… you know, tick the things'* Dave), helping with understanding ('*Some of the staff… are brilliant, cos they will help me read the letters off the Job Centre'* Louise), emotional support ('*I had my family and friends trying to calm me down and not panic as much*' Bob) and financial support *('I got some money off my family*' Dave).

Personal In(ter)dependence Payment: 'When I'm on my own I panic'. Analysis suggested independence, dependence and interdependence were important to the experience of six participants. A consequence of their scary and marginalising experiences appeared to be increased dependency on others to navigate the system safely:

> '*Don't like interviews anymore… I have to take either someone from MENCAP or another person with me* (Louise).

There was also the risk of financial dependency when benefits are stopped:

> *'If next year I get my PIP stopped, I've got to live on [spouse's] money'* (Sue).

Dave highlighted how support increased his confidence to do things independently, rather than promote dependence:

> *'When I've got people around me. I'm ok. If I'm all on my own or something like that, or on the phone, I have to get someone else to erm speak to them'*.

Support appeared to improve participant's experiences (Y*ou're gonna be more relaxed at, erm, you're gonna be more like confident with yourself with someone there that you know and you trust'* Louise). In contrast, the negative impact of being alone was discussed by Jonathan:

> *'Because when I'm on my own I panic, feel like I'm, my chest is about to pop out'*.

Sue appeared to seek reassurance and support from her spouse and carer who was present at her interview (*'I get my PIP now don't I baby?')* which initially suggested dependency. During the interview he fell, and Sue responded by care-giving ('*Are you alright? You ok? You cut yourself… You ok, you alright?'* Sue). This was interpreted as interdependency, highlighting a mutual and reciprocal relationship. Louise described how she supports Mencap, also suggesting a reciprocal, supportive relationship, as opposed to what might be the expected support dynamic within this relationship:

> *'I always help MENCAP out a lot… I can't say no to them'* (Louise).

Coping: 'That's where I really shined'

Seven accounts suggest participants found ways to cope with the assessment process. These fall into subthemes of resistance and finding value.

Resistance: 'You're not getting away with it'. Four participants described resisting powerlessness. Two participants appeared to self-advocate:

> '*I said you do not speak to me like you're speaking to me, you're not getting away with it*' (Sue).

Natasha appeared to want empowerment though leaving feedback and holding the system accountable: '*I think they should send you a letter the week after with like smiley faces on or sad faces on and say what do you give this appointment.*'

Finding Value: 'Confidence and belief in myself'. Analysis suggested value found in other circumstances was important in four participant's experiences of welfare assessment. Jonathan discussed the things he valued about employment*: 'I think, I think I enjoyed the erm, going around [local area], seeing all the new places, making new friends'*. Louise described feeling valued in her volunteer role, about which she felt *'very good… pleased with myself'*. Jonathan discussed how specialist college attendance helped him to value himself ('*That's where I really shined'*) and said his experience of employment, volunteering, and college '*brought me confidence and belief in myself.*'

Two participants spoke with pride about their achievements ('*I've got loads [of certificates]. Two files, one in grey and one in maroon… not only that I've got good attendance certificates'* Sue) as well as their personal attributes ('*My, my kindness. And [Name] can vouch for that'* Louise). Sue is clear about her moral code and her commitment to it, which appeared to help her find value in herself: *'I don't, if they treat me with respect, I'll treat them with respect.'*

Discussion

This research explored the experience of people with intellectual disabilities, who have been subject to welfare assessments related to their welfare benefit eligibility. Five superordinate themes were generated through analysis of the participant's narratives: (1) *Living in fear*; (2) *Marginalisation;* (3) *Relationship with assessor;* (4) *Others as a safe base* and (5) *Coping*.

The themes *living in fear* and *marginalisation* support literature that suggests the eligibility assessments in the UK welfare system are experienced by claimants as largely negative (Headway, 2018), due to being difficult to understand (Allen *et al.,* 2016) and claimants not feeling listened to (Gray, 2014; United Nations, 2016; Gray, 2017). The analysis provides empirical evidence to expand some of Moth & Lavalette's (2017) findings from people with mental health difficulties who claimed benefits to those with intellectual disabilities who are subject to welfare assessments. Their mechanisms of fear, invalidation, double binds, and 'shaming and blaming' were also present in the current study within the themes *living in fear* and *marginalisation*. This suggests some experiences of welfare assessments are similar across different groups, however group and individual differences are evident.

In the current analysis, the *reinforcing intellectual disability stigma* sub-theme was present in more participant's accounts than the *reinforcing benefit stigma* sub-theme, suggesting that the assessment process was more likely to reinforce stigma associated with having an intellectual disability. This supports Scior's (2016) argument that having an intellectual disability remains highly stigmatising, as this experience appeared to be more salient to the participants than benefit stigma. This may suggest that the generally negative experience of undergoing welfare assessments that is documented in the literature, not only applied to the participants, but was compounded by their experience of having an intellectual disability. In the context of literature that demonstrates people with intellectual disabilities feel stigmatised and powerless across multiple spheres of their live (e.g., Scior, 2016), the welfare assessment may be a microcosm of people's general experiences of having an intellectual disability.

Within this analysis, the theme of *marginalisation* illustrates how the welfare assessment process reinforces stigma and disempowers those with intellectual disabilities, serving to socially marginalise them. *Disempowerment* was demonstrated across all participants, which fits with literature that suggests UK welfare claimants experience feelings of powerlessness (de Wolfe, 2012; Ploetner *et al.,* 2019). The *reinforcing stigma* sub-themes suggested some participants internalised stigma while some did not. This supports literature that suggests not all stigma is internalised (Corrigan and Watson, 2002; Trumball, 2008).

More participants discussed the protective factor of others within the *others as a safe base* theme than they discussed *finding value* or *resistance* as forms of coping. Analysis suggested that support from others could promote independence, reflecting critical disability literature that challenges the traditional ideology of independence (e.g., Morris, 2004). Interdependency was demonstrated in the *Personal In(ter)dependence Payment* theme; this reflects current thinking around independence that highlights the importance of building mutual relationships between people with intellectual disabilities, their carers, and services (Giri *et al.,* 2021).

Some participants expressed feeling valued in employment and education settings in the *finding value* subtheme. They discussed having opportunities to travel around, make new friends, and feel equal to peers during employment. This might reflect research that suggests that meaningful roles can reduce the emotional consequences of stigma (Dagnan & Sandhu, 1999). However, for meaningful employment to be an option for people with intellectual disabilities, it is argued that the welfare system would need to address their restricted employment opportunities and support their self-development (Redley, 2009). Furthermore, other roles may be just as beneficial, as illustrated in the *Personal In(ter)dependency* sub-theme.

Reflections

The research team consisted of like-minded academics, who shared political views and incorporated elements of social justice activism into their work. This will have led to a left-aligned, activist perspective permeating the research. While the team focused on the harm caused by the welfare state, it is important to acknowledge how those with alternative perspectives may have affected the research. For example, a more neutral academic may have highlighted the value of providing some sort of state assistance to people with learning disabilities, thus interpreting some of the data differently.

The double hermeneutic required in IPA aligned with the researcher's value of considering what they bring to the research process (see Appendix E). As a politically engaged professional who values social justice as a form of therapeutic intervention, the data will have inevitably been analysed through this lens. It is likely that another researcher with a different political position would have interpreted the data differently; see Appendix E for further discussion.

During the interviews, when participants discussed the negative emotions associated with being oppressed and marginalised, the researcher tended to respond with validation and containment. Supervision highlighted that occasionally direct questions about negative experiences were avoided to 'protect' the participants from emotional distress. This could be viewed as an enactment of the researcher's implicit assumptions associated with their own privilege and power; that people with intellectual disabilities need support and to be protected. The impact of this bias may have disempowered some participants by not giving them as much space to share their negative experiences and therefore limited the data.

Limitations

The findings are based upon the experiences of people with intellectual disabilities who were recruited via two independent Mencap charities, both of which promote equality and social inclusion for people with learning disabilities. While this contributed to homogeneity within the sample, which is beneficial for IPA, it is important to consider how being involved with Mencap may have influenced how the participants made sense of their experiences of welfare assessments, as they were likely exposed to social models of disability and advocacy-based support. Future research might consider the potentially very different experiences of people with intellectual disabilities who are not members of Mencap.

During the recruitment stage no formal assessment of intellectual disability was utilised and diagnosis was assumed through Mencap's service eligibility criteria, which requires the presence of an intellectual disability. This means there is a small chance that some participants may not have met formal diagnostic criteria for an intellectual disability. However the subjective experience and self-disclosure of having an intellectual disability was congruent with IPA principles and reflected the epistemological stance of the researcher (see Appendix E).

The interviews were conducted in the presence of a Mencap staff member in all but one instance to safeguard the wellbeing of the participants. However this may have impacted the participant's emphasis on the 3rd sector as a supportive and safe base, due to potential desire to please and unwillingness to criticise the support they received in front of Mencap staff. The position of the researcher will have impacted the data collection through the open-ended and explorative style of the interview and the double hermeneutic process of data analysis. The final superordinate themes were very closely related, and it is acknowledged that a researcher with a different background and position may have interpreted the data differently. While people with intellectual disabilities were consulted throughout the research process, having a member of the research team who has an intellectual disability may have strengthened the analysis by broadening the interpretations made about the data.

The current research was conducted in the context of the global COVID-19 pandemic. Interviews took place virtually, which increased recruitment bias as only people who were able to access an online interview were included in the sample. Both the participants and the interviewer were living in a period of uncertainty, where fear and anxiety were experienced by most people to some degree. This may have impacted the way the interviews were conducted, the things that felt important to the participants and the interpretations made by the researcher. In terms of relational experiences, many people were not able to have contact with their support network during this time, which again may have impacted the research by highlighting the importance of social connections. Furthermore, the participants had reduced contact with the DWP within this timeframe as all assessments were suspended in line with restrictions.

Multi-level Interventions

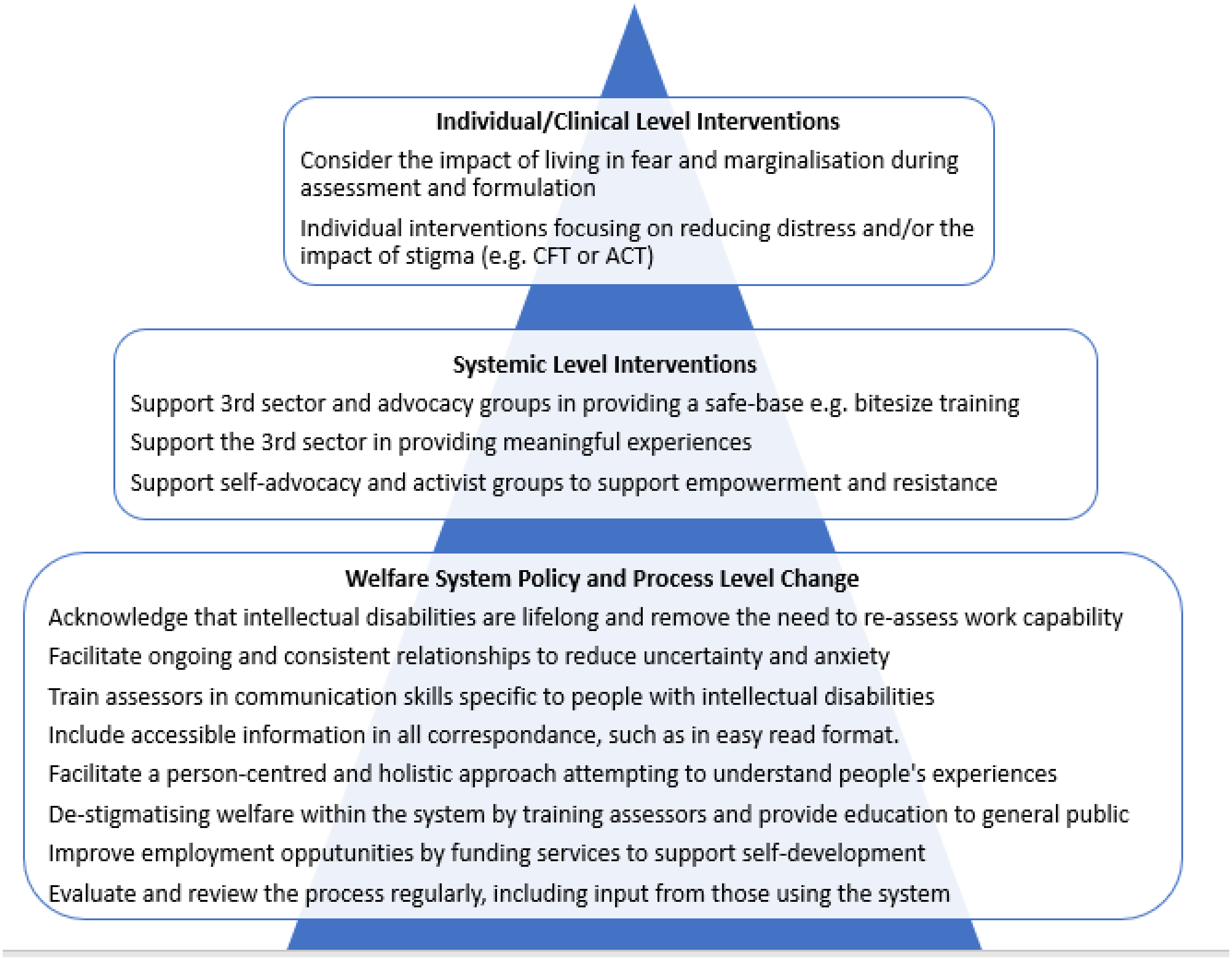
Figure 2.1 summarises recommended interventions based on the analysis. Individual-level therapeutic interventions could be employed by clinicians working in clinical services for people with intellectual disabilities, to understand and target the distress and stigma experienced in relation to welfare assessments. At a systemic level, clinical psychologists could support the work already being doing by 3rd sector and advocacy groups, who provide a safe base for people with intellectual disabilities undergoing welfare assessments and facilitate empowerment and self-advocacy.

Clinical psychologists could also utilise their power to advocate for change within the welfare system, by lobbying for psychological thinking within the system. The changes outlined in this level of intervention in Figure 2.1 would serve to reduce the fear of losing benefits, improve the relationship between assessors and those being assessed, make information more accessible, foster a sense of achievement and facilitate a person-centred approach. Clinical psychologists often have transferable organisational and leadership training that could support them to make effective arguments for this psychological approach to those in power. Recent research by Catrell, Weatherhead and Higson (2021) explored clinical psychologists experiences of working in the context of the benefit system. They found that participants believed they could and should influence higher-level change in the welfare system, however emphasis was placed on the need for professional support and leadership to feel able to engage in this macro-level work.

Recently, The Social Security (Scotland) Act 2018 established a devolved welfare system in Scotland, intending to frame social security as a human right (O'Cinneide, 2019). Changes will include only utilising welfare assessments where necessary and ensuring assessments are carried out by members of public bodies, as opposed to private contractors (O'Cinneide, 2019). These changes are likely to encompass some of the policy recommendations made here and could make a significant difference to the experience of people claiming benefits. The DWP should closely follow the impact of these changes and consider policy changes to the rest of the UK.

Figure 2.1

Multi-level Interventions for Clinical Psychologists to Support and Improve the Experience of People with Intellectual Disabilities Undergoing Welfare Assessments



Individual/Clinical Level Interventions

Consider the impact of living in fear and marginalisation during assessment and formulation

Individual interventions focusing on reducing distress and/or the impact of stigma (e.g. CFT or ACT)

Systemic Level Interventions

Support 3rd sector and advocacy groups in providing a safe-base e.g. bitesize training

Support the 3rd sector in providing meaningful experiences

Support self-advocacy and activist groups to support empowerment and resistance

Welfare System Policy and Process Level Change

Acknowledge that intellectual disabilities are lifelong and remove the need to re-assess work capability

Facilitate ongoing and consistent relationships to reduce uncertainty and anxiety

Train assessors in communication skills specific to people with intellectual disabilities

Include accessible information in all correspondance, such as in easy read format.

Facilitate a person-centred and holistic approach attempting to understand people's experiences

De-stigmatising welfare within the system by training assessors and provide education to general public

Improve employment opputunities by funding services to support self-development

Evaluate and review the process regularly, including input from those using the system

Dissemination

To support the multi-level interventions described above, this research will likely be disseminated to different audiences. Firstly, a participatory approach will be utilised in partnership with Mencap, to ensure people with intellectual disabilities and those who work with them are able to decide how and where the research is disseminated. It is hoped that this partnership will culminate in co-produced feedback to the welfare system and policy decision makers to outline the changes that need to be made to safeguard the wellbeing of those with intellectual disabilities who claim benefits. Secondly, the research will be submitted for publication in journals where clinical psychologists and other professionals working with those with intellectual disabilities can access the findings and the suggested interventions to support wellbeing in this context.

Conclusion

People with an intellectual disability who are subject to work capability assessments in relation to claiming UK welfare benefits experience the system as scary and oppressive. The process and the assessor reinforced the stigma associated with having an intellectual disability and, to a lesser extent, claiming benefits. The participants interactions with both the system and the assessor maintained a power imbalance. Participants coped with their experiences using self-protection strategies, however their relationships with safe and supportive others were the most beneficial in improving their experience. From this analysis, systemic approaches to improving the benefit assessment process for people with learning disabilities seems more likely to be helpful that individual interventions to cope with disempowerment or stigma. This might include making changes to the claiming process and benefit system and the facilitation of meaningful relationships within and beyond the benefit system.

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Appendices

Appendix A: Joanna-Briggs Institute (JBI) critical appraisal checklist

CHECKLIST FOR ANALYTICAL CROSS SECTIONAL STUDIES

Critical Appraisal tools for use in JBI Systematic Reviews

INTRODUCTION

JBI is an JBI is an international research organisation based in the Faculty of Health and Medical Sciences at the University of Adelaide, South Australia. JBI develops and delivers unique evidence-based information, software, education and training designed to improve healthcare practice and health outcomes. With over 70 Collaborating Entities, servicing over 90 countries, JBI is a recognised global leader in evidence-based healthcare.

JBI Systematic Reviews

The core of evidence synthesis is the systematic review of literature of a particular intervention, condition or issue. The systematic review is essentially an analysis of the available literature (that is, evidence) and a judgment of the effectiveness or otherwise of a practice, involving a series of complex steps. JBI takes a particular view on what counts as evidence and the methods utilised to synthesise those different types of evidence. In line with this broader view of evidence, JBI has developed theories, methodologies and rigorous processes for the critical appraisal and synthesis of these diverse forms of evidence in order to aid in clinical decision-making in healthcare. There now exists JBI guidance for conducting reviews of effectiveness research, qualitative research, prevalence/incidence, etiology/risk, economic evaluations, text/opinion, diagnostic test accuracy, mixed-methods, umbrella reviews and scoping reviews. Further information regarding JBI systematic reviews can be found in the JBI Evidence Synthesis Manual.

JBI Critical Appraisal Tools

All systematic reviews incorporate a process of critique or appraisal of the research evidence. The purpose of this appraisal is to assess the methodological quality of a study and to determine the extent to which a study has addressed the possibility of bias in its design, conduct and analysis. All papers selected for inclusion in the systematic review (that is – those that meet the inclusion criteria described in the protocol) need to be subjected to rigorous appraisal by two critical appraisers. The results of this appraisal can then be used to inform synthesis and interpretation of the results of the study. JBI Critical appraisal tools have been developed by the JBI and collaborators and approved by the JBI Scientific Committee following extensive peer review. Although designed for use in systematic reviews, JBI critical appraisal tools can also be used when creating Critically Appraised Topics (CAT), in journal clubs and as an educational tool.

JBI CRITICAL APPRAISAL CHECKLIST FOR ANALYTICAL CROSS SECTIONAL STUDIES

Reviewer______________________________________Date______________________________

Author_______________________________________Year_________ Record Number_________

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	☐	☐	☐	☐
2. Were the study subjects and the setting described in detail?	☐	☐	☐	☐
3. Was the exposure measured in a valid and reliable way?	☐	☐	☐	☐
4. Were objective, standard criteria used for measurement of the condition?	☐	☐	☐	☐
5. Were confounding factors identified?	☐	☐	☐	☐
6. Were strategies to deal with confounding factors stated?	☐	☐	☐	☐
7. Were the outcomes measured in a valid and reliable way?	☐	☐	☐	☐
8. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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EXPLANATION OF ANALYTICAL CROSS SECTIONAL STUDIES CRITICAL APPRAISAL

How to cite: Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). *JBI Manual for Evidence Synthesis.* JBI, 2020. Available from https://synthesismanual.jbi.global

Analytical cross sectional studies Critical Appraisal Tool

Answers: Yes, No, Unclear or Not/Applicable

1. Were the criteria for inclusion in the sample clearly defined?

The authors should provide clear inclusion and exclusion criteria that they developed prior to recruitment of the study participants. The inclusion/exclusion criteria should be specified (e.g., risk, stage of disease progression) with sufficient detail and all the necessary information critical to the study.

2. Were the study subjects and the setting described in detail?

The study sample should be described in sufficient detail so that other researchers can determine if it is comparable to the population of interest to them. The authors should provide a clear description of the population from which the study participants were selected or recruited, including demographics, location, and time period.

3. Was the exposure measured in a valid and reliable way?

The study should clearly describe the method of measurement of exposure. Assessing validity requires that a 'gold standard' is available to which the measure can be compared. The validity of exposure measurement usually relates to whether a current measure is appropriate or whether a measure of past exposure is needed.

Reliability refers to the processes included in an epidemiological study to check repeatability of measurements of the exposures. These usually include intra-observer reliability and inter-observer reliability.

4. Were objective, standard criteria used for measurement of the condition?

It is useful to determine if patients were included in the study based on either a specified diagnosis or definition. This is more likely to decrease the risk of bias. Characteristics are another useful approach to matching groups, and studies that did not use specified diagnostic methods or definitions should provide evidence on matching by key characteristics

5. Were confounding factors identified?

Confounding has occurred where the estimated intervention exposure effect is biased by the presence of some difference between the comparison groups (apart from the exposure investigated/of interest). Typical confounders include baseline characteristics, prognostic factors, or concomitant exposures (e.g. smoking). A confounder is a difference between the comparison groups and it influences the direction of the study results. A high quality study at the level of cohort design will identify the potential confounders and measure them (where possible). This is difficult for studies where behavioral, attitudinal or lifestyle factors may impact on the results.

6. Were strategies to deal with confounding factors stated?

Strategies to deal with effects of confounding factors may be dealt within the study design or in data analysis. By matching or stratifying sampling of participants, effects of confounding factors can be adjusted for. When dealing with adjustment in data analysis, assess the statistics used in the study. Most will be some form of multivariate regression analysis to account for the confounding factors measured.

7. Were the outcomes measured in a valid and reliable way?

Read the methods section of the paper. If for e.g. lung cancer is assessed based on existing definitions or diagnostic criteria, then the answer to this question is likely to be yes. If lung cancer is assessed using observer reported, or self-reported scales, the risk of over- or under-reporting is increased, and objectivity is compromised. Importantly, determine if the measurement tools used were validated instruments as this has a significant impact on outcome assessment validity.

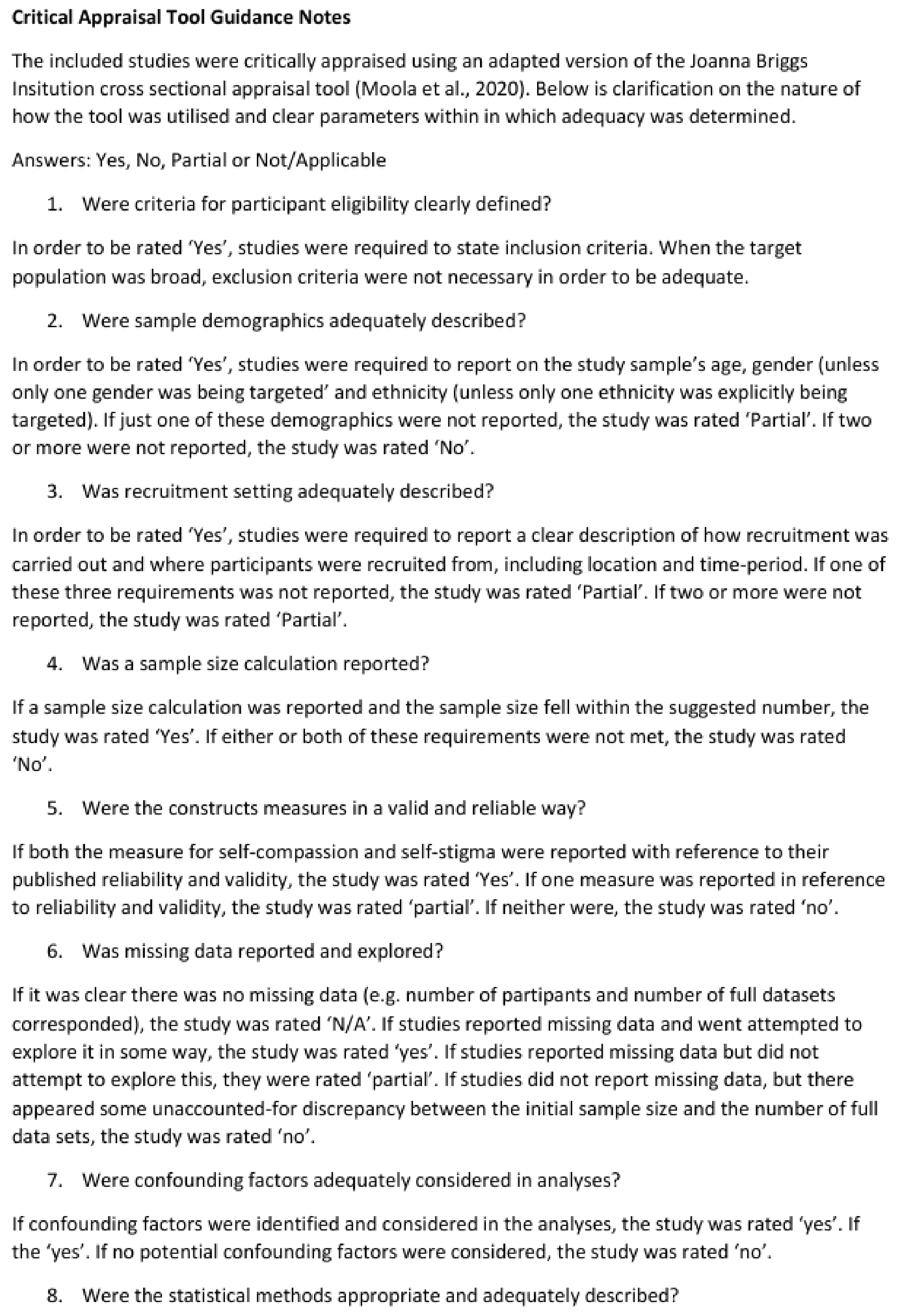
Having established the objectivity of the outcome measurement (e.g. lung cancer) instrument, it's important to establish how the measurement was conducted. Were those involved in collecting data trained or educated in the use of the instrument/s? (e.g. radiographers). If there was more than one data collector, were they similar in terms of level of education, clinical or research experience, or level of responsibility in the piece of research being appraised?

8. Was appropriate statistical analysis used?

As with any consideration of statistical analysis, consideration should be given to whether there was a more appropriate alternate statistical method that could have been used. The methods section should be detailed enough for reviewers to identify which analytical techniques were used (in particular, regression or stratification) and how specific confounders were measured.

For studies utilizing regression analysis, it is useful to identify if the study identified which variables were included and how they related to the outcome. If stratification was the analytical approach used, were the strata of analysis defined by the specified variables? Additionally, it is also important to assess the appropriateness of the analytical strategy in terms of the assumptions associated with the approach as differing methods of analysis are based on differing assumptions about the data and how it will respond.

Appendix B: Critical Appraisal Bespoke Guidance



Critical Appraisal Tool Guidance Notes

The included studies were critically appraised using an adapted version of the Joanna Briggs Insitution cross sectional appraisal tool (Moola et al., 2020). Below is clarification on the nature of how the tool was utilised and clear parameters within in which adequacy was determined.

Answers: Yes, No, Partial or Not/Applicable

1. Were criteria for participant eligibility clearly defined?

In order to be rated 'Yes', studies were required to state inclusion criteria. When the target population was broad, exclusion criteria were not necessary in order to be adequate.

2. Were sample demographics adequately described?

In order to be rated 'Yes', studies were required to report on the study sample's age, gender (unless only one gender was being targeted' and ethnicity (unless only one ethnicity was explicitly being targeted). If just one of these demographics were not reported, the study was rated 'Partial'. If two or more were not reported, the study was rated 'No'.

3. Was recruitment setting adequately described?

In order to be rated 'Yes', studies were required to report a clear description of how recruitment was carried out and where participants were recruited from, including location and time-period. If one of these three requirements was not reported, the study was rated 'Partial'. If two or more were not reported, the study was rated 'Partial'.

4. Was a sample size calculation reported?

If a sample size calculation was reported and the sample size fell within the suggested number, the study was rated 'Yes'. If either or both of these requirements were not met, the study was rated 'No'.

5. Were the constructs measures in a valid and reliable way?

If both the measure for self-compassion and self-stigma were reported with reference to their published reliability and validity, the study was rated 'Yes'. If one measure was reported in reference to reliability and validity, the study was rated 'partial'. If neither were, the study was rated 'no'.

6. Was missing data reported and explored?

If it was clear there was no missing data (e.g. number of partipants and number of full datasets corresponded), the study was rated 'N/A'. If studies reported missing data and went attempted to explore it in some way, the study was rated 'yes'. If studies reported missing data but did not attempt to explore this, they were rated 'partial'. If studies did not report missing data, but there appeared some unaccounted-for discrepancy between the initial sample size and the number of full data sets, the study was rated 'no'.

7. Were confounding factors adequately considered in analyses?

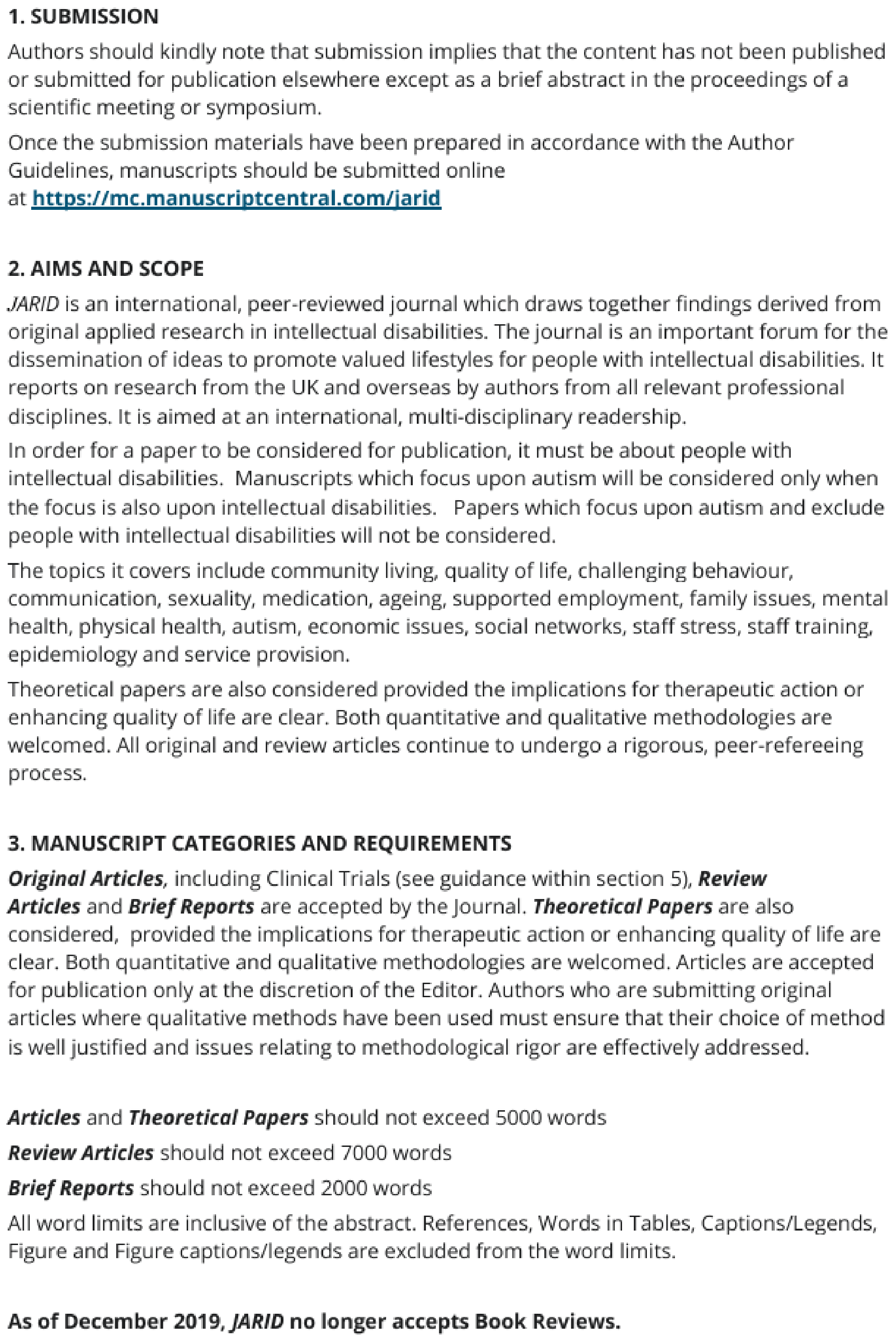
If confounding factors were identified and considered in the analyses, the study was rated 'yes'. If the 'yes'. If no potential confounding factors were considered, the study was rated 'no'.

8. Were the statistical methods appropriate and adequately described?

If the statistical analyses were appropriate for the aims and design of the study and they were described in sufficient detail so as the reader could replicate them, the study was rated 'yes'. If the analyses were appropriate but not described in sufficient detail, the study as rated 'partial'. If the analyses were not appropriate, the study was rated 'No'.

Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis. JBI, 2020. Available from https://synthesismanual.jbi.global

Appendix C: JARID Author Guidelines



1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at **https://mc.manuscriptcentral.com/jarid**

2. AIMS AND SCOPE

JARID is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

In order for a paper to be considered for publication, it must be about people with intellectual disabilities. Manuscripts which focus upon autism will be considered only when the focus is also upon intellectual disabilities. Papers which focus upon autism and exclude people with intellectual disabilities will not be considered.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision.

Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Original Articles, including Clinical Trials (see guidance within section 5), ***Review Articles*** and ***Brief Reports*** are accepted by the Journal. ***Theoretical Papers*** are also considered, provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Authors who are submitting original articles where qualitative methods have been used must ensure that their choice of method is well justified and issues relating to methodological rigor are effectively addressed.

Articles and ***Theoretical Papers*** should not exceed 5000 words

Review Articles should not exceed 7000 words

Brief Reports should not exceed 2000 words

All word limits are inclusive of the abstract. References, Words in Tables, Captions/Legends, Figure and Figure captions/legends are excluded from the word limits.

As of December 2019, *JARID* no longer accepts Book Reviews.

4. PREPARING THE SUBMISSION

Use of Language

The language used to describe disability differs across countries, cultures and disciplinary fields, and continues to evolve. All manuscripts submitted to JARID must use language that promotes the value of all people as full members of our shared society. Pejorative language inclusive of euphemisms must not be used. For JARID this includes the use of older language that has been used to describe people with intellectual disabilities such as "retarded", "handicapped", or "mentally handicapped". Using any terms which are offensive, or patronising may lead to rejection of your submitted manuscript.

JARID recommends using person-first and/or identity-first language thoughtfully and appropriately. For example, the language used to describe both people with intellectual disabilities and autistic people has evolved based on recent advocacy efforts. When referring to people with autism, it is acceptable to use either identity-first language (e.g., "autistic people") or person-first language (e.g., people with autism"), while identity-first language is not used to describe people with intellectual disabilities, where person-first language is preferred. Thus, people with intellectual disabilities should be referred to as people with intellectual disabilities.

We have consulted with over 40 self-advocates through Learning Disability England which included the North West Self-Advocacy Group, as well as Self-Advocacy Together and asked them what language we should use when writing about people with intellectual disabilities.

People with intellectual disabilities said that they do not like to be referred to by acronyms or abbreviations. Authors must therefore not use an abbreviation to describe intellectual disabilities such as "ID" or "LD". Instead, use person-first language such as children, teenagers, adults, or people with intellectual disabilities, avoiding acronyms or abbreviations.

The terms "learning disabilities" and "learning difficulties", though used in some countries to refer to people with intellectual disabilities, can cause confusion among readers. These terms are not used by the journal to refer to people with intellectual disabilities. Authors must only use the term "learning disabilities or difficulties" where this refers to a specific learning disability/disorder– such as a specific learning difficulty in reading, written expression or mathematics. **If "learning disabilities" or "learning difficulties" are used, authors must not use an abbreviation.**

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures.

Title page

The title page should contain:
i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's **best practice SEO tips**);
ii. A short running title of less than 50 characters;
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Acknowledgments.

Authorship
Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgments
Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement
Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Main Text File
As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.
The main text file should be presented in the following order:

i. Title, abstract and key words;
ii. Main text;
iii. References;
iv. Tables (each table complete with title and footnotes);
v. Figure legends;
vi. Appendices (if relevant).

Figures and supporting information should be supplied as separate files.

Abstract
All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study.

Keywords
Please provide up to six Keywords to aid indexing.

References
References should be prepared according to the *Publication Manual of the American Psychological Association* (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. For more information about APA referencing style, please refer to the **APA FAQ**. Note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one, and a DOI should be provided for all references where available.

Journal article

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, *159*, 483–486. doi:10.1176/appi.ajp.159.3.483

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from **http://www.youtube.com/watch?v=Vja83KLQXZs**

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive â€” the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Color Figures. Figures submitted in color may be reproduced in colour online free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white. If an author would prefer to have figures printed in colour in hard copies of the journal, a fee will be charged by the Publisher.

Additional Files

Appendices

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.
Click here for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

The following points provide general advice on formatting and style.

- **Spacing:** Manuscripts should be double spaced with a wide margin.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

Wiley Author Resources

Manuscript Preparation Tips: Wiley has a range of resources for authors preparing manuscripts for submission available **here**. In particular, authors may benefit from referring to Wiley's best practice tips on **Writing for Search Engine Optimization.**

Article Preparation Support

Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design â€" so you can submit your manuscript with confidence.

Also, check out our resources for **Preparing Your Article** for general guidance about writing and preparing your manuscript.

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5. EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

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Manuscripts are judged on the significance of the contribution to the literature, the quality of analysis and the clarity of presentation. Papers are expected to demonstrate originality and meaningful engagement with the global literature.

Except where otherwise stated, manuscripts are double-blind peer reviewed by anonymous reviewers in addition to the Editor. Ensure that all personally identifiable information is removed from your manuscript before you upload it to help protect your identity through the peer review process. Authors are asked not to post information about their submitted manuscripts to social media or websites until a final decision about the paper has been made; again, the reason for this is to help protect the double-blind peer review process. Authors who do not work in such a way as to help maintain the double-blind peer review process may have their manuscript rejected.

Final acceptance or rejection rests with the Editor-in-Chief, who reserves the right to refuse any material for publication or to edit any contribution to ensure that it conforms with the requirements of the journal

In-house submissions, i.e. papers authored by Editors or Editorial Board members of the title, will be sent to Editors unaffiliated with the author or institution and monitored carefully to ensure there is no peer review bias.

Wiley's policy on the confidentiality of the review process is **available here.**

Wiley Developmental Science Publishing Network
This journal participates in the **Wiley Developmental Science Publishing Network**. This exciting collaboration between a number of high quality journals simplifies and speeds up the publication process, helping authors find a home for their research. At the Editors' judgement, suitable papers not accepted by one journal may be recommended for referral to another journal(s) in the network. Authors decide whether to accept the referral, with the option to transfer their paper with or without revisions. Once the referral is accepted, submission happens automatically, along with any previous reviewer reports, thereby relieving pressure on the peer review process. While a transfer does not guarantee acceptance, it is more likely to lead to a successful outcome for authors by helping them to find a route to publication quickly and easily.

Human Studies and Subjects
For manuscripts reporting medical studies that involve human participants, a statement identifying the ethics committee that approved the study and confirmation that the study conforms to recognized standards is required, for example: **Declaration of Helsinki**; **US Federal Policy for the Protection of Human Subjects**; or **European Medicines Agency Guidelines for Good Clinical Practice**. It should also state clearly in the text that all persons gave their informed consent prior to their inclusion in the study.

Patient anonymity should be preserved. Photographs need to be cropped sufficiently to prevent human subjects being recognized (or an eye bar should be used). Images and information from individual participants will only be published where the authors have obtained the individual's free prior informed consent. Authors do not need to provide a copy of the consent form to the publisher; however, in signing the author license to publish, authors are required to confirm that consent has been obtained. Wiley has a **standard patient consent form** available for use.

Clinical Trial Registration
The journal requires that clinical trials are prospectively registered in a publicly accessible database and clinical trial registration numbers should be included in all papers that report their results.

Clinical trials should be reported using the CONSORT guidelines available at **www.consort-statement.org**. A CONSORT checklist should also be included in the submission material (**www.consort-statement.org**).

The Journal encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: **www.clinicaltrials.org**, **www.isrctn.org**.

Authors are asked to include the name of the trial register and the clinical trial registration number at the end of the abstract. If the trial is not registered, or was registered retrospectively, the reasons for this should be explained.

Conflict of Interest
The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be

disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Authorship

The list of authors should accurately illustrate who contributed to the work and how. All those listed as authors should qualify for authorship according to the following criteria:

1. Have made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; and
2. Been involved in drafting the manuscript or revising it critically for important intellectual content; and
3. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; and
4. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section (for example, to recognize contributions from people who provided technical help, collation of data, writing assistance, acquisition of funding, or a department chairperson who provided general support). Prior to submitting the article all authors should agree on the order in which their names will be listed in the manuscript.

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The journal encourages authors to share the data and other artefacts supporting the results in the paper by archiving it in an appropriate public repository. Authors should include a data accessibility statement, including a link to the repository they have used, in order that this statement can be published alongside their paper.All accepted manuscripts may elect to publish a data availability statement to confirm the presence or absence of shared data. If you have shared data, this statement will describe how the data can be accessed, and include a persistent identifier (e.g., a DOI for the data, or an accession number) from the repository where you shared the data. Sample statements are available on Author Services. If published, statements will be placed in the heading of your manuscript.

Publication Ethics

This journal follows the core practices of the **Committee on Publication Ethics (COPE)** and handles cases of research and publication misconduct accordingly (**https://publicationethics.org/core-practices**)”

Note this journal uses iThenticate’s CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Read Wiley’s Top 10 Publishing Ethics Tips for Authors **here**. Wiley’s Publication Ethics Guidelines can be found **here**.

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Self-Archiving Definitions and Policies: Note that the journal's standard copyright agreement allows for **self-archiving** of different versions of the article under specific conditions.

7. PUBLICATION PROCESS AFTER ACCEPTANCE

Accepted article received in production

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Accepted Articles

The journal offers Wiley's Accepted Articles service for all manuscripts. This service ensures that accepted 'in press' manuscripts are published online very soon after acceptance, prior to copy-editing or typesetting. Accepted Articles are published online a few days after final acceptance, appear in PDF format only, are given a Digital Object Identifier (DOI), which allows them to be cited and tracked. After publication of the final version article (the article of record), the DOI remains valid and can continue to be used to cite and access the article.

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Authors will receive an e-mail notification with a link and instructions for accessing HTML page proofs online. Page proofs should be carefully proofread for any copyediting or typesetting errors. Online guidelines are provided within the system. No special software is required, all common browsers are supported. Authors should also make sure that any renumbered tables, figures, or references match text citations and that figure legends correspond with text citations and actual figures. Proofs must be returned within 48 hours of receipt of the email. Return of proofs via e-mail is possible in the event that the online system cannot be used or accessed..

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The journal offers rapid speed to publication via Wiley's Early View service. **Early View** (Online Version of Record) articles are published on Wiley Online Library before inclusion in an issue. Note there may be a delay after corrections are received before the article appears online, as Editors also need to review proofs. Once the article is published on Early View, no further changes to the article are possible. The Early View article is fully citable and carries an online publication date and DOI for citations.

Citing this Article: eLocators

This journal now uses eLocators. eLocators are unique identifies for an article that service the same function page numbers have traditionally served in the print world. When citing this article, please insert the eLocator in place of the page number. For more information, please visit the Author Services eLocator page **here.**

8. POST PUBLICATION

Access and sharing

When the article is published online:

- The author receives an email alert (if requested).
- The link to the published article can be shared through social media.
- The author will have free access to the paper (after accepting the Terms & Conditions of use, they can view the article).
- The corresponding author and co-authors can nominate up to ten colleagues to receive a publication alert and free online access to the article.

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In cases where authors wish to change their name following publication, Wiley will update and republish the paper and redeliver the updated metadata to indexing services. Our editorial and production teams will use discretion in recognizing that name changes may be of a sensitive and private nature for various reasons including (but not limited to) alignment with gender identity, or as a result of marriage, divorce, or religious conversion. Accordingly, to protect the author's privacy, we will not publish a correction notice to the paper, and we will not notify co-authors of the change. Authors should contact the journal's Editorial Office with their name change request.

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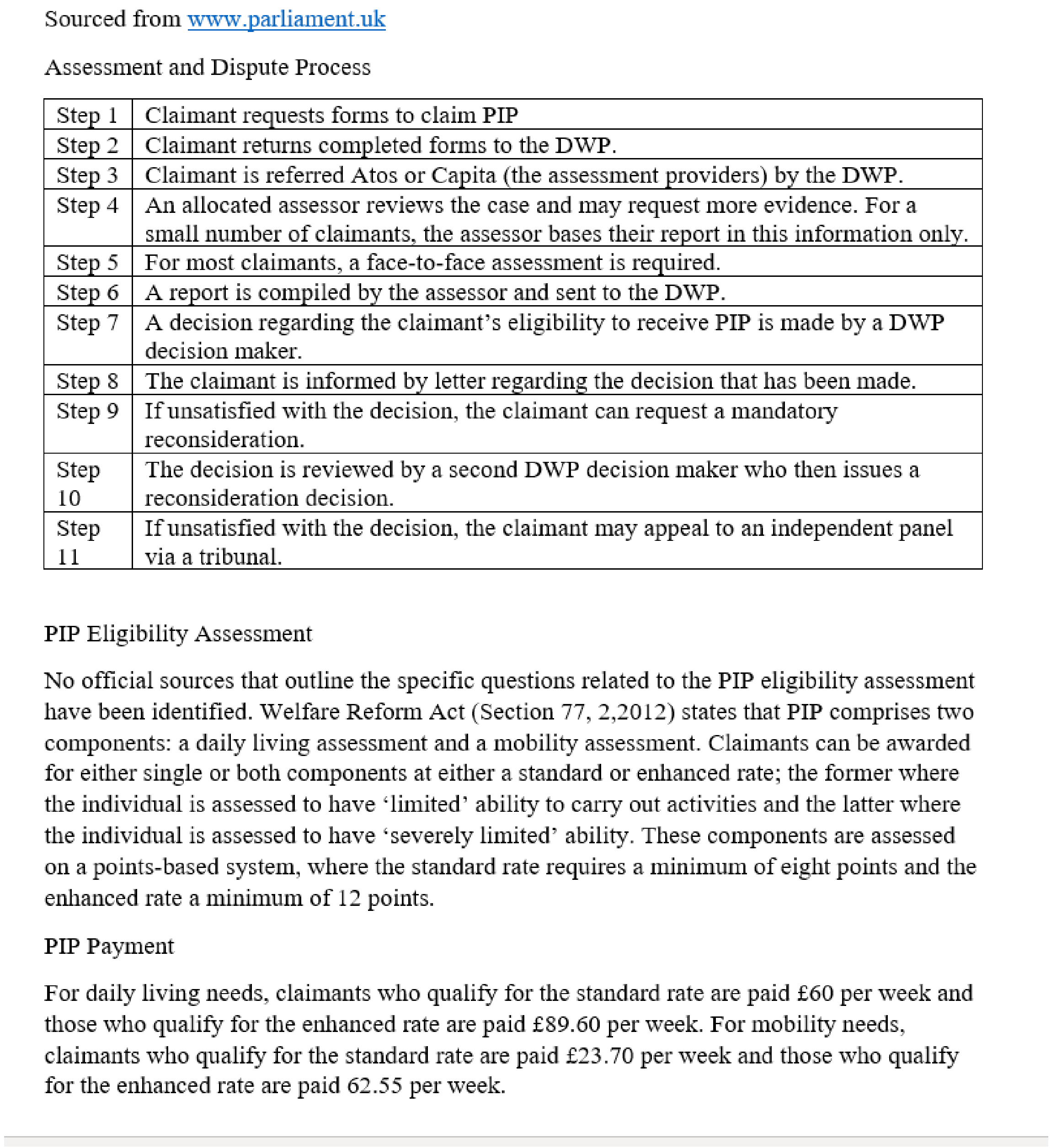
9. EDITORIAL OFFICE CONTACT DETAILS

For queries about submissions, please contact the *JARID* Editorial Office.

Pat Clelland
patriciaclelland@gmail.com

Author Guidelines Updated December 2019

Appendix D – Personal Independence Payment Context



Sourced from www.parliament.uk

Assessment and Dispute Process

Step 1	Claimant requests forms to claim PIP
Step 2	Claimant returns completed forms to the DWP.
Step 3	Claimant is referred Atos or Capita (the assessment providers) by the DWP.
Step 4	An allocated assessor reviews the case and may request more evidence. For a small number of claimants, the assessor bases their report in this information only.
Step 5	For most claimants, a face-to-face assessment is required.
Step 6	A report is compiled by the assessor and sent to the DWP.
Step 7	A decision regarding the claimant's eligibility to receive PIP is made by a DWP decision maker.
Step 8	The claimant is informed by letter regarding the decision that has been made.
Step 9	If unsatisfied with the decision, the claimant can request a mandatory reconsideration.
Step 10	The decision is reviewed by a second DWP decision maker who then issues a reconsideration decision.
Step 11	If unsatisfied with the decision, the claimant may appeal to an independent panel via a tribunal.

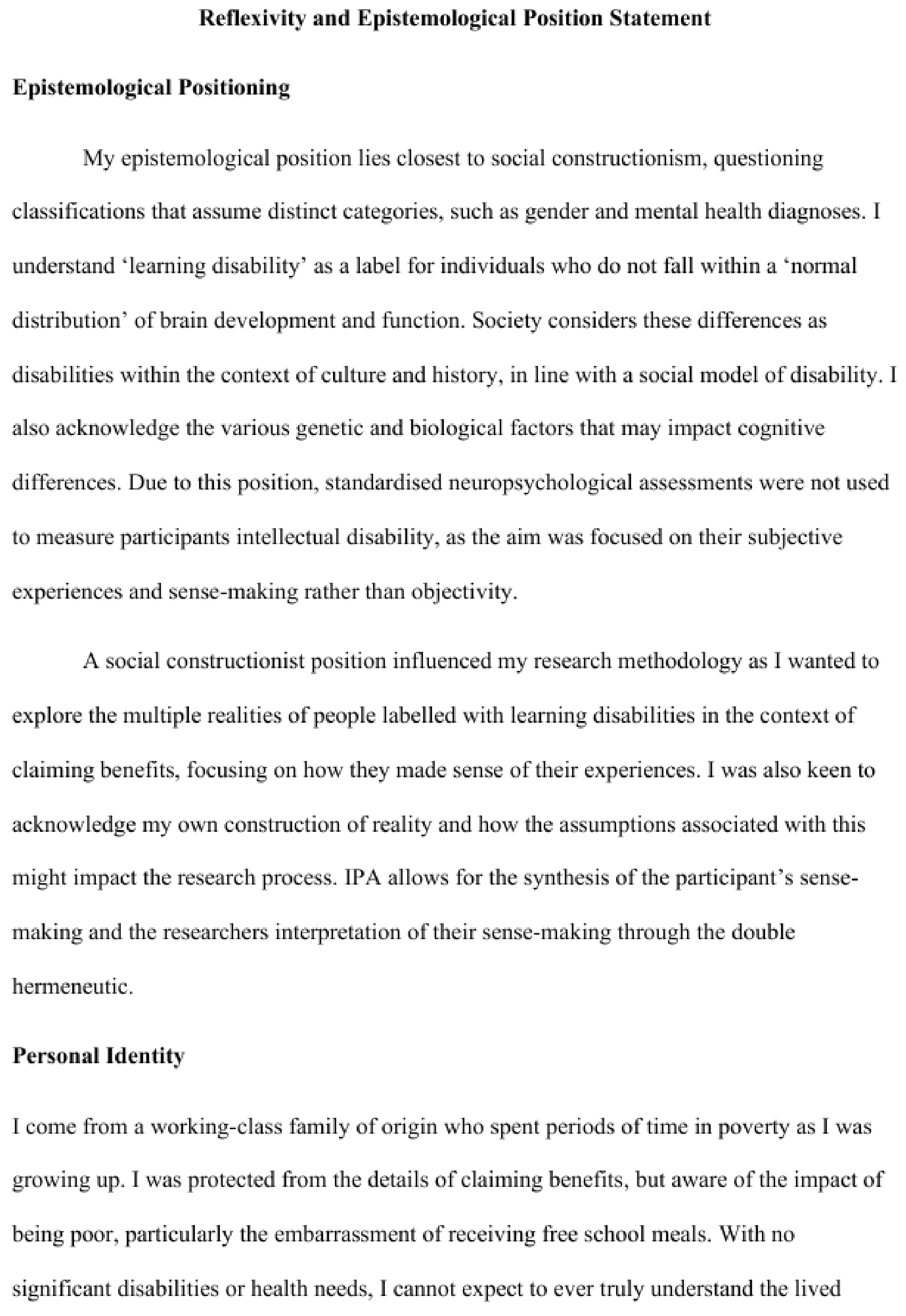
PIP Eligibility Assessment

No official sources that outline the specific questions related to the PIP eligibility assessment have been identified. Welfare Reform Act (Section 77, 2,2012) states that PIP comprises two components: a daily living assessment and a mobility assessment. Claimants can be awarded for either single or both components at either a standard or enhanced rate; the former where the individual is assessed to have 'limited' ability to carry out activities and the latter where the individual is assessed to have 'severely limited' ability. These components are assessed on a points-based system, where the standard rate requires a minimum of eight points and the enhanced rate a minimum of 12 points.

PIP Payment

For daily living needs, claimants who qualify for the standard rate are paid £60 per week and those who qualify for the enhanced rate are paid £89.60 per week. For mobility needs, claimants who qualify for the standard rate are paid £23.70 per week and those who qualify for the enhanced rate are paid 62.55 per week.

Appendix E: Epistemological and Position Statement



Reflexivity and Epistemological Position Statement

Epistemological Positioning

My epistemological position lies closest to social constructionism, questioning classifications that assume distinct categories, such as gender and mental health diagnoses. I understand 'learning disability' as a label for individuals who do not fall within a 'normal distribution' of brain development and function. Society considers these differences as disabilities within the context of culture and history, in line with a social model of disability. I also acknowledge the various genetic and biological factors that may impact cognitive differences. Due to this position, standardised neuropsychological assessments were not used to measure participants intellectual disability, as the aim was focused on their subjective experiences and sense-making rather than objectivity.

A social constructionist position influenced my research methodology as I wanted to explore the multiple realities of people labelled with learning disabilities in the context of claiming benefits, focusing on how they made sense of their experiences. I was also keen to acknowledge my own construction of reality and how the assumptions associated with this might impact the research process. IPA allows for the synthesis of the participant's sense-making and the researchers interpretation of their sense-making through the double hermeneutic.

Personal Identity

I come from a working-class family of origin who spent periods of time in poverty as I was growing up. I was protected from the details of claiming benefits, but aware of the impact of being poor, particularly the embarrassment of receiving free school meals. With no significant disabilities or health needs, I cannot expect to ever truly understand the lived experiences of people with learning disabilities. It is likely that someone with a learning disability may have interpreted the data differently, leading to a different analysis.

Due to my personal history, I am drawn to ‘give back’ to people I consider ‘worse off’ than me financially or socially, perhaps due to some sense of guilt or shame that I have moved towards a middle-class social position and an awareness of the privilege that affords me. This may have exacerbated my emotional response to the interviews, where I felt a strong sense of injustice and frustration that the welfare system appeared to fail those who need it the most. This will have influenced what I saw in the data, particularly the theme of marginalisation which is based on stigma and disempowerment. This theme also reflects my personal experiences of feeling socially excluded and ‘othered’ around families who appeared more financially stable when I was growing up. Through the analysis process, I may have projected my own experiences of feeling marginalised on to the participant’s accounts.

Political Identity

I am aligned with the political left and believe in equality and parity of wealth and resources. I am critical of neoliberal ideology and its focus on individualism and consumerism. However, I am aware that my occupation and lifestyle does not always fully reflect this, which can lead tension between my values and actions. This may have positioned the research as an outlet for my political beliefs, to align my work and my values.

The immense privilege and power my position affords me has allowed me to engage with political ideologies, with the luxury of time and resources. With these resources I have been able to attend political campaigns and strategy meetings such as ‘Scrap Universal Credit’. This has allowed me to form critical opinions on UK welfare system and learn from others. However, many others do not have the social power with which to explore politics or to freely express their views and opinions. Someone without these resources may have formulated different readings of the research data that are less politically positioned.

Due to my experiences at the 'Scrap Universal Credit' strategy meetings, I entered the research pre-conceived ideas about how people experience welfare assessments as distressing. As a healthcare professional I was shocked that other healthcare professionals would carry out these assessments and be instrumental in removing people's welfare support. Hearing the participant's accounts added to this, which were highly personalised to the assessors, to the point where I developed a view of the workers as agents of the state, with an almost villain-like characterisation. Discussing this in research supervision was important and allowed me to hold in mind the lack of training the assessors receive and pressure they are likely to be under.

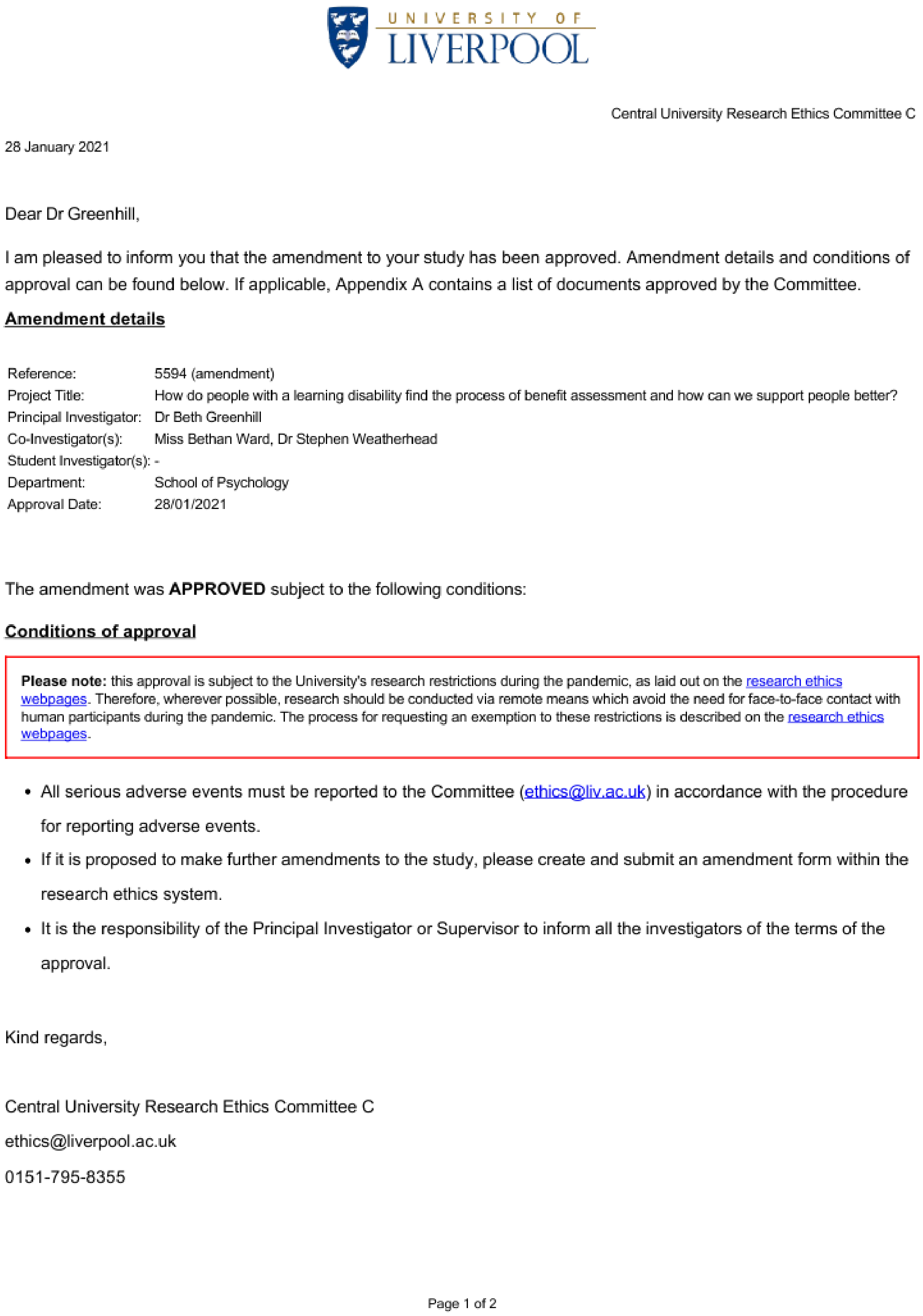
Professional Identity

As a trainee clinical psychologist, I worked in clinical settings throughout the research process. My training encourages me to look for specific indicators in conversation, related to problems, cognitions, and emotions. There was a pull to focus on these areas during the interviews and I found it helpful to have a print-out of my research questions and aims on my desk to ground myself in the research.

I practice clinical psychology from a critical and systemic perspective, and I believe in the power of social justice in reducing emotional distress. This means that the interpretations I made within the analysis will have been impacted by this and people with other experiences and assumptions are likely to make alternative readings if they review the data. Through transparency in my position and the data, I provide the tools with which readers can form alternate readings.

Prior to conducting the interviews and analysis, I completed a systematic review of literature pertaining to the relationship between self-stigma and self-compassion. The focus on stigma is likely to have meant I was primed to interpret instances of stigma in the data during analysis. Someone who had done a different systematic review may not have had the same elements of stigma in their final analysis.

Appendix F: University of Liverpool Ethical Approval Confirmation



UNIVERSITY OF LIVERPOOL

Central University Research Ethics Committee C

28 January 2021

Dear Dr Greenhill,

I am pleased to inform you that the amendment to your study has been approved. Amendment details and conditions of approval can be found below. If applicable, Appendix A contains a list of documents approved by the Committee.

Amendment details

Reference:	5594 (amendment)
Project Title:	How do people with a learning disability find the process of benefit assessment and how can we support people better?
Principal Investigator:	Dr Beth Greenhill
Co-Investigator(s):	Miss Bethan Ward, Dr Stephen Weatherhead
Student Investigator(s):	-
Department:	School of Psychology
Approval Date:	28/01/2021

The amendment was **APPROVED** subject to the following conditions:

Conditions of approval

Please note: this approval is subject to the University's research restrictions during the pandemic, as laid out on the research ethics webpages. Therefore, wherever possible, research should be conducted via remote means which avoid the need for face-to-face contact with human participants during the pandemic. The process for requesting an exemption to these restrictions is described on the research ethics webpages.

- All serious adverse events must be reported to the Committee (ethics@liv.ac.uk) in accordance with the procedure for reporting adverse events.
- If it is proposed to make further amendments to the study, please create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator or Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Central University Research Ethics Committee C
ethics@liverpool.ac.uk
0151-795-8355

Appendix G: Participant Information Sheet

What is it like to have a learning disability and to be assessed for your benefits?

INFORMATION LEAFLET

UNIVERSITY OF
LIVERPOOL

Part 1: What is this leaflet?

This leaflet is about some **research**.

Research is when we want to understand something better.

A **researcher** does research.

A researcher asks people questions to understand something better.

This research is about

People with Learning Disabilities and Benefit Assessments

This leaflet tells you about our research.

It will tell you why we are doing our research.

It will tell you how to join in if you want to.

You do not have to make up your mind straight away.

Think about it before you say yes or no.

Talk to someone you trust about your decision, if that will help.

Part 2: The people who are doing the research.

This is Bethan Ward (Beth W).

She is the researcher.

Beth W goes to the University of Liverpool.

She is a **Trainee Clinical Psychologist**.

This means he is learning to be a **Clinical Psychologist.**

Clinical Psychologists help people.

They talk to them when they have a problem.

Clinical Psychologists also do research. This helps them understand how to help people.

This research will help Beth W to become a Clinical Psychologist.

Beth does not have any links with the people who approve your benefits.

Beth Greenhill (Beth G) is in charge of the research.

She is a Clinical Psychologist.

Beth works at the University of Liverpool.

She makes sure Beth W does the research right.

If you want to ask Beth G any questions you can telephone her.

Her number is: **0151 794 5534**

Before any research is allowed to happen, it has to be checked by a group of people.

The group of people is called a Research Ethics Committee. They make sure the research is fair.

This research has been checked by XXX.

They said it okay for Beth W to do this research.

Part 3: What we want to understand better

We want to speak to people who have a learning disability and have been to talk to someone to see if they are still able to get their benefit money.

These might be for PIP, ESA or Universal Credit.

We want to know how people found filling in forms for their benefit meetings.

We want to know what the benefit meeting was like for you.

We want to know if someone helped you before your meeting or during your meeting.

We want to know if you have any ideas about how to help people with learning disabilities when they go to benefit meetings.

We want to know what is good and bad about going to meetings about your benefit money.

We hope our research tells us the best help to offer.

If you have a learning disability and have had a meeting to find out if you are still able to get benefit money you can join in too.

10

We want about 10 people to join in.

Part 4: Joining in with the research

You do not have to join in the research.

You can say no if you do not want to join in.

It is ok to say no.

If you want to join in we will ask for your **consent**.

Consent means you say yes to join in the research.

We will ask you to sign a consent form if you want to join in.

Please keep this leaflet and think about it for a while.

It will help you say yes or no to joining in.

You can say no if you change your mind.

It is ok to change your mind at any time.

It is ok to change your mind for any reason.

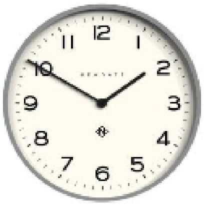
Part 5: What happens if you say yes to join in?

You will have an **interview** with Beth.

She will talk to you and ask you some questions.

She will ask you about having a learning disability and having meetings about your benefits.

The interview will be on Zoom.



The interview will last about one hour.

You can stop the interview any time you want to.

1

You will only have one interview.

What you say will be recorded.

Beth will listen to the interview again.

She will write down everything you say.

Beth will write about this in her work.

Other people will read Beth’s work.

This will help others learn from the research.

Beth will not use your name when she writes about what you say.

You can pick a name to be used when Beth writes about what you say.

This means other people will know what you said, but not that it was you who said it.

Mencap staff will know you joined in the research but they will not know what you say.

You do not have to tell anyone what you say to Beth if you do not want to.

Beth will interview you in **private**.

This means only you and Beth will be in the Zoom meeting.

You can have a support worker or someone else that you trust with you. They might be in the room with you (if you live together) or they might join you and Beth on Zoom.

But Beth will only ask you the questions. Your support worker will not be able to join in the research.

If you say someone hurt you, Beth might have to tell someone.

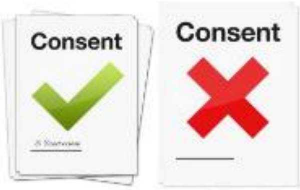
If you say you might hurt yourself or someone else, Beth might have to tell someone.

If you feel really sad, worried or angry, Beth might have to tell someone.

This is to check you are ok.

Beth will tell you if she has to do this.

This is to keep you and other people safe.



If you do not agree with this you will not be able to join in.

It is ok if you do not agree with this.

It is ok if you do not join in.

Beth will try to answer questions you have.

If you join in the research, you might enjoy your interview with Beth.

But we cannot promise this.

We do not know if joining in the research will help you.

But it might help us to think of some good ideas to help other people in the future.

Part 6: What would happen after the interview?

When Beth has interviewed everyone, she will think about what everyone said. What you said will be typed up.

Beth will read what you said. She will read what other people said. She will look for the things which seemed important to you and other people.

Beth will put this in a report. She will ask you what you think about the report.

Beth will show her report to people who work at the University of Liverpool. If they think her ideas are good enough she will be able to tell other people about the research.

This will help other people learn from the research.

The research might help people with learning disabilities when they go to benefit meetings.

There are different ways to tell people about the research.

Beth might talk to other people with learning difficulties who go to benefit meetings.

Beth might talk to staff who support people with learning disabilities.

Beth might write about the research in a **journal**.

A journal is a bit like a magazine. But a journal does not talk about celebrities, it only talks about research.

Lots of people read journals.

Journals are in libraries

and on the internet.

When Beth tells other people about the research, she will say some things that people said in their interview.

But she will not say who said it.

This means she might say the words you said, but she will use the n.

People can learn from what you said but they will not know that you said it.

The University of Liverpool is organising this research.

They pay for the research to happen.

You do not pay any money to join in the research.

We will not give you money to join in the research.

Before any research is allowed to happen it has to be checked by a group of people.

The group of people are called a **Research Ethics Committee**.

The Research Ethics Committee makes sure the research is fair.

This research has been checked by University of Liverpool Research Ethics Committee.

They said it is ok to do this research.

If you are unhappy about the research you can tell Beth Greenhill.

She is in charge of the research.

She checks what Beth W does.

Her telephone number is 0151 794 5534.

PALS

Patient Advice and Liaison Service

You do not have to tell Beth if you are unhappy about the research.

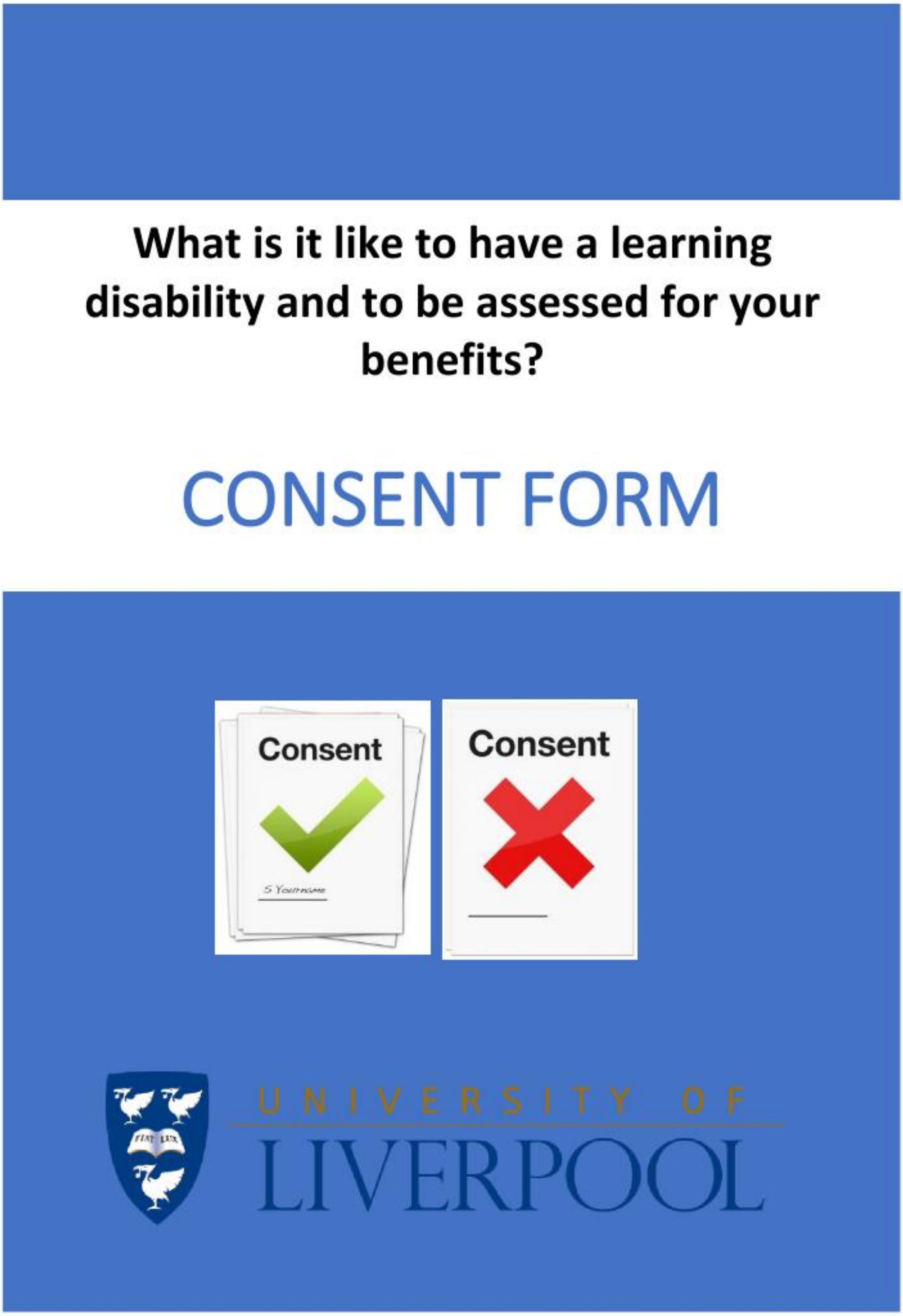
You can tell **PALS** instead if you want to.

PALS is the Patient Advice and Liaison Service.

They help people who are unhappy about research.

PALS telephone number is **0800 073 1106**.

Appendix H: Consent Form



What is it like to have a learning disability and to be assessed for your benefits?

CONSENT FORM

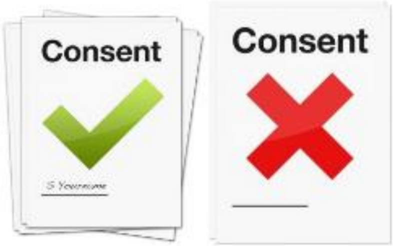
What is it like to have a learning disability and to be assessed for your benefit money?

Consent form

Today’s date is: 29th March 2021

Please can you tell me your full name?

Consent is about you saying **yes or no** to being part of this research.



If you say **yes** you will be interviewed.

If you say **no** you will not be interviewed.

Whatever you decide, thank you for thinking about it.

You can say no if you want to.

Do not say yes if you want to say no.

I am going to read out some sentences. Please listen carefully.

You can read the statements on the screen too.

Please say yes or no after each sentence.

Consent

I have read the leaflet called:

What is it like to have a learning disability and be assessed for your benefits?

What is it like to have a learning disability and to be assessed for your benefits?

INFORMATION LEAFLET

Please say

YES or NO

Someone helped me read it.

Please say

YES or NO

I asked the questions I wanted.

Please say

YES or NO

Beth W answered all my questions.

Please say

YES or NO

I know what the research is about.

Please say

YES or NO

I know I can say no if I do not want to join in.

Please say

YES or NO

I want to join in the research.

Please say

YES or NO

3

I know what I say will be recorded.

Please say

YES or NO

Beth will listen to it again. She will write down everything I said.

Please say

YES or NO

Beth will write about this in her work.

Please say

YES or NO

Beth will not use my name when she writes about the things I say

I will pick what name Beth uses when she writes about the things I say.

Please say

YES or NO

This means other people will know what I said, but not that it was me who said it.

Beth W might have to tell someone if

- Someone has hurt me
- I want to hurt myself or someone else
- I feel very sad or worried.

Please say

YES or NO

If she can, Beth W will visit Mencap at the end of the research. She will tell people the most important things she found out.

She will tell people about all the research, not just what I said.

I want to know what Beth W finds out.

Please say

YES or NO

Do you agree to continue with this online video interview about how you found getting your benefits?

Please say

YES or NO

This research is organised by the University of Liverpool, with permission and support from Mencap.

Appendix I – Proposed Interview Schedule

Proposed Interview Schedule

Key objectives:

1) To understand how participants experience and make sense of the benefit system, particularly work capability assessments (WCA).
2) To understand the psychological impact of WCA on participants and explore the potential mechanisms that underlie this.
3) To describe what participants perceive as helpful support through the process of WCA.

Topics for discussion (umbrella questions)	**Interviewer notes (prompts will be used at the discretion of the interviewer, if needed to aid understanding of the question)**
1. Welcome and introduction to interview	
• Explain aim of interview.	E.g. to learn more about what it is like to have a LD and attend meetings to see if you are allowed your benefit money. We are here for 1 hour or so.
• Reminder of key information (consent form)	➢ Role of researcher ➢ Having someone present if wanted ➢ Confidentiality and limits of ➢ Stopping and pausing ok ➢ No longer than one hour ➢ Audio recording of the interview ➢ Revisit consent.
• Any questions?	
2. Introduction to the participant	
• Introductory questions that are simple to answer – ice-breakers to facilitate participant to feel more comfortable talking in first few minutes.	➢ What would you like the name to be that I use when I talk about the research? ➢ What else have you done today? ➢ What will you do later, after this meeting? ➢ What’s your favourite thing to do? ➢ How are you feeling today?

3. The Benefit System & Employment	
• What does "The Benefit System" mean to you?	➢ Do you get money from the government to help you pay for things like rent, food and bills? ➢ What does the benefit system do? ➢ What happens in the benefit system? ➢ What part does the benefit system play in your life?
• What has the benefit system been like for you?	➢ What do you have to do to get your benefit money? ➢ What was that like? ➢ How did that make you feel? (Use of emotions visual aid)
4. Invitation to Assessment	
• What was it like to get a letter to say you need to go and talk to someone about whether you would keep your benefit money?	➢ How did you find out you needed to go and talk to someone about whether you would keep your benefit money? ➢ What was that like when you got a letter through your door? ➢ What did you think the letter meant? ➢ How did that make you feel? (Use of emotions visual aid) ➢ Why do you think you felt this way? ➢ What did you do about the letter? ➢ Did you tell anyone about the letter? ➢ Did you read the letter by yourself? ➢ Did anyone else help you read the letter? ➢ Did you know what to do if you could not understand the letter?
• Did you find the letter easy to understand?	➢ Did anyone help you understand what the letter meant? ➢ Did anyone help you with your feelings?

• Was there anything you didn't like about getting the letter? • Is there anything that was helpful to you when you got the letter?	➢ What could be helpful for other people with learning disabilities who get this letter? ➢ What didn't you like about it? ➢ Why do you think you didn't like it? ➢ Why do you think that was helpful? ➢ Did anyone help you with your feelings? ➢ What do you think could have been helpful to you, or for other people with learning disabilities who find out they have to go to this meeting?
6. Preparation for WCA	
• What was it like when you were waiting for the meeting? • Was there anything you had to do while you waited for the meeting**?**	➢ Did you think about what the meeting would be like? ➢ Did you have any worries about the meeting? ➢ Were you looking forward to the meeting at all? ➢ Why do you think you felt this way? ➢ Did the way you felt about the meeting coming up change the things you did? ➢ Why do you think that happened? ➢ Did the way you felt about the meeting coming up change if you wanted to spend time with other people? ➢ Why do you think that happened? ➢ Did you have to fill in any forms? ➢ What was it like filling in those forms? ➢ Were there things you needed to take with you to the meeting? ➢ What did you think about having to take these things? ➢ What was it like having to take these things? ➢ How did you get these things? ➢ Did anyone help you get these things?

• Was there anything you didn't like about waiting for the meeting?	➢ What didn't you like about it? ➢ Why do you think you didn't like it?
• Is there anything that was helpful to you when you were waiting for the meeting?	➢ Why do you think that was helpful? ➢ Did anyone help you with your feelings? ➢ What do you think could have been helpful to you, or for other people with learning disabilities who are waiting to have this meeting?
7. During the Assessment	
• What happened during the meeting?	➢ Did you take anyone with you? ➢ What did you think about the questions that they asked you?
• What was the benefits meeting like?	➢ How did you feel when you were in the meeting? (use emotion visual aid) ➢ Why do you think you felt this way? ➢ What did you think the person you had the meeting with was like? ➢ Did you feel comfortable/relaxed in the interview? ➢ What was the best bit about the meeting? ➢ Why was this the best bit? ➢ What was the worst bit about the meeting? ➢ Why was this the worst bit?
• Was there anything in particular you did not like about being in the meeting?	➢ What didn't you like about it? ➢ Why do you think you didn't like it?
• Was anything helpful for you during the meeting?	➢ Did anyone help you understand what was happening in the meeting? ➢ Did anyone help you with your feelings? ➢ What could be helpful for other people with learning disabilities who are in this meeting?
8. After the Assessment	

• What happened straight after the meeting?	➢ What did you next? ➢ Do you think your day was different to days where you had not been to a meeting like this? ➢ How did you feel after the meeting? ➢ Why do you think you felt this way?
• What happened while you were waiting to find out whether you could keep your benefit money?	How long were you waiting to find out whether you could keep your benefit money? What did you think about while you were waiting to find out whether you could keep your benefit money? How did you feel while you were waiting to find out whether you could keep your benefit money? Why do you think you felt this way? Did the way you felt about the meeting change the things you did? Why do you think that happened? Did the way you felt about the meeting change if you wanted to spend time with other people?
• What happened when you found out whether you could keep your benefit money?	Why do you think that happened? How did you find out? Were you able to keep your benefit money?
• **If yes**, how did you feel when you were told you would still get your benefit money?	
• **If no**, what happened next?	How did you feel when you were told you could not keep your benefit money? Why do you think you felt this way? Did you appeal this e.g. go back to try again? What was that like? How did that make you feel?

• Is there anything that was helpful to you after the meeting?	Did anyone help you understand what was happening with your benefit money? Did anyone help you with your worries? What could be helpful for other people with learning disabilities who have had this meeting?
9. General Emotional Impact & Psychological Mechanisms	
• What do you think about needing to get money from the government to help you pay for things like rent, food and bills?	➢ What stops you from being able to have your own money for these things? ➢ Would you like to be able to go to work and make your own money for these things? ➢ How does getting money to help pay for these things make you feel? (Use of emotions visual aid)
• Overall, how did this process effect you and your life?	➢ How did it make you feel? ➢
• Why do you think this happened?	➢ What part made it feel like that? ➢ Why do you think it make you feel like that?
10. Conclusions	
• Summarise key points of interview.	➢ Is there anything else you think we should talk about?
• Check in with wellbeing & debrief	➢ How are you feeling now that the interview is almost over? ➢ What are you going to do after the interview ➢ Would you like any leaflets?

• Feedback options. • Thank you for participating. • End of interview.	➢ Come in to Mencap and tell you about the research when is has ended so I can explain what I learned from the research. ➢ Option to have hot drink or play a game of pool for 'cool down'

Appendix J: Easy-read Interview Schedule

Interview Questions

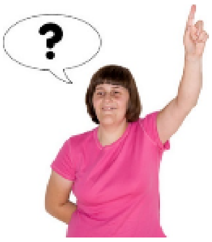
This easy-read guide is to help you understand the questions I will ask you.

I might ask you some questions that are not here.

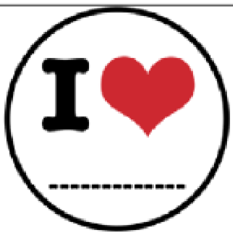
If you do not understand any of the questions, please tell me and I will try to explain them for you.

	Hello! Thanks for coming to meet me.
	We are here to talk about the meeting you went to see if you are still allowed your benefit money.
	I'm Beth an I am learning to be a Clinical Psychologist. I do not work with anyone who decides if you get any benefit money.

 	Have you bought anyone with you today? They can stay if you want them to. They cannot answer any of the questions I ask though.
	Beth will not tell anyone else what you say in this interview. Beth will not use your name when she writes about what you say. If you say you might hurt yourself or someone else, Beth might have to tell someone. If you feel really sad, worried or angry, Beth might have to tell someone. This is to check you are ok.
	This talk will be recorded.

	Do you still want to do this interview?
	Do you have any questions?

	We will start with some easy questions!
	What would you like the pretend name to be that I use when I write up this interview?
	What have you done today?
	What will you do later, after this interview?

	What is your favourite thing to do?
	How are you feeling today?

Questions about the Benefit System	
	What do the words ‘The Benefit System mean to you?
	Why do you think you get money from the government to help you pay for things like rent, food and bills?
	What has the benefit system been like for you?

Questions about Being told to go to a Benefits Meeting

	What was it like to get a letter to say you need to go and talk to someone about whether you would keep your benefit money?
	Did you find the letter easy to understand?
	Is there anything that was helpful to you when you got the letter to go to the benefits meeting?

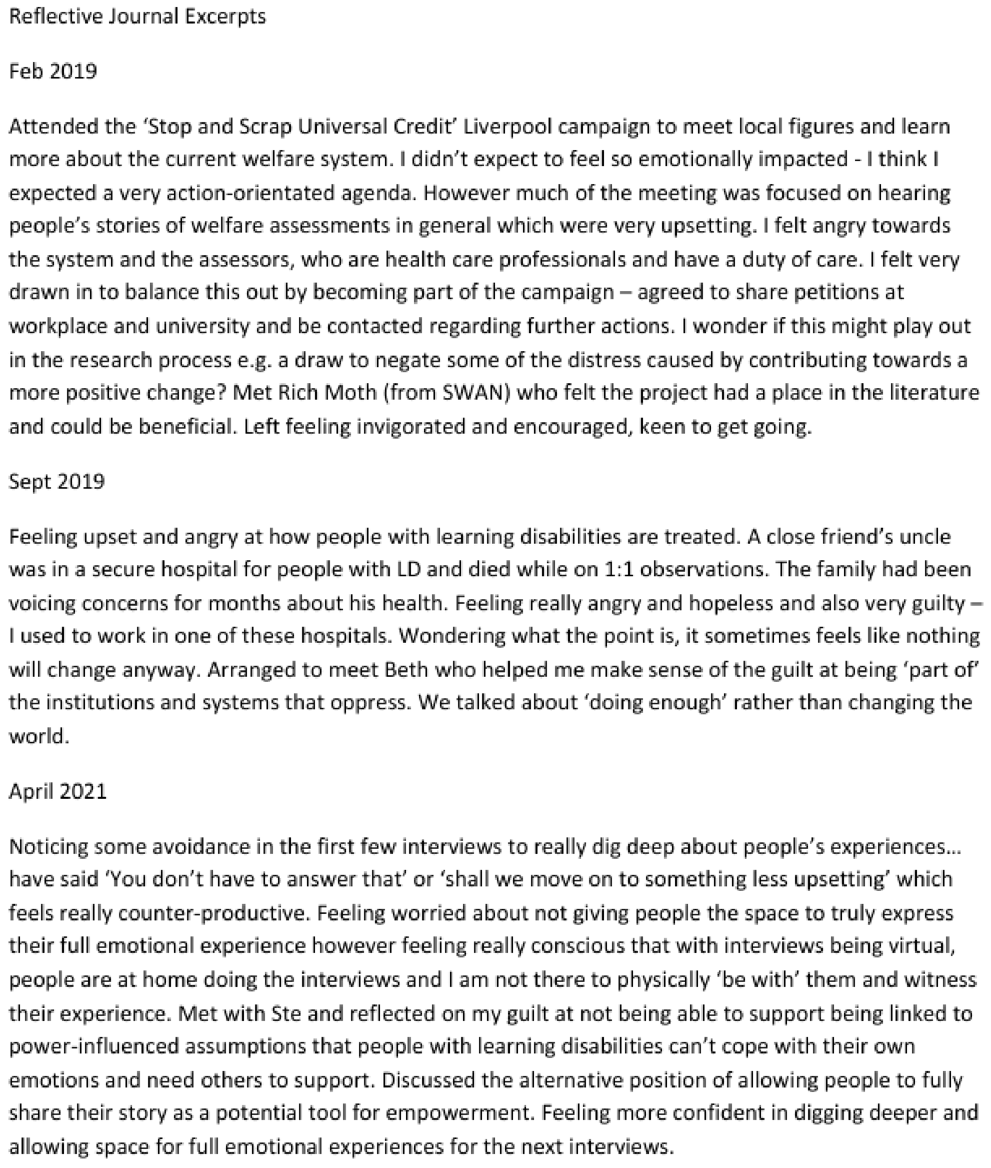
Questions about Waiting to go to the Meeting	
	Was there anything you had to do while you waited for the benefits meeting?
	What was it like when you were waiting for the benefits meeting?
	Is there anything that was helpful to you when you were waiting for the benefits meeting?

Questions about Being at the Benefits Meeting	
	What happened during the benefits meeting?
	What was the benefits meeting like?
	Was anything helpful for you during the meeting?

Questions about After the Benefits Meeting	
	What happened after the benefits meeting?
	What happened while you were waiting to find out whether you could keep your benefit money?
	What happened when you found out whether you could keep your benefit money?
	Is there anything that was helpful to you after the meeting?

<table>
<tr><th colspan="2">Finishing the Interview</th></tr>
<tr><td></td><td>Let me check I have your ideas right.</td></tr>
<tr><td></td><td>Is there anything else about your benefit meetings that you think we should talk about?</td></tr>
<tr><td></td><td>How are you feeling now that the interview is finished?</td></tr>
<tr><td></td><td>If you like I will come into Mencap and meet you to talk about the research when it is finished.
You can always change your mind later.</td></tr>
</table>

Appendix K – Reflective Diary Excerpts



Reflective Journal Excerpts

Feb 2019

Attended the 'Stop and Scrap Universal Credit' Liverpool campaign to meet local figures and learn more about the current welfare system. I didn't expect to feel so emotionally impacted - I think I expected a very action-orientated agenda. However much of the meeting was focused on hearing people's stories of welfare assessments in general which were very upsetting. I felt angry towards the system and the assessors, who are health care professionals and have a duty of care. I felt very drawn in to balance this out by becoming part of the campaign – agreed to share petitions at workplace and university and be contacted regarding further actions. I wonder if this might play out in the research process e.g. a draw to negate some of the distress caused by contributing towards a more positive change? Met Rich Moth (from SWAN) who felt the project had a place in the literature and could be beneficial. Left feeling invigorated and encouraged, keen to get going.

Sept 2019

Feeling upset and angry at how people with learning disabilities are treated. A close friend's uncle was in a secure hospital for people with LD and died while on 1:1 observations. The family had been voicing concerns for months about his health. Feeling really angry and hopeless and also very guilty – I used to work in one of these hospitals. Wondering what the point is, it sometimes feels like nothing will change anyway. Arranged to meet Beth who helped me make sense of the guilt at being 'part of' the institutions and systems that oppress. We talked about 'doing enough' rather than changing the world.

April 2021

Noticing some avoidance in the first few interviews to really dig deep about people's experiences… have said 'You don't have to answer that' or 'shall we move on to something less upsetting' which feels really counter-productive. Feeling worried about not giving people the space to truly express their full emotional experience however feeling really conscious that with interviews being virtual, people are at home doing the interviews and I am not there to physically 'be with' them and witness their experience. Met with Ste and reflected on my guilt at not being able to support being linked to power-influenced assumptions that people with learning disabilities can't cope with their own emotions and need others to support. Discussed the alternative position of allowing people to fully share their story as a potential tool for empowerment. Feeling more confident in digging deeper and allowing space for full emotional experiences for the next interviews.

Appendix L - Sample Coding

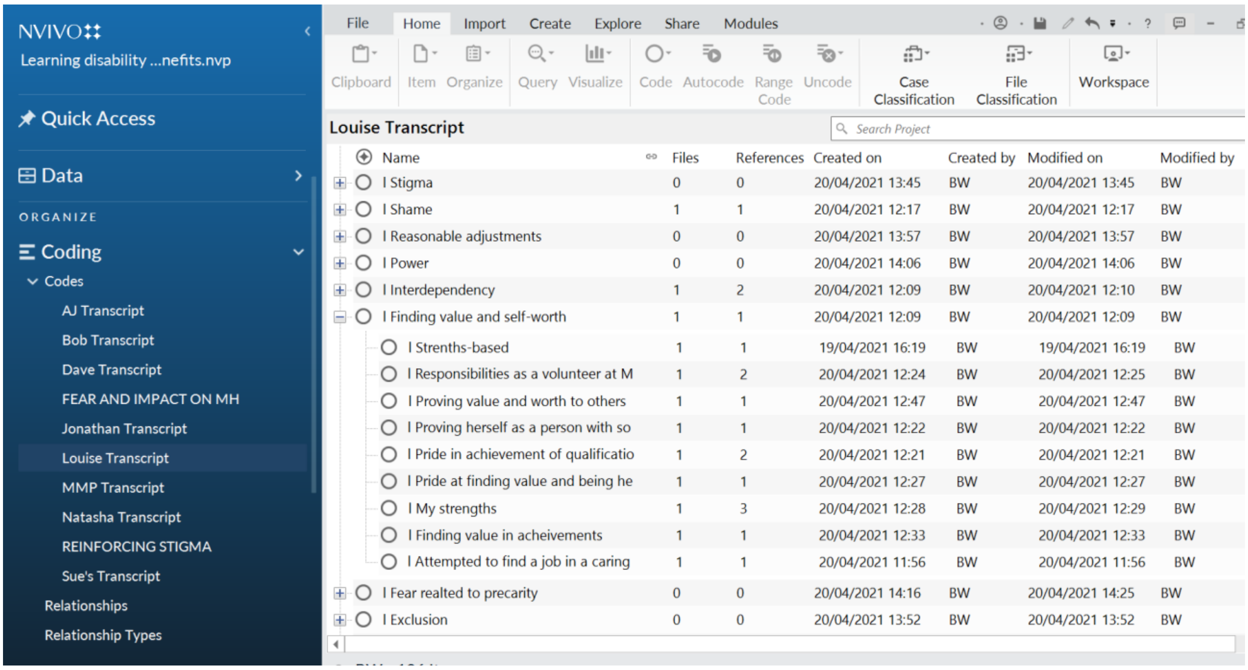
From Jonathan's Interview

Physical manifestation of anxiety	**Respondent:** I was nervous, I couldn't sit still.	Physical manifestation of anxiety
	Interviewer: Ok.	
Fear	**Respondent:** I just wanted er, wanted to know what it said, I was shaking. Just moving my leg up and down, well my foot.	Anxiety related to uncertainty *Shaking – connotes fear*
	Interviewer: Mm.	Mum told him the news. *Spoken with a sense of foreboding, signifying the weight of bad news.*
Foreboding	**Respondent:** And then my Mum told me.	
	Interviewer: What did she say?	*Knocked back – physical blow.*
Physical blow of rejection Freeze response to threat Internalised stigma Other as 'insider'	**Respondent:** The first time we got knocked back, I was, er, I can't remember how I felt. So we just kept trying and, and we tried with my cousin cos she deals with people like me, people with special needs or, with disabilities.	Can't remember how he felt – emotional numbness? Freeze response to threat. *Someone like me – derogatory* Help from his cousin Someone with 'inside knowledge' of the system and the plight of people with special needs.
	Interviewer: Mm.	
Powerlessness	**Respondent:** So she helped us out.	Needs help. Indicator of dependency on others who have more power - lack of autonomy and power?
	Interviewer: Ok, ok. And was that erm, something like an appeal?	
	Respondent: Yeah.	

From Sue’s Interview

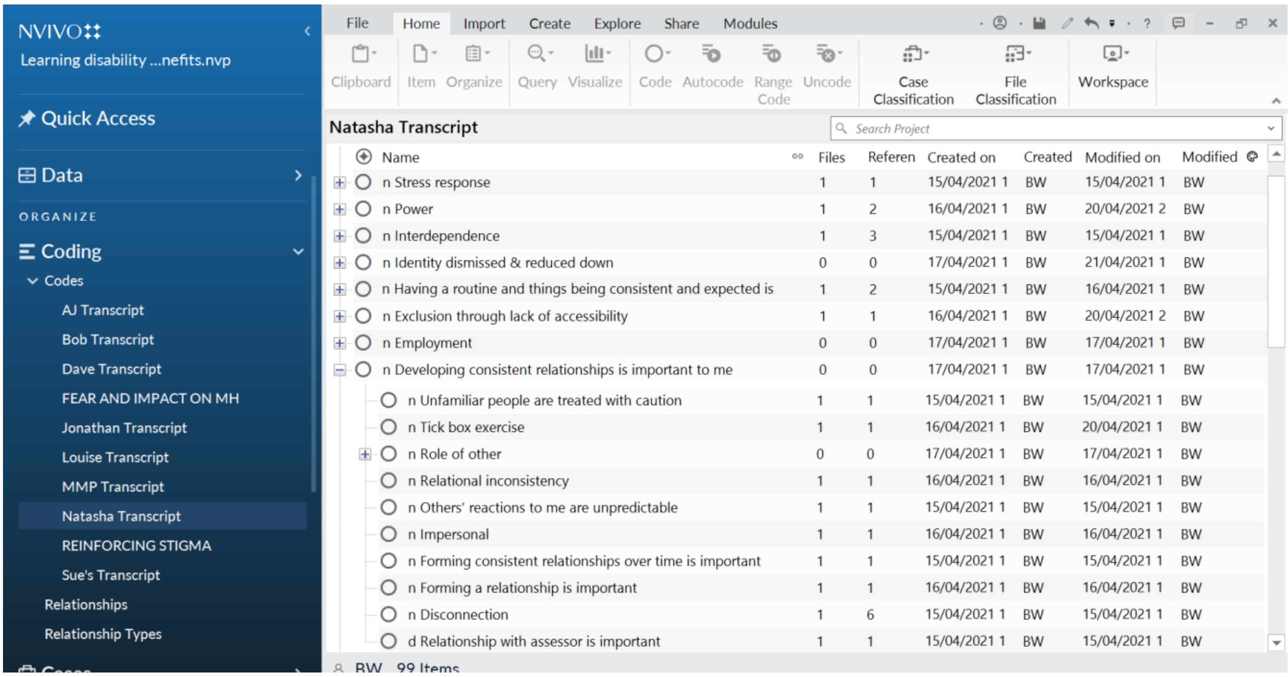
Points-based system Negative experience of assessor	**Respondent:** And I told him, I can, he said can you bath yourself and stuff, and I said yeah. And he, they didn't give, he didn't give me any points whatsoever. And it was horrible, his attitude towards me was horrible.	Functional element of assessment Not getting any points Link to failure? Attitude of assessor
	Interviewer: Ah.	
Fight/flight response to threat	**Respondent:** I was glad to get out to be honest. Didn't like him.	Glad to get out *Escape, flight*
	Interviewer: Yeah.	*Use of he suggests personal and relational difficulty*
The assessor as the problem	**Respondent:** He was just horrible.	Sue see’s the problem as located within the assessor on the microlevel. How does the relate to her view of her relationship with the system on a more macro level?
	Interviewer: Yeah. Does it...	
Professional and smart but cold and contemptuous	**Respondent:** It wasn't because, he did, he wasn't dressed nice, he was just horrible.	The way the assessor dressed. Sue feels it is important that he was dressed well – does this symbolise professionalism/friendliness?
	Interviewer: Yeah. Can you remember any of the types of things that he was saying?	*Horrible – evoking horror – fear.*
Impersonal	**Respondent:** He was just like, can you, can you er, bath yourself, can you shower yourself, can you go the loo yourself, can you feed yourself, can you	Functional assessment. *Lists number of tasks in a list.* Does this reflect Sue’s experience of the assessment being impersonal, like a script? No human discussion, just functional questions?

Appendix M: Examples of NVivo Case by Case Theme Clusters



Louise Transcript

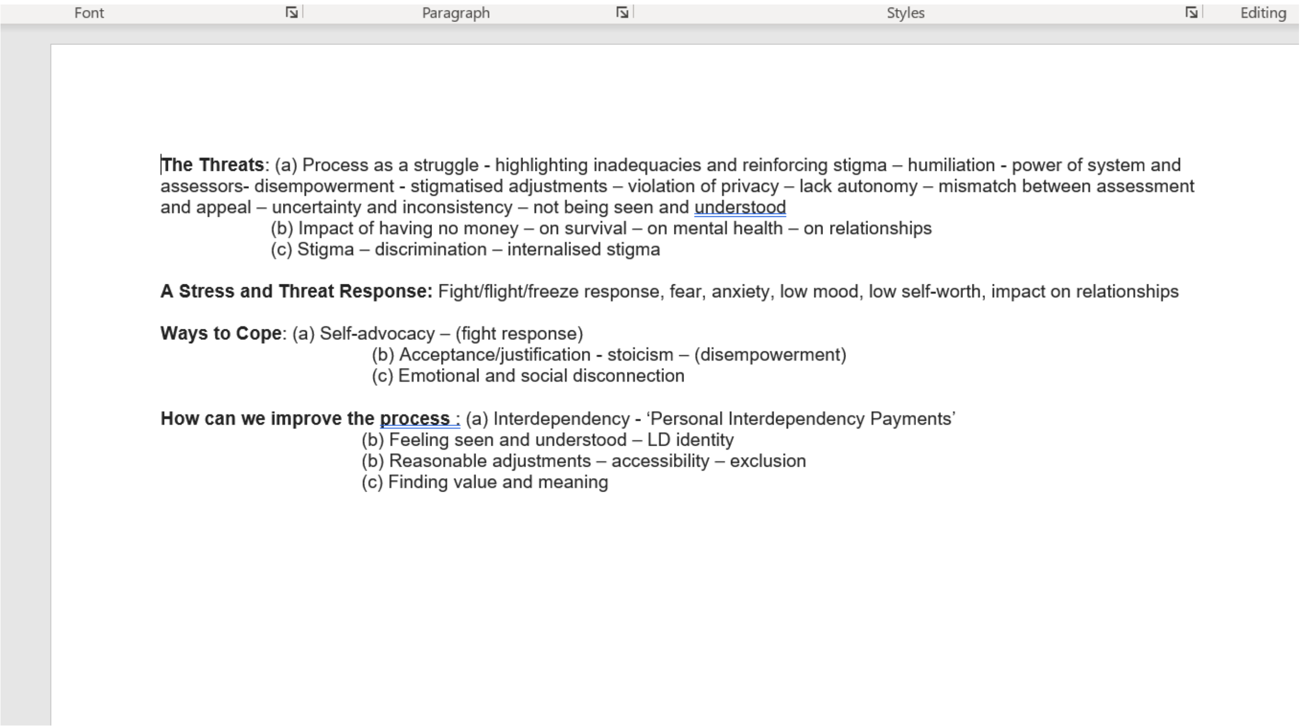
Name	Files	References	Created on	Created by	Modified on	Modified by
l Stigma	0	0	20/04/2021 13:45	BW	20/04/2021 13:45	BW
l Shame	1	1	20/04/2021 12:17	BW	20/04/2021 12:17	BW
l Reasonable adjustments	0	0	20/04/2021 13:57	BW	20/04/2021 13:57	BW
l Power	0	0	20/04/2021 14:06	BW	20/04/2021 14:06	BW
l Interdependency	1	2	20/04/2021 12:09	BW	20/04/2021 12:10	BW
l Finding value and self-worth	1	1	20/04/2021 12:09	BW	20/04/2021 12:09	BW
l Strenths-based	1	1	19/04/2021 16:19	BW	19/04/2021 16:19	BW
l Responsibilities as a volunteer at M	1	2	20/04/2021 12:24	BW	20/04/2021 12:25	BW
l Proving value and worth to others	1	1	20/04/2021 12:47	BW	20/04/2021 12:47	BW
l Proving herself as a person with so	1	1	20/04/2021 12:22	BW	20/04/2021 12:22	BW
l Pride in achievement of qualificatio	1	2	20/04/2021 12:21	BW	20/04/2021 12:21	BW
l Pride at finding value and being he	1	1	20/04/2021 12:27	BW	20/04/2021 12:27	BW
l My strengths	1	3	20/04/2021 12:28	BW	20/04/2021 12:29	BW
l Finding value in acheivements	1	1	20/04/2021 12:33	BW	20/04/2021 12:33	BW
l Attempted to find a job in a caring	1	1	20/04/2021 11:56	BW	20/04/2021 11:56	BW
l Fear realted to precarity	0	0	20/04/2021 14:16	BW	20/04/2021 14:25	BW
l Exclusion	0	0	20/04/2021 13:52	BW	20/04/2021 13:52	BW



Natasha Transcript

Name	Files	Referen	Created on	Created	Modified on	Modified
n Stress response	1	1	15/04/2021 1	BW	15/04/2021 1	BW
n Power	1	2	16/04/2021 1	BW	20/04/2021 2	BW
n Interdependence	1	3	15/04/2021 1	BW	15/04/2021 1	BW
n Identity dismissed & reduced down	0	0	17/04/2021 1	BW	21/04/2021 1	BW
n Having a routine and things being consistent and expected is	1	2	15/04/2021 1	BW	16/04/2021 1	BW
n Exclusion through lack of accessibility	1	1	16/04/2021 1	BW	20/04/2021 2	BW
n Employment	0	0	17/04/2021 1	BW	17/04/2021 1	BW
n Developing consistent relationships is important to me	0	0	17/04/2021 1	BW	17/04/2021 1	BW
n Unfamiliar people are treated with caution	1	1	15/04/2021 1	BW	15/04/2021 1	BW
n Tick box exercise	1	1	16/04/2021 1	BW	20/04/2021 1	BW
n Role of other	0	0	17/04/2021 1	BW	17/04/2021 1	BW
n Relational inconsistency	1	1	16/04/2021 1	BW	16/04/2021 1	BW
n Others' reactions to me are unpredictable	1	1	15/04/2021 1	BW	15/04/2021 1	BW
n Impersonal	1	1	16/04/2021 1	BW	16/04/2021 1	BW
n Forming consistent relationships over time is important	1	1	15/04/2021 1	BW	15/04/2021 1	BW
n Forming a relationship is important	1	1	16/04/2021 1	BW	16/04/2021 1	BW
n Disconnection	1	6	15/04/2021 1	BW	15/04/2021 1	BW
d Relationship with assessor is important	1	1	15/04/2021 1	BW	15/04/2021 1	BW

Appendix N: Previous Analysis Iterations



The Threats: (a) Process as a struggle - highlighting inadequacies and reinforcing stigma – humiliation - power of system and assessors- disempowerment - stigmatised adjustments – violation of privacy – lack autonomy – mismatch between assessment and appeal – uncertainty and inconsistency – not being seen and understood
(b) Impact of having no money – on survival – on mental health – on relationships
(c) Stigma – discrimination – internalised stigma

A Stress and Threat Response: Fight/flight/freeze response, fear, anxiety, low mood, low self-worth, impact on relationships

Ways to Cope: (a) Self-advocacy – (fight response)
(b) Acceptance/justification - stoicism – (disempowerment)
(c) Emotional and social disconnection

How can we improve the process : (a) Interdependency - 'Personal Interdependency Payments'
(b) Feeling seen and understood – LD identity
(b) Reasonable adjustments – accessibility – exclusion
(c) Finding value and meaning