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PEOPLE WITH LEARNING DISABILTIES’ EXPERIENCES OF NAVIGATING SOCIETY AND SYSTEMS

Section A: People with learning disabilities’ experiences of social inclusion/exclusion

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Section B: “How can I survive?”: A grounded theory of people with learning disabilities’ experiences of navigating the UK benefits system

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Summary of the Major Research Project

Section A: Presented here, is a systematic review of qualitative literature exploring people with learning disabilities' experiences of social inclusion and exclusion. A critical appraisal of the 15 included studies is discussed. The studies were synthesised using thematic synthesis. Two major analytic themes emerged: "Striving for an 'ordinary' life" and "Being denied an 'ordinary' life". Implications for service- and policy-level changes to alter approaches to promoting social inclusion and develop anti-stigma initiatives are made. Recommendations for future research include understanding social inclusion/exclusion following the Covid-19 pandemic and exploring experiences of personal finances and benefits.

Section B: Presented here, is a study exploring the processes by which people with learning disabilities navigate the UK benefits system. Informed by a constructivist grounded theory methodology, the constructed model identifies 15 interacting categories organised within five concepts: "Being stigmatised and excluded in society", "The dependence trap", "Navigating the 'circles and roundabouts", "Feeling abused by the system" and "Responding to the system". Findings highlight the negative impacts of navigating the benefits system on people with learning disabilities' mental health, identity, and potential for independence. Implications for clinical practice and research are discussed.

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ABSTRACT

Introduction: Social inclusion has typically been poorly defined and implemented for people with learning disabilities, despite significant shifts in policy and research attention. Social exclusion remains a reality for many people with learning disabilities, having potential consequences for their mental health and wellbeing. Increasing understanding of subjective experiences of social inclusion/exclusion for people with learning disabilities may further the ability to promote meaningful social inclusion. This paper sought to critically evaluate and synthesise the literature detailing experiences of social/exclusion for people with learning disabilities.

Methodology: Systematic searches were conducted using PsycInfo, Web of Science, Medline and ASSIA databases. 15 qualitative studies met eligibility criteria.

Literature review: Thematic synthesis was employed, identifying seven descriptive themes, and two major analytic themes. These include “Striving for an ‘ordinary’ life” and “Being denied an ‘ordinary’ life”.

Clinical and research implications: Findings indicate that while social inclusion may still be aspirational, people with learning disabilities value moments of inclusion and being familiar in their communities. However, many continue to experience the detrimental effects of social exclusion. Further research is needed to understand the impact of the Covid-19 pandemic on social inclusion/exclusion and to explore experiences of benefits and personal finances.

Keywords: People with learning disabilities, social inclusion, social exclusion

Introduction

Definitions

Learning disabilities

The term 'learning disabilities' (LD) is socially constructed, time-bound and determined by social meanings (Albrecht & Levy, 1981), however, it is recognised and enshrined into UK cultural and legal contexts (British Psychological Society [BPS], 2010). People with learning disabilities (PWLD) are a heterogenous group, determined to have a significant impairment in cognitive and adaptive/social functioning that occurred before the age of 18. The term 'intellectual disability' (ID) can be used interchangeably and is often the preferred term in research communities, however, Cluley (2018) found that professionals and laypeople, including carers of PWLD, found it unfavourable and felt it was a regression to pejorative terminology. It was highlighted that before such terminology be formally adopted in the UK, PWLD would need to be consulted. Therefore, the terms 'learning disability' (LD) and 'people with learning disabilities' (PWLD) are used throughout this review to reflect what is most used and preferred in the UK (Malli et al., 2018).

Social inclusion

Social inclusion is considered a core domain of quality of life for PWLD (Schalock, 2004) which can lead to increased psychological wellbeing (Cobigo et al., 2012). However, it has typically been poorly defined and broadly determined (e.g. Amado et al., 2012). Ambiguous definitions of social inclusion have led to researchers describing it as community participation, social integration, social capital (Bourdieu, 1985) and social networks. This may cause difficulties in communication across stakeholders, possibly impacting on policies and service delivery (Simplican et al., 2015). Attempting to define social inclusion related to PWLD, Simplican et al.'s (2015) ecological model of social inclusion encompasses community participation and interpersonal relationships, highlighting that at the individual level, social inclusion may result in a sense of belonging. Hall (2010) argued that belonging is essential for social inclusion to be meaningful and positively impact on wellbeing. This review will adopt a definition of social inclusion as a dynamic process, reflecting PWLD's community participation and social networks, particularly when they lead to felt belonging.

Social exclusion

While social inclusion and exclusion are not a simple dichotomy (Barnes & Roulstone, 2005), PWLD are a disadvantaged and socially excluded group (Redley, 2009). In the UK, the term 'social exclusion' emerged from critical social policy in the 1980s to expand on understandings of poverty, encompassing the ways in which those in poverty were excluded from ordinary activities of living (Levitas, 2006). This definition has evolved to an understanding of "a complex and multi-dimensional process … (involving) the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas" (Levitas et al., 2007, p.9). This review will consider the experiences of social exclusion among PWLD, meaning lack of involvement and participation in their communities, being socially isolated and feeling unaccepted.

PWLD and social inclusion/exclusion: The wider context

PWLD are a historically marginalised group; many were housed in institutions in the UK from the 19th century to the latter half of the 20th century, until government-issued guidance led to the introduction of community-based care (Burrell & Tripp, 2011; Department of Health [DoH], 1971). The move towards community-based living was strengthened by the normalisation movement (Wolfensberger, 1972). The principle of normalisation, later known as social role valorisation theory (SRVT; Wolfensberger, 1983), advocated for equal provision of opportunities for PWLD, suggesting that they were devalued and disabled by the societal roles assigned to them. SRVT suggests that if PWLD are enabled to adopt, and perceived by others to have, socially valued roles, they will become viewed as socially valued by others. Consequently, PWLD would have access to the same social and cultural opportunities available to the general public, be more likely to have positive interpersonal relationships and be viewed more favourably by others. The concept of social inclusion emerged from French social policy at a similar time to the normalisation movement, highlighting the shifting attitudes towards disability (Gooding et al., 2017).

In the UK, the values of community living, social inclusion, independence, and choice were reinforced by government white papers, *Valuing People* (DoH, 2001), *The same as you?* (Scottish Executive, 2000), *Fulfilling the promises* (Learning Disability Advisory Group, 2001) and *Valuing People Now* (DoH, 2010). Internationally, the United Nations Convention on the Rights of Persons with Disabilities (United Nations Convention, 2006), advocated for people with disabilities to be enabled to fully participate in society. However, despite widespread shifts towards deinstitutionalisation and increased social opportunities, PWLD continue to experience marginalisation, discrimination and abuse (Overmars-Marx et al., 2014). Moreover, abuse and neglectful practices in care services continue to be reported despite government intervention following the Winterbourne View scandal (British Broadcasting Corporation [BBC], 2011; BBC, 2019; DoH, 2012; DoH 2015). Additionally, bullying (Chatzitheochari et al., 2016), hate crime (Simmonds et al., 2018), abuse (Skelly et al., 2018), poverty (Tucker, 2017) and poor employment rates (NHS Digital, 2019) continue as issues in PWLD’s lives, maintaining social exclusion. Goffman's (1963) theory of social stigma proposes stigmatised individuals possess an attribute that is considered socially discrediting, leading them to be rejected and ignored by others in society. Thus, pervading stigma can contribute to the social exclusion of PWLD despite their increased presence in the community. This has significant consequences, as social exclusion for people with disabilities is associated with increased psychological distress (Temple & Kelaher, 2018) and stigma is linked to decreased wellbeing (Ali et al., 2012).

Rationale and aims

As challenges to social inclusion remain, it is important to further the understanding of the concept of inclusion/exclusion in relation to the lives of PWLD. Several reviews have focused on social inclusion and PWLD (Amado et al., 2012; Bigby, 2012; Cobigo et al., 2012; Overmars-Marx et al., 2014; Merrells et al., 2018; Louw et al., 2020; Verdonschot et al., 2009a; Verdonschot et al., 2009b). These noted that despite deinstitutionalisation, community presence, rather than inclusion, has been achieved. They found that multiple factors can promote or inhibit inclusion, such as personal skills, family or staff's ability to support inclusion, where someone lives and government policy. Structured intervention and groups aimed at promoting social inclusion were found to benefit PWLD (Merrells et al., 2018; Louw et al., 2020). However, these reviews differed in the way they defined social inclusion and had narrow focuses, such as inclusion in the neighbourhood (Overmars-Marx et al., 2014), urban community recreational programmes (Merrells et al., 2018), and intervention studies aiming to enhance the inclusion of young adults (Louw et al., 2020). They noted gaps in the current understanding of social inclusion from the perspective of PWLD (Merrells et al., 2018; Overmars-Marx et al., 2014); as well as difficulties with eligibility criteria, broad age ranges, and variation in methodologies and measurement tools (Louw et al., 2020). Further reviews were recommended to be more methodologically specific.

Considering the aims of previous reviews, alongside the limitations and recommendations for research, this review aims to synthesise findings from experiential, qualitative research exploring experiences of social inclusion/exclusion for PWLD, furthering the understanding of social inclusion/exclusion, and amplifying the voices of PWLD as experts in their experiences. Given the failings of policies to date in achieving social inclusion for PWLD, they need to be allowed to define what social inclusion/exclusion means and feels like. Thus, the current review asks:

- What is the experience of social inclusion/exclusion for PWLD?

Method

Eligibility criteria

The inclusion and exclusion criteria are outlined in Table 1. No time limits were applied to the search. Studies deemed to be of insufficient quality following review using the Critical Appraisal Skills Programme (CASP; 2018) qualitative checklist criteria were excluded, as poorer quality studies may contribute little to the results (Thomas & Harden, 2008).

Table 1.

Inclusion and exclusion criteria.

Inclusion Criteria	**Exclusion criteria**
Peer-reviewed	Employed secondary data analysis
English language articles	Non-English language papers
Primary research studies employing qualitative, experiential methodology	Studies using quantitative methodology exclusively to look at social inclusion/exclusion
Adults over the age of 18 with LD as the central voice in the sample	Deemed to be of insufficient quality to be included in the review
Focused on social inclusion/exclusion as it relates broadly to community participation and interpersonal relationships (Simplican, 2015)	

Literature search

A systematic search of PsycInfo, Web of Science, Medline and ASSIA databases was conducted up to 19th February 2021 (Figure 1). Search terms (Table 2) were adopted from other reviews in the area of social inclusion and PWLD (e.g. Louw et al., 2020) and reviews focused on qualitative literature (Evans & Randle-Phillips, 2020). Reference lists of identified papers and reviews were hand-searched to identify relevant papers.

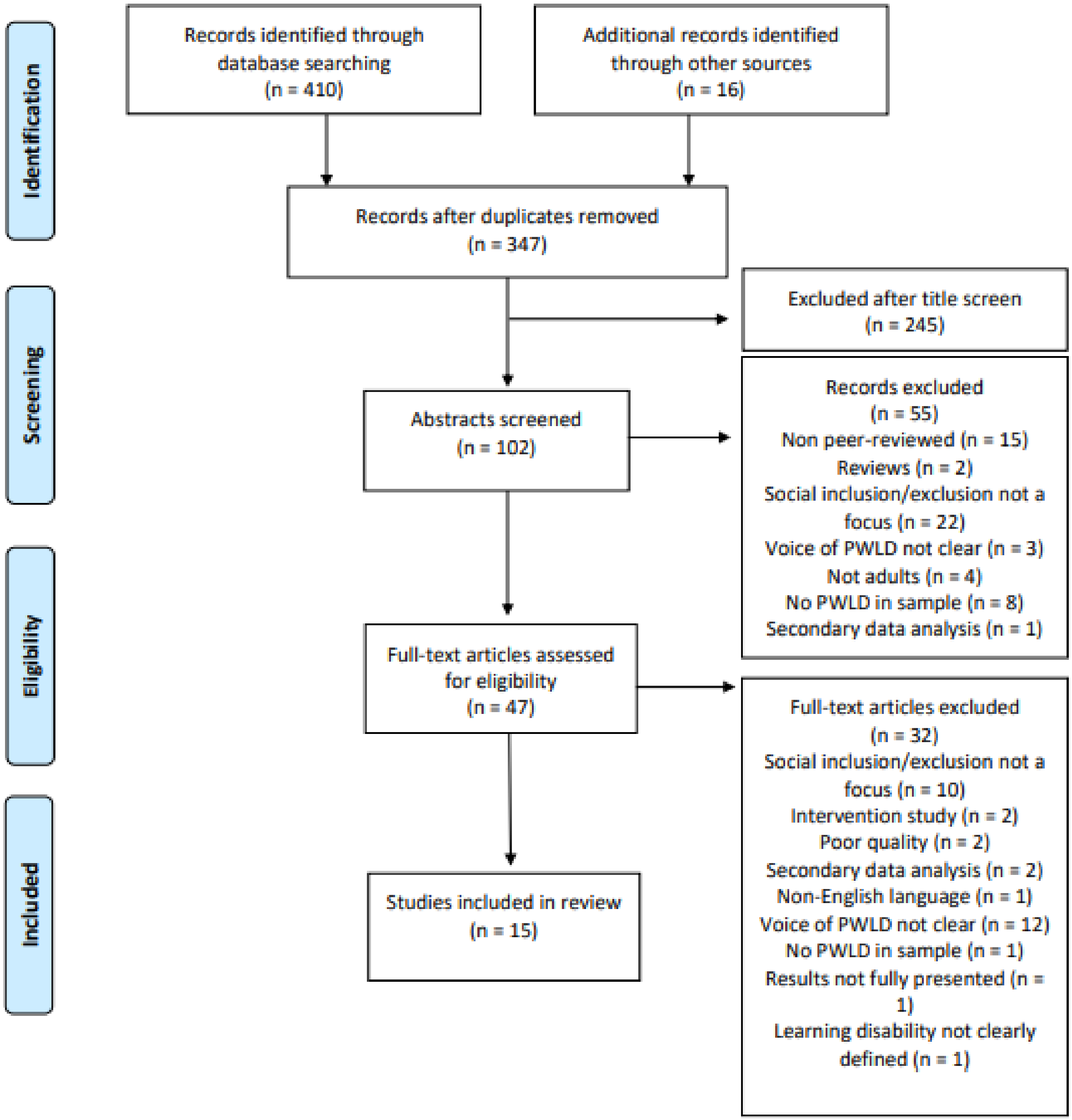
Table 2.

Search terms used in the systematic search

Specific search terms
(“social inclusi*” OR “community inclusi*” OR “belonging” OR “social integrat*” OR “social participat*” OR “community inclusi*” OR “community participat*” OR “social interact*” OR “social network*” OR “social exclusi*” OR “community exclusi*”)
AND
(“intellectual dis*” OR “learning dis*” OR “developmental dis*” OR “mental retardation” OR “learning difficulties” OR “mental handicap”)
AND
(“experience*” OR “view*” OR “perception*” OR “perspective*” OR “attitude*” OR “insight*”)
AND
(“qualitative” OR “qualitative research” OR “qualitative method” OR “thematic analys*” OR “content analys*” OR “interpretative phenomenological analys*” OR “grounded theory” OR “discourse analys*”)

Figure 1.

PRISMA Diagram



Synthesis method

A thematic synthesis (Thomas & Harden, 2008) was used to facilitate the exploration of PWLD’s perspectives and experiences. This was informed by Braun and Clarke’s (2006) method: results sections of the papers were coded line-by-line; codes were organised into descriptive themes; and analytical themes were applied, allowing the researcher to ‘go beyond’ original findings (Appendix I). Line-by-line coding and themes were inductively developed by the lead researcher with the research question in mind, and a research supervisor checked these themes. Appendix II highlights the process of theme development, with codes grouped into descriptive themes and overarching analytical themes.

Results

The literature search yielded 15 qualitative papers, after two papers were excluded due to insufficient quality (Table 3). The included papers were considered to be good enough quality for their findings to be relatively trustworthy, within the limitations of qualitative research. The studies will be summarised, synthesised, then critiqued.

Table 3.

Summary of studies

Study	Setting	Design	Aim	Methods	Sample	Analysis	Key Findings
1.Abbot & McConkey (2006)	Residential homes and supported living schemes in Northern Ireland	Qualitative, semi-structured focus groups	Gain an insight into how PWLD who lived mainly in supported housing perceived the barriers to their social inclusion and the ways these barriers could be lessened or removed	Semi-structured focus group questions	68 adults (aged 21-82) with LD (23 males, 45 females)	Latent content analysis	Themes around talking to people, being accepted, using community facilities and opportunities. Barriers and solutions to the barriers considered personal abilities and skills, staff and management, the community and the home/scheme.
2.Callus (2017)	Self-advocacy group in Malta	Qualitative, semi-structured focus groups	Gain understanding of how PWLD experience friendships and what friendship means to them	Semi-structured focus group questions	7 adults (aged early 20s to late 50s) with LD (2 males, 5 females)	Thematic analysis	Two themes around the groups of people whom the participants consider as being their friends and the behaviours and actions that the participants consider to be markers of friendship.
3.Chadwick & Fullwood (2018)	Self-advocacy and social group in West-Midlands England	Qualitative, semi-structured interviews	Gain insight into adults with LD's experiences of being online and using social media relate to their sense of self, social relationships, and identity	Semi-structured interview guide	11 adults (aged 22-43) with LD (6 males, 5 females)	Thematic network analysis	Global themes of online relatedness and sharing and support, development and occupation online derived from the data

4.Corby et al. (2020)	Service providers in Ulster, Northern Ireland	Qualitative, semi-structured interviews	To explore the lived experiences and meanings of PWLD’s attendance at post-secondary and higher education settings	Semi-structured interview guide	27 adults (aged 21-57) with LD (13 males, 14 females)	Heideggerian hermeneutic phenomenology	One overarching theme of ‘living an authentic life’ emerged with three themes of ‘learning’, ‘perceptions and realities’ and ‘relationships’ described
5.Hall. (2017)	Day services in Midwestern United States	Qualitative, semi-structured interviews	To describe the community involvement of young adults with LD	Semi-structured interview guide	14 adults (aged 21-35) with LD	Phenomenological analysis	Four themes were identified from the data: vocational endeavours, leisure pursuits, social inclusion and supports
6.Merrells et al. (2017)	Large government disability service in Perth, Australia	Qualitative, semi-structured interviews	Gain insight into how young PWLD living in the community spend their time, form relationships and feel included; and explore how young PWLD experience social inclusion	Semi-structured interview guide	10 adults (aged 18-24) with LD (5 males, 5 females) living receiving community-based services	Phenomenological analysis	Two overarching themes derived from the data: segregated and treated like an outcast in my community; challenges in experiencing, initiating and maintaining peer friendships
7.Mooney et al. (2019)	Building Bridges Research Group, West Midlands, UK	Inclusive qualitative, semi-structured focus group discussion with picture cards	To identify barriers to community inclusion and the opportunity to develop friendships	Semi-structured focus group topics	8 adults with LD	Qualitative analysis using picture cards to organise data into themes	Themes included feeling welcome, fear of harm and being a victim of crime, family members having control, lack of local opportunities, not knowing what is available locally, anxiety of going to new places, travel

							difficulties, lack of money
8. Overmars-Marx (2019)	Service providers for PWLD in the Netherlands	Qualitative, interviews based on Photovoice pictures	To investigate the perspectives of PWLD on neighbourhood social inclusion from an ecological point of view	Pictures to prompt interview discussion	18 adults (aged 24-65) with LD (8 males, 10 females)	Grounded theory	Six themes identified: attractiveness of the neighbourhood; social contacts in the neighbourhood; activities in the neighbourhood; social roles in the neighbourhood; independence; public familiarity
9. Rodriguez Herrero et al. (2020)	Autonomous University of Madrid, Spain	Qualitative, semi-structured focus groups	To explore the perceptions of graduates with LD from an inclusive university	Focus group questions based on Universal Design for Learning Guidelines (CAST, 2011)	14 adults (aged 22-44) with LD (6 males, 8 females) who graduated from the university’s Promentor Programme	Content analysis	Four categories derived from the data: following categories: quality of life and training received; barriers encountered; supports received; lecturers’ competences
10. Shpigelman (2018)	Disability advocacy groups and service providers, Israel	Qualitative, observations and semi-structured interviews	To understand social capital benefits of using Facebook for adults with LD	Participant observations while using Facebook; semi-structured interviews	20 adults (aged 21-43) with LD (10 males, 10 females) who actively used Facebook and live in the community	Thematic content analysis	Five major themes identified: an opportunity to be like (non-disabled) others; becoming a member of the community; becoming visible to others; increasing one’s popularity; positive vs. negative feelings
11.Spassiani et al. (2017)	Trinity College Dublin and	Participatory qualitative, Photovoice and	To understand the experiences of students with	Photovoice and Nominal Group Technique to	12 adults (aged 19-39) with LD	Themes formed by grouping similar items together	Findings answers the four research questions in turn,

	University College Dublin, Ireland	Nominal Group Technique	disabilities in inclusive university education	answers four research questions: What do we like about going to college? What do we dislike about going to college? What supports do students with disabilities experience to participation in college? What barriers do students with disabilities experience to participation in college?	attending university		with socialising being the main liked element, study/exams and traffic/road works/travel being the main disliked elements, classroom support was most important in supporting participation in university and physical barriers were the main barriers identified, despite no group members having physical disabilities
12.Strnadová et al. (2018)	Self-advocacy organisations, New South Wales and Victoria, Australia	Qualitative, semi-structured focus groups	Introduces a framework for belonging and explores the views of PWLD about belonging	Semi-structured focus group protocol	24 adults (aged 20-61) with LD (15 males, 9 females)	Inductive content analysis	Four meanings of belonging described : belonging in relation to place; as being part of a community; as having relationships; as identity. Barriers to belonging also presented
13.Sullivan et al. (2016)	People First Scotland advocacy organisation, central Scotland	Qualitative, semi-structured interviews	To explore how PWLD perceive and experience close relationships	Semi-structured interview schedule	10 adults (aged 31-60) with LD (6 males, 4 females; 10 White Scottish)	Interpretive phenomenological analysis	Five superordinate themes were identified: relationships feeling safe and being useful; who's in charge?; struggling for an ordinary life; hidden

							feelings; touching people in relationships. The first three themes were presented in the results
14.Van Asselt et al. (2015)	Inclusive community leisure program, Perth, Australia	Qualitative multiple case study, semi-structured interviews and field observations	To explore the enablers and barriers to social inclusion for PWLD	Semi-structured, empirically informed interview questions and field observations of participation at program events	4 adults (aged 23-27) with LD (2 males, 2 females) and 1 parent and 1 sister of PWLD who were involved in an inclusive community leisure program	Thematic analysis	Seven themes were identified relating to the experience of social inclusion in stage 1 analysis; 24 enablers and 10 barriers to social inclusion were derived from stage 2 analysis
15.White (2015)	Sydney, Australia	Qualitative, semi-structured interviews	To investigate how older women with LD create and maintain their social networks	Semi-structured interview guide based on the Support Interview Guide (Family Support & Services Project, 2000)	5 adults (aged 51-77) with LD (5 females)	Thematic analysis	Three overarching themes identified: creating networks; maintaining networks; barriers and facilitators to creating and maintaining social networks

Study characteristics

There was variation in the focus of studies with regards to the areas of social inclusion/exclusion explored. For example, three papers (Corby et al., 2020; Rodríguez Herrero et al., 2020; Spassiani et al., 2017) focused on the experiences of students who accessed inclusive post-secondary education programmes, whereas others focused on experiences of using social media (Chadwick & Fullwood, 2018; Shpigelman, 2017). Some papers looked at experiences with(in) interpersonal relationships (Callus, 2017; Sullivan et al., 2016; White & McKenzie, 2015), while others looked at social inclusion/exclusion more broadly (Abbott & McConkey, 2006; Hall, 2017; Merrells et al., 2019; Strnadová et al., 2018) or barriers to community participation (Mooney et al., 2019). Two papers sought to understand social inclusion within local neighbourhoods specifically (Overmars-Marx et al., 2019) and an inclusive community leisure programme (Van Asselt et al., 2015).

Qualitative methods and methodologies used included thematic analysis ($n = 4$), content analysis ($n = 5$), interpretive phenomenological analysis ($n = 1$), hermeneutic phenomenology ($n = 1$) and phenomenological analysis ($n = 2$). Spassiani et al. (2017) used Photovoice to gather data, which was then grouped into themes and voted on using Nominal Group Technique, while Mooney et al. (2019) used Photosymbols to capture areas of focus group discussion and then organised these into themes. These two papers used inclusive or participatory research designs, where the participants held dual roles as researchers and were involved in formulating research questions, design, gathering and analysing data, and disseminating the findings. Rodríguez Herrero et al. (2020) also reported an inclusive research design, although limited to having four researchers with LD involved in designing the focus group questions.

Sample sizes varied from five (White & McKenzie, 2015) to 68 (Abbott & McConkey, 2006), although Van Asselt et al. (2015) only included four participants with LD in their sample of six; the remaining two were family members. Participant ages ranged across the studies from 18-82, which may have provided a breadth of findings. Three studies (Hall, 2017; Mooney et al., 2019; Spassiani et al., 2017) did not report gender, while Mooney et al. (2019) did not report ages.

Synthesis

The thematic synthesis resulted in two themes: "Striving for an 'ordinary' life" and "Being denied an 'ordinary' life", further divided into subthemes aiming to capture the participants' overall experiences. Themes and subthemes are interrelated, as highlighted below.

Striving for an 'ordinary' life

This theme describes participants' experiences of working towards greater social inclusion and moments where this was felt to be achieved within their community, their interpersonal relationships, their personal, internal experiences or through technology. There was sometimes the sense that social inclusion remained aspirational.

Being "treated like everyone else": Inclusion and the community

When invited to share their experiences of social inclusion, participants in 13 studies spoke about community-linked factors (Abbott & McConkey, 2006; Callus, 2017; Corby et al., 2020; Hall, 2017; Merrells et al., 2019; Mooney et al., 2019; Overmars-Marx et al., 2019; Rodríguez Herrero et al., 2020; Spassiani et al., 2017; Strádnova et al., 2018; Sullivan et al., 2016; Van Asselt et al., 2015; White & McKenzie, 2015). Frequently, moments of being "treated like everyone else" (Hall, 2017, p.866) in community spaces seemed indicative of social inclusion. These experiences were seemingly unremarkable in their nature, exchanges where "they talk to me, and I talk back to them" (Abbot & McConkey, 2006, p.279) or being "greeted … by shaking his hand" (Mooney et al.,2019, p.243), however, they made participants feel valued and accepted. The likelihood of having these 'ordinary' exchanges seemed to be enhanced when participants experienced a degree of public familiarity: relationships that contributed to recognising and being recognised by others in public (Blokland & Nast, 2014). For some, this was achieved by having a job that meant one was well-known (Overmars-Marx et al., 2019), for others, by taking familiar transport routes or living in a community for a long time (Strádnova et al., 2018).

Geography was a central aspect of participants' experiences: "…living near the town centre" (Abbott & McConkey, 2006, p.280) meant participants could easily access communities and friendships (White & McKenzie, 2015). Local amenities were valued; participants enjoyed having "a nice park nearby" (Overmars-Marx et al., 2019, p.86), being able to "go to different shops or have lunch at different restaurants" and appreciate the atmosphere of "historical" buildings (Spassiani et al., 2017, p.902). In four studies (Callus, 2017; Hall, 2016; Overmars-Marx et al., 2019; Strádnova et al., 2018), membership with a self-advocacy group facilitated a sense of belonging and acceptance that was meaningful: "I'm more happier here than home, actually" (Strádnova et al., 2018, p.1096).

Education and employment were community-based settings where participants felt included. Attending post-secondary institutions was enjoyable; creating opportunities where participants felt "I am equal and it's great" (Corby et al., 2020, p.346). This did not just refer to feeling equal in society; participants also felt "just like" their siblings (Spassiani et al., 2017, p.901). It increased opportunities to socialise with peers with and without LD (Rodríguez Herrero et al., 2020). Those employed held their jobs in high regard and felt "that working makes you feel … valued” (Strádnova et al., 2018, p.1095). Working allowed people to feel “part of a team” (Merrells et al., 2019, p.17) and created social opportunities (Callus, 2017; Hall, 2017; Overmars-Marx et al., 2019; White & McKenzie, 2015).

Being included by others: Inclusion and interpersonal experiences

Interpersonal experiences were discussed across papers. Family relationships were spoken about positively in 10 studies (Callus, 2017; Corby et al., 2020; Hall, 2017; Merrells et al., 2019; Overmars-Marx et al., 2019; Spassiani et al., 2017; Strádnova et al., 2018; Sullivan et al., 2016; Van Asselt et al., 2015; White & McKenzie, 2015). Participants described enjoying social activities with family. For some, family members facilitated a wider range of community experiences than they might have otherwise had, like attending “an integrated community recreational club” (Merrells et al., 2019, p.17). For others it meant having a relationship where they were treated equally, such as with Oliver, who reported “working alongside his father, rather than for him” (Sullivan et al., 2016, p.179). However, Merrells et al. (2019, p.18) observed that often “family (were) … a replacement to friends”. While these relationships were appreciated, this presented a problem when the possibility of loss was considered: “I mean if my mum’s wasn’t there, what’s going to happen to me?” (Sullivan et al., 2016, p.176).

Positive relationships with support staff were described in 10 studies (Callus, 2017; Corby et al., 2020; Hall, 2017; Merrells et al., 2019; Overmars-Marx et al., 2019; Rodríguez Herrero et al., 2020; Sullivan et al., 2016; Van Asselt et al., 2015; White & McKenzie, 2015). This varied from viewing staff members as friends (Callus, 2017) to appreciating feeling understood (Overmars-Marx et al., 2019) and cared for (Sullivan et al., 2016). Participants valued reciprocity in interpersonal relationships, valuing emotional and practical support: “...she gets my washing off, I get hers off... it’s great friends...” (White & McKenzie, 2015, p.634). The desire for 'ordinary' relationships was spoken about, involving feeling safe, talking, and sharing time with others. However, for some, these 'ordinary' relationships seemed to be an aspiration rather than a reality: "...talking to me, not down to me … treating me with respect..." (Sullivan et al., 2016, p.178).

Feeling "happy and belonging": Inclusion and personal experiences

Almost all studies touched on personal experiences related to social inclusion (Abbott & McConkey, 2006, Chadwick & Fullman, 2018; Callus, 2017; Corby et al., 2020; Hall, 2017; Merrells et al., 2019; Mooney et al., 2019; Overmars-Marx et al., 2019; Rodríguez Herrero et al., 2020; Spassiani et al., 2017; Strádnova et al., 2018; Van Asselt et al., 2015; White & McKenzie, 2015). The importance of independence was highlighted in terms of enabling greater social inclusion and resulting from opportunities to be included. Being able to access the community alone offered further opportunities to socially connect (White & McKenzie, 2015), whilst attending post-secondary institutions increased independence (Corby et al., 2020). Intrapersonal experiences of feeling accepted (Hall, 2017), proud (Overmars-Marx et al., 2019), happy (Strádnova et al., 2018) and increased self-esteem (Corby et al., 2020) were attached to experiences where social inclusion was a felt reality.

Being included through technology

Participants discussed technology in five studies (Chadwick & Fullman, 2018; Merrells et al., 2019; Shpigelman, 2017; Strádnova et al., 2018; White & McKenzie, 2015). Using social media, email or phones enabled participants to develop and maintain interpersonal relationships. Using online platforms allowed participants to overcome barriers associated with location or finances to connect with friends, family and romantic partners (Chadwick & Fullman, 2018). Participants enjoyed and felt cared for when interacting with others through technology

(Strádnova et al., 2018). The ease and accessibility meant that participants could have a high volume of social contacts which brought them joy: "…a participant received over 40 happy birthday wishes … She smiled and replied to each person … 'you made me happy'". Participants developed personal identities online, presenting themselves as autonomous and having their positive self-views reinforced (Chadwick & Fullman, 2018).

Being denied an 'ordinary' life

This theme described participants' experiences of feeling socially excluded from their communities, within interpersonal relationships and their personal experiences of exclusion.

Feeling "left out": Exclusion and the community

Participants frequently discussed community factors relating to social exclusion (Abbott & McConkey, 2006; Callus, 2017; Corby et al., 2020; Hall, 2017; Merrells et al., 2019; Mooney et al., 2019; Overmars-Marx et al., 2019; Rodríguez Herrero et al., 2020; Spassiani et al., 2017; Strádnova et al., 2018; Sullivan et al., 2016; Van Asselt et al., 2015; White & McKenzie, 2015). Merrells et al. (2019, p16) coined participants' experiences of stigma as being "treated like an outcast" in communities. These experiences varied in extremity from being ignored, made a joke of (Abbot & McConkey, 2006) and stared at (Merrells et al., 2019) to incidents of physical abuse and harassment (Strádnova et al., 2018). Regardless of the level of stigma, participants experienced significant impacts to their psychological wellbeing. For those who described past bullying, the fear of this happening again limited their ability to interact with others. A participant in Merrells et al.'s (2019, p.16) study disclosed that the repeated anguish caused by "always feel(ing) left out" became intolerable: "I just completely shut down and felt like killing myself and I said, 'Nuh, can't handle any more'". The "us and them" (Merrells et al., 2019) attitude of the wider community appeared to be internalised by some, adopting the narrative of themselves as different and lesser: "..if I was a sort of, kind of an ordinary, well I am ordinary [clear voice, laugh] person." (Sullivan et al., 2016, p.180). Experiences of stigma and mistreatment may have informed the worries participants had of being exploited (Abbot & McConkey, 2006) or becoming a victim of crime (Mooney et al., 2019; Strádnova et al., 2018). Inaccessible community facilities were noted across eight studies (Abbott & McConkey, 2006; Hall, 2017; Mooney et al., 2019; Rodríguez Herrero et al., 2020; Spassiani et al., 2017; Strádnova et al., 2018; Van Asselt et al., 2015; White & McKenzie, 2015). Some participants' involvement in their local communities was limited by physical access issues (Hall, 2017). For others, lack of accessible information (Mooney et al., 2019) or transport (Van Asselt et al., 2015) prevented them being active in their communities. A participant in Strádnova et al.'s (2018) study noted that even when physical accessibility issues were addressed, one could still feel excluded if physically segregated from people without disabilities. Participants in six studies indicated feeling excluded from the workforce (Abbott & McConkey, 2006; Hall, 2017; Merrells et al., 2019; Strádnova et al., 2018; Sullivan et al., 2016). Difficulties in gaining or sustaining meaningful employment fostered feelings of rejection and reinforced stigmatised identities.

Feeling disempowered in relationships: Exclusion and interpersonal experiences

All studies included accounts of interpersonal experiences linked to social exclusion. Of these, 11 detailed disempowering relationships with staff members (Abbott & McConkey, 2006; Chadwick & Fullman, 2018; Callus, 2017; Corby et al., 2020; Hall, 2017; Overmars-Marx et al., 2019; Shpigelman, 2017; Strádnova et al., 2018; Sullivan et al., 2016; Van Asselt et al., 2015; White & McKenzie, 2015). Participants shared having personal and private information revealed in front of others, leaving them embarrassed and frustrated (Callus, 2017). A participant in Strádnova et al.'s (2018, p.1098) study described a secondhand incident where a staff member told a PWLD “we’re paid to like you”. As PWLD can spend significant amounts of time with staff, this leaves them feeling disrespected and diminished. Participants also described relying on staff to facilitate them with social or community opportunities, presenting an issue when there were limited staff resources and time (Abbott & McConkey, 2006).

Relationships with family could present further challenges. Participants in six studies (Callus, 2017; Merrell et al., 2019; Mooney et al., 2019; Shpigelman, 2017; Strádnova et al., 2018; Sullivan et al., 2016) described being controlled by family, from parents being protective and imposing rules on internet use (Chadwick & Fullman, 2018; Sphigelman, 2017) and bedtimes (Mooney et al., 2019) to being overly involved in relationships (Merrells et al., 2019; Sullivan et al., 2016). In one study, family members controlled someone’s welfare benefits and restricted access to their money (Mooney et al., 2019), indicating that familial control could be extended to abusive practices. These experiences left participants feeling frustrated and significantly limited their ability to have agency over their lives.

Participants generally had limited social contacts, and often when they made friends in particular settings, relationships were not extended beyond that situation: “There is craft friends at craft, but they are friends at the craft… I just talk to them there.” (White & McKenzie, 2015, p.634).

Feeling under-resourced: Exclusion and personal experiences

Participants spoke about personal experiences and factors in relation to social exclusion across nine studies (Abbott & McConkey, 2006; Hall, 2017; Merrells et al., 2019; Mooney et al., 2019; Overmars-Marx et al., 2019; Rodríguez Herrero et al., 2020; Spassiani et al., 2017; Strádnova et al., 2018; Sullivan et al., 2016). Intrapersonal experiences of low confidence were barriers for participants feeling able to meet others. Participants felt “afraid of going to places on their own" (Mooney et al., 2019, p.243) and described new experiences making them feel "anxious and cry" (Rodríguez Herrero et al., 2020, p.11). Having limited social networks was described as "hard, because I'm a bit lonely…" (Strádnova et al., 2018, p.1096) by one participant and another in Mooney et al.'s (2019, p.243) elaborated; "lonely means feeling sad, depressed, having nobody to turn to, nowhere to go…". Rejection was felt from family members (Sullivan et al., 2016) and society (Merrells et al., 2019). Consequentially, participants felt frustrated and bored, craving activities which could "fill their time" (Hall, 2017, p.863). This boredom was sometimes borne out of being in unstimulating services for PWLD. Participants felt stuck when there were no other activities available: "…just to get me out … I would just be bored sitting there all day." (Corby et al., 2020, p.352).

Restricted personal finances were mentioned in six papers (Abbott & McConkey, 2006; Hall, 2017; Merrells et al., 2019; Mooney et al., 2019; Sullivan et al., 2016; White & McKenzie, 2015). This impacted participants' potential for social inclusion in several ways. It meant that there was "not enough money to get taxis to places I want to go" (Abbott & McConkey, 2006, p.280) and limited their ability chances to maintain their networks as they "don't want to waste money" (Merrells et al., 2019, p.18). In Mooney et al.'s (2019) study, participants were unable to be involved in their local communities as they would have liked due to not having enough money from their welfare benefits, thus needing to prioritise their basic needs, such as utility bills. Lack of money could increase feelings of frustration and anxiety as participants "worried about how … to handle … finances" (Hall, 2017, p.863).

Critique

The studies were critiqued using the CASP (2018) checklist for qualitative research, chosen due to being a widely used and endorsed tool recommended for novice reviewers (Long et al., 2020; Appendix III). Quality assessment tools that provide ratings were not chosen due to the overly simplistic nature of these, and the assumption that different indicators of quality can have equal weighting, which can provide an unrealistic representation of quality (Fenton et al, 2015). Appendix IV details how each study was assessed using this checklist.

Research question and design

All papers stated their research aims. The differences in aims and settings provided a breadth of experiences. Qualitative methodologies were appropriate to the studies' aims to gain understandings of the subjective, lived experiences of PWLD. The two inclusive papers (Mooney et al., 2019; Spassiani et al., 2017) provided unique examples of experiential research where there was limited input from people without LD, consequentially having different styles of write-up to the other papers, using accessible formats. While qualitative designs appeared appropriate in these studies, the authors did not explicitly justify the research design. This omission may have been linked to the non-traditional writing styles, highlighting a limitation in the CASP (2018) checklist to account for stylistic differences in assessing participatory research. Only seven papers justified which qualitative method was applied (Corby et al., 2020; Hall, 2017; Merrells et al., 2019; Rodríguez Herrero et al., 2020; Spassiani et al., 2017; Sullivan et al., 2016).

Recruitment strategy

Most papers provided clear details of sampling procedures used. One study did not detail how participants were initially provided with information about the study (Corby et al., 2020). While Chadwick and Fullman (2018) detailed their recruitment strategy, they did not provide sufficient justification of this. Purposive sampling was widely used across the papers. Six studies did not explicitly state their sampling strategy (Corby et al., 2020; Overmars-Marx et al., 2019; Shpigelman, 2017; Strnadová et al., 2018; Van Asselt et al., 2015; White & McKenzie, 2015), however, all but Corby et al. (2020) provided enough detail to infer their strategies. Both papers with inclusive designs (Mooney et al., 2019; Spassiani et al., 2017) did not discuss sampling in the same detail as the participants were the researchers and did not extend recruitment outside of their research groups.

Two studies (Sullivan et al., 2016; Merrells et al., 2019) explicitly stated inclusion and exclusion criteria, whereas five other studies detailed their inclusion criteria only (Corby et al., 2020; Hall, 2017; Overmars-Marx et al., 2019; Shpigelman, 2017; Van Asselt et al., 2015). Only Merrells et al. (2019) and Van Asselt et al. (2015) explained why some participants dropped out or declined to consent, and in these instances, only timing and availability issues were discussed, limiting understanding of possible selection biases, and whether individuals who declined to consent had different experiences. Those who chose to participate may have had unique positive or negative experiences in relation to social inclusion/exclusion. Incidences of non-consent are particularly important in research with PWLD, as these can be indicative of the consent process being valid and reduce concerns around coercion (Dobson, 2008).

While generalisability is not the aim of qualitative research, smaller sample sizes (e.g. Callus, 2017; White & MacKenzie, 2015 Van Asselt et al., 2015) can present a difficulty in research with PWLD, particularly when using thematic analysis, where the "richness" of interviews can vary and larger samples may be recommended to counter this (Beail & Williams, 2014). The limited demographic information presented may have aimed to preserve anonymity, however, restricted the ability to situate the sample (Elliott et al., 1999). Previous research indicates that 'race', a socially constructed concept that has shifted over time and across cultures, but which carries consequences for how one is societally advantaged/disadvantaged (Smedley, 1998), may increase experiences of stigma in communities (Ali et al., 2015a). Differences were also identified in social networks between different ethnic groups (Bhardwaj et al., 2018). However, only Sullivan et al. (2006) explicitly stated the ethnicity and 'race' of participants, while Strádnova et al. (2018) noted that most of the participants had been White Australian in their limitations. This limits the application and usefulness of the findings, as it is not possible explore cultural and racialised differences in experiences of social inclusion/exclusion. Six studies reported on participants' level of LD (Chadwick and Fullman, 2018; Hall, 2017; Overmars-Marx, 2019; Rodríguez Herrero et al., 2020; Shpigelman, 2017; White & McKenzie, 2015), with most participants reported as having mild LD. Two studies (Corby et al., 2020; Merrells et al., 2019) recruited from services for those with LD and a diagnosis was required to be included. The potential lack of screening for or assessing participants' LD and not recruiting from LD services could have resulted in inclusion of participants who might not meet criteria for a LD in the remaining studies (Evans & Randle-Phillips, 2018). All studies relied on verbal communication which likely excluded the perspectives of those deemed to have more severe LD.

Ethical issues

All papers discussed ethical issues, however, the extent to which these were considered varied. Six studies (Abbot & McConkey, 2006; Callus, 2017; Chadwick & Fullman, 2018; Overmars-Marx et al., 2019; Rodríguez Herrero et al., 2020; Spassiani et al., 2017) did not mention approval being granted by an ethics committee, making it unclear if they were subject to scrutiny over their ability to protect the dignity and welfare of participants (BPS, 2014; Schroter et al., 2006). Participants providing informed consent without coercion is an essential component of ethical research (BPS, 2014). In research conducted with PWLD, issues such as power imbalances, challenges with comprehension, memory and attention can impact on gaining consent (Cameron & Murphy, 2007). Spassiani et al. (2017) did not discuss consent or confidentiality. The 12 researchers in that study were also the participants, receiving guidance from three of their academic lecturers, and it was clearly stated that they chose to conduct the research and to write it in an accessible, non-traditional format, suggesting informed consent was present although not mentioned. In comparison, Mooney et al. (2019) outlined their consent and confidentiality procedures, providing insight into how this was ensured in an inclusive research design. Corby et al. (2020) did not discuss consent, although reported safeguarding participants and discussed confidentiality. The remaining papers provided varying levels of detail on their procedures for gaining informed consent. Five studies (Callus, 2017; Chadwick & Fullman, 2018; Strnadová et al., 2018; Sullivan et al., 2016; White & McKenzie, 2015) detailed that information and consent forms were adapted to be accessible for PWLD, ensuring that participants had sufficient information to make an informed choice. Hall (2017) explicitly considered consent as an ongoing process, detailing non-verbal indicators of consent being assessed throughout the interview process (Cameron & Murphy, 2007). Few papers discussed the potential effects of participation. One study outlined that participants were briefed on the protocol if they became distressed (Sullivan et al., 2016), while another mentioned that participants were debriefed (Chadwick & Fullman, 2018) although no further information was given. Mooney et al. (2019) indicated that if people experienced distress, they could withdraw and get support, although it was not clear what this would entail. Finally, none of the studies considered acquiescence, which potentially threatens findings as PWLD may provide responses they believe the researcher wants to hear (Morrissey, 2012).

Data collection

All studies included clear information on data collection. Most studies used individual semi-structured interviews (Chadwick & Fullman, 2018; Corby et al., 2020; Hall, 2017;

Overmars-Marx et al., 2019; Shpigelman, 2017; Sullivan et al., 2016; Van Asselt et al., 2015; White & McKenzie, 2015). Two studies also collected observational data, one justifying this as optimising the depths of the data (Van Asselt et al., 2015), the other mentioning triangulation (Shpigelman, 2017). Five studies employed semi-structured focus groups (Abbot & McConkey, 2006; Callus, 2017; Mooney et al., 2019; Rodríguez Herrero et al., 2020; Strnadová et al., 2018). Two studies collected data via Photovoice, one using it to inform the interviews, to counteract difficulties verbal communication but not as part of the analysis (Overmars-Marx et al., 2019). Spassiani et al. (2017) used Photovoice as an accessible method of collecting data and used Nominal Group Technique to vote on important issues. Mooney et al. (2019) supplemented focus group discussions with picture cards to increase accessibility. Six papers included interview or focus group protocols, increasing replicability (Abbot & McConkey, 2006; Chadwick & Fullman, 2018; Rodríguez Herrero et al., 2020; Strádnova et al., 2018; Van Asselt et al., 2015; White & McKenzie, 2015).

Data analysis, quality assurance and findings

Most studies offered sufficient data analysis descriptions, however, two studies provided limited information about their content analysis process (Abbot & McConkey, 2006; Rodríguez Herrero et al., 2020). The majority of findings were grounded in enough examples to allow the ‘fit’ between the data and the results to be gauged. Callus (2017) used brief quotes sparsely, limiting how well the data could be brought to life. The inclusive studies (Mooney et al., 2019; Spassiani et al., 2017) did not use quotes, however, the authors provided descriptive examples under each theme, clearly grounded in the data. The extent to which the authors critically examined their own roles in relation to bias varied and was generally lacking. Six studies (Corby et al., 2020; Merrells et al., 2019; Shpigelman, 2017; Sullivan et al., 2016; Van Asselt et al., 2015; White & McKenzie, 2015) highlighted some degree of reflexivity, e.g. employing bracketing interviews and a reflective diary. Mooney et al. (2019) and Spassiani et al. (2017) held dual roles as participants and researchers, with all participants being involved in the data collection and analysis, thus minimising bias as they were reporting their own views, with limited input from researchers without LD. The remaining papers did not clearly state their reflexive positioning, potentially limiting their quality assurance processes. Credibility checks in qualitative research can establish the rigour or trustworthiness of the findings (Lincoln & Guba, 1985). Callus (2017) was the only author who failed to provide evidence of undergoing credibility checks, weakening confidence in her findings. The two inclusive studies (Mooney et al., 2019; Spassiani et al., 2017) did not explicitly discuss credibility, however, all of the participants engaged in the analysis, there was evidence of data triangulation and there was limited input from researchers without LD, increasing the trustworthiness. The other studies discussed different credibility checks, such as having multiple researchers involved in some stage of the analysis (Abbot & McConkey, 2006; Merrells et al., 2018; Overmars-Marx et al., 2019; Strádnova et al., 2018; White & McKenzie, 2015), carrying out member checks (Hall, 2017), triangulation (Rodríguez Herrero et al., 2020) or a combination (Chadwick & Fullman, 2018; Sullivan et al., 2018; Shpigelman, 2017; Van Asselt et al., 2015). White and McKenzie (2015) considered member checking, but the service from which they recruited considered this inappropriate due to participants’ varied reading comprehension, raising a question over who can give consent and the accessibility of their findings. All papers explicitly stated their findings, discussing these in relation to their aims.

Discussion

The current review explored the experiences of PWLD in relation to social inclusion/exclusion. These were captured across two analytical themes derived from the 15 papers included in this review: striving for, and being denied an ‘ordinary’ life. A recent review on the social networks of PWLD (Harrison et al., 2021) found that an ambition for ‘normality’ was present throughout the qualitative literature, similarly to what was represented in the first of these themes. This has been a long-felt desire, highlighted in service user groups (Learning Disability Coalition, 2012). It was the everyday moments of connection in communities that fostered a sense of being similar to people. Such encounters do not represent full community participation; however, they can provide moments of connection and reduce some of the social difference often experienced by PWLD (Bigby & Wiesel, 2019). These experiences seem to be increased when there was a degree of public familiarity (Blokland & Nast, 2014), achieved in settings where repeated encounters happened, and where each party had a role, such as bus driver and passenger (Strádnova et al., 2018). Such boundaried encounters can positively impact on PWLD who can share social moments with others that are not jeopardised by lacking social skills (Bredewold et al., 2016). Home location has been highlighted as an important factor in social inclusion/exclusion (Hall, 2005). Similarly, participants across these studies identified the importance of local facilities and atmosphere as fostering their sense of inclusion, whereas participants in areas with poorer accessibility and limited transport faced experiences of exclusion.

Wolfensberger’s (1972) concept of normalisation was relevant to the experiences of those accessing socially valued roles within education and employment who described benefits of feeling like equal and valued members of society. Employment can offer the ability to counter the notion of ‘disability’ to an extent for PWLD, highlighting that they are able and equivalent to people without disability (Bates et al., 2017). Involvement with self-advocacy organisations can engender empowerment and belonging (Fenn & Scior, 2019). Understanding this sense of belonging may be aided by social identity theory (Tajfel & Turner, 1979) which posits that one’s sense of self can be shaped by identification with an in-group. While being stigmatised and marginalised lead to negative feelings about oneself, feeling accepted in a stigmatised group can protect against negative experiences (Logeswaran et al., 2019).

Consistent with the literature, this review highlights the central roles of family and professional figures in the interpersonal lives of PWLD (Harrison et al., 2021; Lippold & Burns, 2009). Families could facilitate greater social and community participation for PWLD (Heller et al., 2002) and provided moments of inclusion through time spent together (Power & Bartlett, 2018). Relationships with staff are valued by PWLD (Giesbers et al., 2019; van Asselt-Goverts et al., 2013); these may be important in fulfilling social needs when there are limited other relationships. Sullivan et al. (2016) concluded that PWLD appreciate and want equivalent relationships as people without LD, however, as also highlighted in Harrison et al.’s (2021) review, these aspirations can be marked by thwarted opportunities and fail to be fulfilled. The positive intrapersonal experiences of increased happiness and self-esteem support those highlighted elsewhere (Cobigo et al., 2012).

Building and maintaining social relationships, developing social identity and deriving pleasure and enjoyment from using social media, have been documented in the literature (Caton & Chapman, 2016). Social presence theory (Short et al., 1976) considers the extent to which social interactions and togetherness can be fostered over remote means of communication. The findings of this review suggest that PWLD experienced social presence when using technology and it may provide an important means to feeling socially included.

“Being denied an ‘ordinary’ life” related to community, interpersonal and personal experiences in the literature. The prevalence of negative community attitudes and stigma towards PWLD and their harmful effects are well documented (Ali et al., 2012; Scior et al., 2020; Scior & Werner, 2015) and the findings of this review suggest that experiences of stigma were tied to participants’ felt experiences of social exclusion. Goffman’s (1963) theory helps to explain these findings as, for participants in this study, having a LD subjected them to a range of experiences that discredited them, increased their awareness of being held at the fringe of communities, and denied them the life that others may have. Internalised stigma was evident in participants’ description of those without LD as “mainstream people” (Merrells et al., 2019, p.16) and the effects of this self-stigma may be linked to reported personal experiences of fear, rejection and loneliness (Ali et al., 2015b). Stigma may explain the exclusion from the workforce described, who want to work but feel they are denied the opportunity (Bates et al., 2017).

Similarly, disempowering relationships with staff have been described by PWLD elsewhere, where lack of confidentiality, being told what to do and being told hurtful things were experienced (Taylor et al., 2007). Limited staff availability has been more pronounced in times of austerity, limiting the possibility of PWLD forming positive bonds with staff and for them to facilitate social inclusion (Giesbers et al., 2019). Feeling controlled and overprotected by family can be common for PWLD (Hall, 2005; McConkey & Smyth, 2003) and can negatively impact on progress towards social inclusion. The financial control exerted by one participant’s family in Mooney et al.’s (2019) study suggest a worrying situation that could be considered abusive.

Despite 20 years of choice and control being a priority for PWLD (DoH, 2001), it appears many are denied this reality.

Financial issues prevented participants from being involved in their community and developing relationships. Maslow's (1943) hierarchy of needs considers humans as motivated to achieve certain needs, however, some are more crucial than others and must be reasonably satisfied before one can be motivated to achieve higher order needs. For participants who were focused on 'making ends meet' (Money, Friends and Making Ends Meet Research Group, 2012), they needed to prioritise food and bills before considering socialising or doing activities. Thus, it may be impossible to move towards social inclusion, or achieving their human potential (Maslow, 1943). While austerity has led to welfare benefits cuts (Malli et al., 2018), there is a dearth of literature focusing on personal finances and benefits in relation to PWLD, despite findings suggesting that the financial reality and denial of economic resources (Levitas et al., 2007) faced by PWLD significantly curtails the possibility of social inclusion.

The current findings add to existing theories related to social inclusion/exclusion and were in line with SRVT (Wolfensberger, 1983). Additionally, reports of participants being cast out and facing abuse due to their disability seems evident of the stigma described by Goffman (1963). However, issues of accessibility and financial barriers were novel findings in relation to factors which perpetuated social exclusion; SRVT (Wolfensberger, 1983), while accounting for the need to build skills and competencies, does not account for PWLD attempting to adopt socially valued roles in an inaccessible world, where further considerations are needed for how inclusion could be achieved with wide-ranging access issues.

Limitations

Despite efforts to clearly define social inclusion, the scope of the included papers remained broad. Restricting inclusion to papers that specifically explored experiences of social inclusion/exclusion, rather than of experiences within places where participants may be considered to be included, e.g. academic settings, or of experiences within interpersonal relationships, may have increased the usefulness of the findings. However, this would not resolve variation across studies resulting from varying definitions across the literature.

The reviewed papers largely failed to report on the ‘race’ and ethnicities of their participants. These omissions limit the usefulness of the results as they cannot explore important racialised and cultural differences in experiences of social inclusion/exclusion.

A limitation raised in several of the studies (e.g. Sullivan et al., 2016) was the focus on participants who had higher levels of verbal ability. The inclusion criteria stipulating that the voice of PWLD be central in studies may have benefitted from being altered to consider how the experiences of those less able to verbally participate could have been included.

Implications

Several important practice implications have been identified through conducting this review. Participants valued the ‘ordinary’ moments in their communities, being greeted, recognised and having exchanges with others. This could be crucial to how staff and services conceptualise supporting the social inclusion of PWLD. It may be beneficial for staff to provide support which increases the numbers of encounters that PWLD have in their community, increasing the likelihood of them having increased public familiarity and feeling more accepted (Bigby & Anderson, 2021). Findings highlight the important role of family and staff as significant relationships in the lives of PWLD, offering the possibility of feeling included, but also in facilitating or restricting opportunities. Staff often prioritise more practical, care tasks over tasks oriented to promote social inclusion (McConkey & Collins, 2010). Services should ensure that staff have adequate training and time to work with PWLD to support social inclusion.

For service-level interventions to be successful, community attitudes also need to shift. This review highlighted the prevalence of stigma in the lives of participants which went hand-in-hand with experiences of social exclusion. Educating the public about PWLD and working towards destigmatising LD identities requires long-term government-level anti-stigma initiatives (Scior et al., 2020). Findings highlight that membership of self-advocacy groups can provide an important sense of belonging and buffer against negative effects of stigma. Difficulties with funding and lack of policy support can leave self-advocacy groups continuously struggling to survive financially (Fenn & Scior, 2019). These groups need committed funding to continue providing support for PWLD that fosters inclusion and acceptance.

Education and employment were important places of inclusion and belonging for PWLD. Despite this, numbers of PWLD in post-secondary education are lower than the general population (Spassiani et al., 2017) and UK employment rates are estimated at 6% (NHS Digital, 2019). Education and employment pathways need to be strengthened for PWLD if they are to achieve an 'ordinary' life. The findings highlight a promising alternative route to inclusion through the use of technology and social media. However, accessibility issues and safeguarding concerns can hinder PWLD's use of technology (Caton & Chapman, 2016). Services must work towards upskilling PWLD to use technology safely as well as training staff to support this. Austerity measures have led to cuts in social care and welfare benefits affecting PWLD greatly over the last 11 years (Malli et al., 2018). Findings of this review highlighted small but significant concerns around staff availability and finances which can be seen in the wider literature (Giesbers et al., 2019; Money, Friends and Making Ends Meet Research Group, 2012). Additional social care cuts during the Covid-19 pandemic have further impacted the lives of PWLD and limited their support (Wall, 2021). It is imperative that services and systems that support PWLD are adequately funded and that policies fully account for the needs and wishes of PWLD. If the 'ordinary' life of social inclusion is ever to be achieved, people's basic physiological and security needs must be ensured (Maslow, 1943).

Research implications

The experiences of those with more severe LD were absent from this review. A previous review on social inclusion, challenging behaviour and PWLD identified little research in this area (Bigby, 2012). However, there may be recent research in this area that would be helpful to review, meaningfully including and exploring the experiences of those with more severe LD. Future research would benefit from more transparency about the ethnicity and 'race' of participants and aim to recruit representative samples as there may be cultural and racialised differences in experiences in experiences of social inclusion/exclusion. For example, differences in experiences of stigma have been found across Black, Mixed race, and White PWLD in previous studies (Ali et al., 2015a). It may be useful to explore these differences as they relate to social inclusion/exclusion and explore different cultural understandings of these terms.

The impact of the Covid-19 pandemic is yet to be fully understood. However, it is likely that many PWLD will have felt more isolated and excluded, particularly if they were limited in their access to and use of technology, in their understanding of what was happening or suffered loss of work (Hughes & Anderson; 2020; Embregts et al., 2020). Future research into the Covid-19 pandemic and its impact on social inclusion/exclusion for PWLD would be important to understand this.

Austerity measures and financial limitations linked to employment and benefits were identified as barriers to social inclusion. However, there is limited literature into austerity and benefits as they relate to the lives of PWLD. Malli et al. (2018) called for further research and it would be beneficial to understand more about how PWLD experience social care cuts and the benefits system. This could highlight essential policy changes needed to facilitate greater social inclusion.

Conclusion

This review provides a thematic synthesis of the current literature on PWLD’s experiences of social inclusion/exclusion. The overall experiences were of participants “Striving for an ‘ordinary’ life”, which included moments of inclusion (Power & Bartlett, 2018) but which also captured a range of experiences of “Being denied an ‘ordinary’ life”. The papers described participants’ experiences of feeling included in communities, interpersonal relationships, through technology and the personal experiences which facilitated or were a consequence of inclusion. The importance of being treated like others in encounters, where one lives, education, employment, self-advocacy, positive relationships and access to technology were highlighted. The papers also highlighted participants’ community, interpersonal and personal experiences of exclusion. Stigma, inaccessible communities, disempowering relationships with staff and family and lack of finances left participants feeling bored, rejected and lonely. This review adds to the understanding of social inclusion/exclusion by presenting the experiences and perceptions of PWLD. Further research into PWLD’s experiences of specific barriers, such as experiences with their finances and with the benefits system, is needed.

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Major Research Project: Section B

"How can I survive?": A grounded theory of people with learning disabilities' experiences of navigating the UK benefits system

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ABSTRACT

Aims: This research aimed to explore the experiences of people with learning disabilities navigating the UK benefits system, and how it impacts on their lives, wellbeing, personal and social identities.

Design: This study utilised an exploratory, qualitative design, guided by constructivist grounded theory. It collected data via interviews and a focus group with people with learning disabilities and a family carer.

Methods: Twelve people with learning disabilities and one family carer participated in semi-structured interviews. Five people with learning disabilities partook in a focus group to check the emerging model. Data were analysed following constructivist grounded theory guidelines.

Results: The results present a grounded theory of how inaccessible benefits systems perpetuate the stigmatisation and social exclusion of PWLD. Highlighting the embedded, multi-layered nature of their experiences, the constructed model identified 15 interacting categories organised across five concepts: “Being stigmatised and excluded in society”, “The dependence trap”, “Navigating the ‘circles and roundabouts”, “Feeling abused by the system” and “Responding to the system”.

Conclusions: This study explored the processes by which people with learning disabilities navigate the UK benefits system. Findings highlight the negative impacts of navigating the benefits system on people with learning disabilities’ mental health, identity, and potential for independence. Ways of responding to the system are considered. Implications for clinical practice and research are discussed.

Key words: People with learning disabilities, Welfare benefits, Benefits system, Social policy, Austerity, Grounded Theory

Introduction

A learning disability can be defined as significant impairment in intellectual and adaptive functioning occurring before age 18 (British Psychological Society, 2010). This term has been ubiquitous in the UK since the *NHS and Community Care Act 1990* (Department of Health [DoH], 1990). However, the terms ‘learning disability’ (LD) and ‘people with learning disabilities’ (PWLD) are culturally bound, influenced by historical and political contexts, and the particular social constructions of LD has consequences for the care and treatment of PWLD over time (Rapley, 2004).

State-sanctioned care of PWLD in the UK can trace its origins to the 1601 and 1834 Poor Laws, which viewed PWLD as unprofitable threats to wider society, segregating them in poorhouses or workhouses: early forms of institutions (Jackson, 2016). Since the 20th century, deinstitutionalisation significantly altered the landscape of care for PWLD (Burrell & Tripp, 2011). Such changes followed the creation of the post-war welfare state to ease social difficulties like inadequate housing, ill-health, and poverty (Beresford, 2005). However, the welfare state has evolved into a liberal model (Esping-Andersen, 1990), where welfare benefits are means-tested with rules governing who is entitled to them. Consequently, state benefits are modest in relation to other welfare models and claiming benefits can be linked to stigma (de Chenu et al., 2016).

PWLD and welfare benefits

The provision of welfare benefits for people with disabilities began in the 1970s for ‘severely disabled’ people requiring 24-hour ‘supervision’ (House of Commons [HoC], 1998). This coincided with the disability rights movement, spearheaded by people with physical disabilities, demanding different support and understandings of disability (Oliver, 1990), and social role valorisation theory (SRVT; Wolfensberger, 1983), which called for increased opportunities for PWLD. SRVT would require services to support PWLD to gain skills and competencies to help them take up socially valued community roles, such as meaningful employment or membership of a neighbourhood group, which would increase their positive perception by others and enable access to further cultural and social opportunities. Only in 1992, Disability Living Allowance (DLA) was introduced in recognition that existing benefits were not meeting the needs of many people with disabilities (HoC, 1998). The development of welfare benefits has meant that PWLD may now be eligible for several benefits, including DLA, Employment Support Allowance (ESA), Universal Credit (UC) and Personal Independence Payments (PIP; Public Health England, 2020).

Welfare reform

The 2008 global financial crisis led to economic recession in the UK (Gamble, 2009). Ostensibly to mitigate the effects of the recession and budget deficits, in 2010 austerity measures introduced social welfare cuts, disproportionately affecting the most vulnerable in society, including PWLD (Psychologists for Social Change [PSC], 2016). Cuts were implemented through tightening eligibility criteria for access to social care support and reductions in benefits (Malli et al., 2018). Changes have resulted in many claimants being subjected to reassessments for their benefits, stricter assessments, and harsh sanctions, leading to numerous claimants experiencing benefit cuts (Beatty & Fothergill, 2015; Grover & Soldatic, 2013). Alongside welfare reform, a narrative of “strivers and skivers” surrounded austerity measures (Afoko & Vockins, 2013, p.4), with people with disabilities increasingly cast as ‘scroungers’ by the media (Briant et al., 2013). The growing hostile public attitude towards benefits claimants may be understood through social identity theory (Tajfel & Turner, 1979), which suggests that people naturally engage in social categorisation. The dominant narrative of ‘strivers and skivers’ may have been fuelled by political rhetoric used to justify the cuts by creating an out-group, ‘benefits’ scroungers’. For in-group members, those not on benefits, a sense of self-esteem and social worth would be fostered by membership to the ‘strivers’ group. In-group members will tend to attribute negative characteristics to those positioned in an out-group, furthering their prejudiced social identities and increasing animosity towards them.

While austerity measures were initially forecast to continue until 2014, this was later extended to 2018 (Kirkup, 2014), when it was announced that the austerity programme could end in 2019, following ‘Brexit’ (Stewart, 2018). However, the Covid-19 global pandemic introduced new economic instability, and while short-term measures, such as the increase in UC, protected some benefits claimants, the long-term economic response is uncertain (Emmerson et al., 2021).

Navigating welfare reform

Saffer et al. (2018) explored the experiences of people with physical disabilities whose benefits had been affected since 2010. This research highlighted the dehumanisation, judgement and negative self-concept associated with claiming benefits in the climate of austerity. This echoed the findings of The United Nations Committee on the Rights of Persons with Disabilities (2016) inquiry concerning the UK; highlighting that cuts encroached on human rights, and perpetuated the negative public portrayal of claimants. The grounded theory (GT) model developed (Saffer et al., 2018) showed that interactions between navigating a dehumanising system and living in a judgemental society can lead to losses of personal resources and a struggle to maintain a positive identity. Identity informs one’s view of oneself and influences how we make choices, act and feel about and regulate ourselves (Oyserman et al., 2012). Positioning theory (Harré & Langenhove, 1999) suggests identity is socially and linguistically constructed in interactions, meaning that self-perceived identities can shift in different interactional episodes, previously assumed identities can be challenged, and that some institutionally supported identities stand in opposition to the individual attributes that can contribute to identity construction. Saffer et al. (2018) found that dominant identity narratives can negatively impact self-identity, leading to poorer mental wellbeing and quality of life. Some participants in this study tried to reposition themselves by challenging this dominant narrative, however, others tried to distance themselves from the negative identity by ascribing it to others, thus upholding the dominant, socially supported narrative around benefits claimants.

A thematic synthesis of the impact of austerity on PWLD indicated that they and their families face financial difficulties, social isolation and reduced wellbeing due to cuts (Malli et al., 2018). PWLD experienced losses of autonomy, becoming increasingly reliant on family support when care was cut. Their opportunities to participate in their communities were lessened through limited personal budgets, loss of day centres and reduced support staff hours. This review highlighted how under-researched this area is, with only 11 studies identified. The quality of these studies was considered poor, with minimal participant descriptions, limited reflexivity, and looking at austerity measures across a range of countries. Saffer et al. (2018) identified particular challenges with the UK benefits system for people with disabilities resulting from welfare changes, however, excluded PWLD. The current study aimed to build on this study and those identified by Malli et al. (2018) by exploring the processes by which PWLD navigate the UK benefits system.

Navigating the benefits system

Aims

To develop a GT of the process of navigating the benefits system for individuals with a LD in the UK, the following questions are explored:

What is the perceived impact of…

- … navigating the benefits system when you have a LD?
- … claiming benefits on daily functioning, ability to participate in local community, physical health and emotional wellbeing?
- … claiming benefits on how others respond to PWLD, including family, friends and members of the public and on those people supporting PWLD?

How does the process of navigating the benefits system interact with…

- … sense of self/identity?
- … sense of their role in society?

Method

Design

A GT research design was utilised in this study (Glaser & Strauss, 1967). GT enables data to be analysed and a consequent theoretical understanding of a social process to be developed inductively from the data. A social constructionist epistemological position was adopted, viewing 'knowledge' as mediated by time, culture and language (Willig, 2013); recognising that research results are an interpretive account of studied phenomena, not undisputed 'truths' (Charmaz, 2014). Adopting this position enabled the perception of 'disability' as a socially and culturally bound label, with 'disability' occurring through environmental and social barriers (Oliver, 1990). This method acknowledges the role of the researcher in shaping the research and the importance of the participants’ and researcher’s social contexts (Charmaz, 2014). Participants partook in semi-structured interviews about their experiences of navigating the benefits system; subsequently, a focus group was used to check the emerging model (Starkey, 2015).

Recruitment

Participants were recruited using purposive sampling through four self-advocacy organisations across city areas. Participants were informed about the research by these organisations, receiving accessible information sheets (Appendix V). Participants were given more detailed information sheets (Appendix VI-VIII) if interested. Carers were recruited via participants with LD.

Theoretical sampling (Charmaz, 2014) was used initially to have diversity in the sample and later allowed information to be sought from carers and interview questions to be refined based on emerging theory. Sampling continued until theoretical sufficiency was reached; when the data had captured enough meaningful information to develop a GT (Dey, 1999). Eligibility criteria are described in Table 1.

Table 1.
Inclusion and exclusion criteria.

Inclusion Criteria	**Clarifying definitions**
Adults with a LD	Adults over 18 who identified as having a LD or were accessing LD services
In receipt of state benefits	Adults with an LD who were claiming or eligible to claim state benefits, including those who had lost their benefits
Having the verbal ability to take part in an interview or focus group	Participants were required to be able to participate in a verbal interview or focus group adapted to meet their needs
Have capacity to provide informed consent	Having capacity consent to the research as assessed using the Mental Capacity Act (MCA; 2005)
Carer or family member	Informal or formal carer of someone who identifies as having a LD and is in receipt of benefits
Exclusion criteria	
If involvement in the study would put them at risk of harm to themselves or to others	If in initial discussions, it was felt that being asked about benefits, emotional wellbeing, how others view them, and other areas of their life may be difficult and incur significant distress or put themselves or others at harm

Participants

18 participants were involved in this study. Six participants with LD had face-to-face interviews, six participants with LD and one family carer had remote interviews. Five participants partook in the focus group. Participants with LD were invited to choose their own pseudonyms. Participant characteristics and benefits can be viewed in Tables 2-3.

Table 2.

Summary of participants with LD demographic and benefits information

Name	**Method of data collection**	**Gender**	**Age**	**Ethnicity**	**Housing**	**Benefits**
Michael	Interview	Male	41-45	Black African	Supported living	ESA, PIP, Severe Disability Allowance, Income Support
Bob	Interview	Male	56-60	White Irish	Supported living	ESA, PIP
Mabel	Interview	Female	46-50	Black British	Housing association	ESA, DLA, Housing benefit
Leon	Interview	Male	46-50	Black Caribbean	Supported living	Lost benefits due to an administrative error; previous benefits unknown
John	Interview	Male	41-45	White British	Housing association	UC, Housing benefit
Josh	Interview	Male	31-35	White British	Council flat	DLA, ESA, Housing benefit
Christopher	Interview	Male	41-45	White British	Housing association	UC with add on, Housing benefit
Julie	Interview	Female	56-50	White British	Housing association	PIP, Housing benefit
Craig	Interview	Male	56-60	White British	Housing association	PIP, Housing benefit
Adam	Interview	Male	31-35	White British	Housing association	PIP, ESA
Katie	Interview	Female	26-30	White British	Housing association	UC
Mary	Interview	Female	41-45	White British	Housing association	UC, Housing benefit
Daisy	Focus group (FG)	Female	66-70	White British	Housing association	Pension credit, State credit, PIP

Tara	FG	Female	36-40	British Indian	Family	Income support, unsure of other benefits
Yusuf	FG	Male	26-30	British Pakistani	Supported living	PIP, UC, Housing benefit
Anika	FG	Female	36-40	British Indian	Family	PIP, unsure of other benefits
Fatima	FG	Female	46-50	British Pakistani	Family	DLA, Income support

Note: DLA = Disability Living Allowance, ESA = Employment Support Allowance, PIP = Personal Independence Payments, UC = Universal Credit

Table 3.
Summary of carer participant demographic information

Name	**Gender**	**Age**	**Ethnicity**	**Relationship to PWLD**
Patricia	Female	61-65	White British	Family carer

Data collection

Interviews were conducted either face-to-face in a private community hub room, or, following the Covid-19 pandemic lockdown, via Zoom, WhatsApp or telephone, depending on participant need. Individual interviews ranged from 31 to 70 minutes; the focus group was 33 minutes. These were audio recorded and transcribed.

Interview guides (Appendix IX-X) provided prompts for participants to discuss their experiences (Willig, 2008). Guides were adapted throughout to develop and refine categories and concepts from the data analysis (Charmaz, 2014). Focus group participants were presented with the GT model and asked how it compared to their experiences, and encouraged to discuss this with each other (Starkey, 2015).

Data analysis

Data were analysed using NVivo 12, following the structure outlined by Charmaz (2014). Table 4 describes the stages of analysis, which were not linear. Rather, constant comparison (Glaser & Strauss, 1967) was used to refine codes and categories as new information emerged through the analysis.

Table 4.
Stages of data analysis

Stage of analysis	**Description**
Familiarisation	The transcribed data were read and re-read to enable familiarity with the data.
Open coding	Line-by-line coding was completed for the first six individual interviews. This used gerunds, such as “hearing about cuts”, and ‘in vivo’ codes, such as “that’s what I’ve been told”. Coding in this way enabled me to remain close to the data and reflect the participants’ perspectives as closely as possible.
Focused coding	For the remaining interviews, focused codes were developed in order to categorise initial codes into larger chunks of related meaning. Focused coding facilitated a move towards more abstract analysis of the data.
Theoretical coding	Theoretical coding (Thornberg & Charmaz, 2014) enabled the exploration of hypothesised relationships between codes and a further level of abstraction. Diagramming aided this process of theoretical integration (Charmaz, 2014) and allowed the model to emerge and evolve through these iterative stages.

Focus group data were analysed and used to enrich the model. Memos were written throughout to ensure that a continuous awareness was held of the codes and the data, how well these related to each other, how my perspective impacted on the coding process and to influence further analysis. This aimed to improve analysis and reduce the risk of bias. The analysis process is demonstrated in Appendices XI-XIV.

Quality assurance

Quality in the GT process was prioritised by holding in mind the credibility, originality, resonance and usefulness of the study (Charmaz, 2014), and following qualitative research guidelines (Elliot et al., 1999; Mays & Pope, 2008). While a constructivist GT acknowledges the role of the researcher in shaping and socially constructing the data (Charmaz, 2014), several strategies were used to encourage reflexivity.

Supervision and peer-led GT workshops provided opportunities to discuss the process of analysis and reflect on and refine codes, categories and the developing model. Discussion with a peer researcher prior to data collection enhanced my awareness of personal biases linked to the research topic. While not having personal experience of the benefits system, coming from a working-class background shaped my view of welfare systems and imbued a desire to work towards creating societies that provide for everyone. Care was taken to maintain openness to people's varied experiences, and to adopt an empathic approach to some of the difficulties described; trying to 'be alongside' the participants. Supervision, reflective journaling (Appendix XV) and memoing enabled continuous reflexive engagement with the topic.

Ethical considerations

Approval was received from the Salomons Institute Ethics Panel (Appendix XVI).

Informed consent

Capacity to consent to the research was initially assessed using the MCA (2005). Subsequently, both verbal and non-verbal, where visually available, indicators of consent were assessed (Cameron & Murphy, 2007). Consent was viewed as an ongoing process, with constant monitoring for indicators of non-consent, e.g. if participants seemed tired, they were reminded of their right to withdraw, take breaks or to decline answering particular questions. As an additional process for remote interviews, where face-to-face initial meetings were not possible, a staff member from the self-advocacy organisation who was familiar with potential participants assessed their consent prior to their participation. Participants were given accessible information sheets and consent forms (Appendix XVII) prior to assessing consent, and interviews began by checking that participants understood the purpose of the study and allowing time for questions. A record sheet for assessing consent (Appendix XVIII) aided this process (Head, 2017).

Acquiescence

Research participants with LD may answer in ways they believe researchers would like them to (Morrisey, 2012). While open-ended questions may reduce the likelihood of acquiescence, they can be difficult for PWLD to answer (Booth & Booth, 1996). Therefore, a range of open and closed questions were asked. Questions were rephrased, and visual aids were available if needed.

Confidentiality and anonymity

Recorded interviews and associated data were anonymised, encrypted and stored securely on a password-protected laptop. Audio data was deleted once transcribed.

Risk of distress

Initial contact with participants was offered a minimum of 48 hours prior to interviews to enable a period of familiarisation (Cambridge & Forrester-Jones, 2003). Risk of distress was assessed prior to the interview through a brief risk assessment (Appendix XIX), with clinical judgment used throughout. Four participants discussed historical suicidal ideation and psychological distress in relation to their experiences. All participants were debriefed and signposted to local services (Appendix XX) for support if required. No participants became distressed during the interviews nor were any excluded following the risk assessment.

Service-user consultation

PWLD were consulted at two main stages of the study. A research supervisor consulted with the first self-advocacy charity involved on the research area and design. A university-based

Expert by Experience provided feedback on the information sheets, consent forms and interview guides, resulting in various amendments.

Results

GT model

The results present a grounded theory of how inaccessible benefits systems perpetuate the stigmatisation and social exclusion of PWLD. The model presented in this section outlines the processes by which PWLD navigate the benefits system. Findings were constructed across five concepts, “Being stigmatised and excluded in society”, “The dependence trap”, Navigating the ‘circles and roundabouts’”, “Feeling abused by the system” and “Responding to the system”, encompassing 15 categories (Table 5). The model is illustrated (Figure 1) and highlights the multi-layered nature of participants’ experiences. Each concept and their interactions are explained in more detail, with illustrative quotes and additional visual representations.

Table 5.

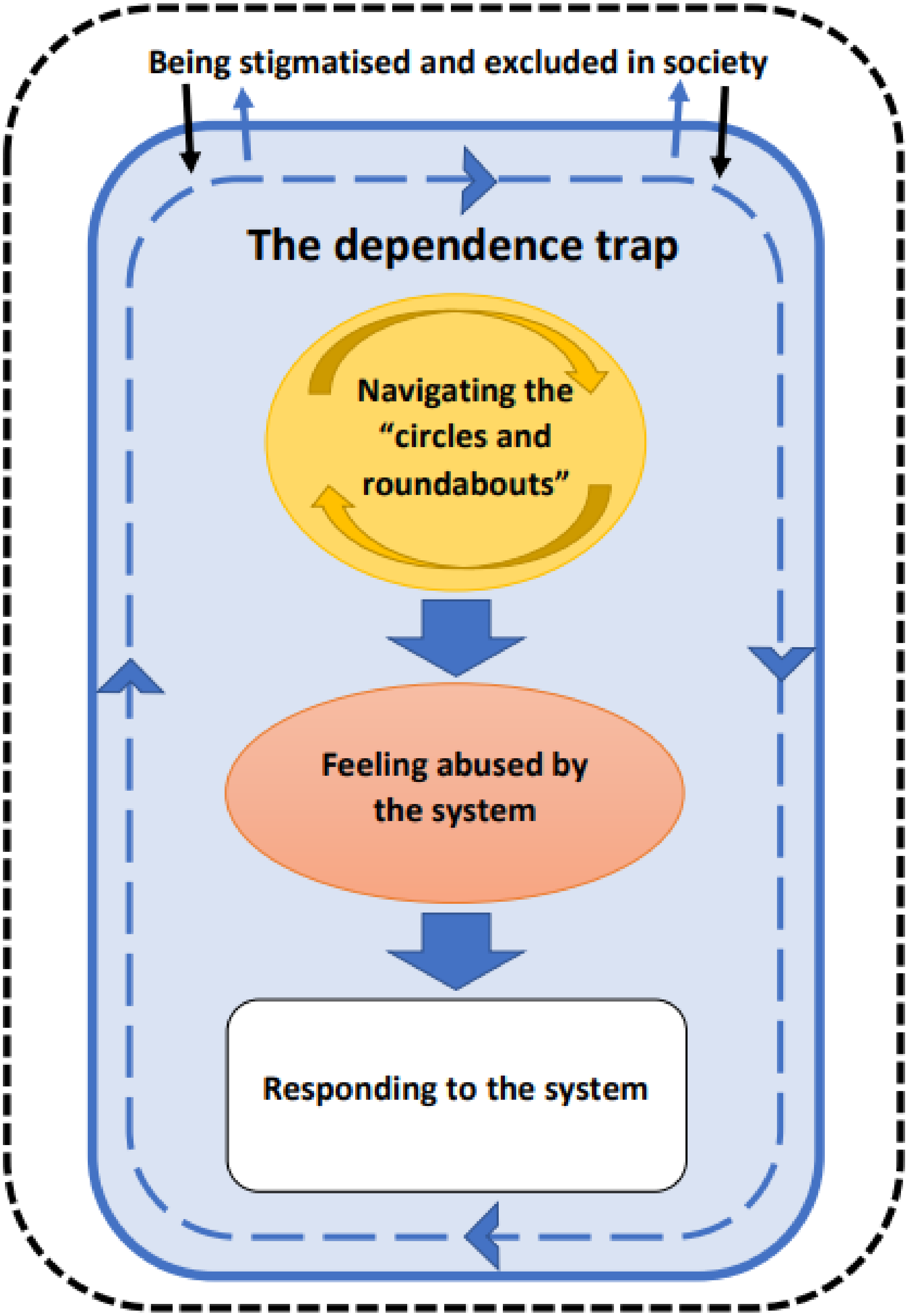
Social processes in the grounded theory model

Concept	Category	Sub-category
Being stigmatised and excluded in society	Facing disability stigma	Being dehumanised, cast out and treated like dirt
		Feeling excluded from the workforce
		Being denied a life with choices
	"Some people look down on you when you've got benefits"	
The dependence trap	"I'm independent but I do need help"	Wanting independence
		Needing help "for lots of things"
		Needing help with benefits
	"It's good when you get them"	
Navigating the "circles and roundabouts"	Navigating an inaccessible system	"It's like big and it's complicated"
		"It's harder for people with learning disabilities"
	"You have to prove yourself"	"All these dumb questions they have to ask you"
		"They just look at everyone like a number"
	Being left in the dark	"What's going on?"
		"I didn't get that at all"
		"that's what I've been told"
	Being in an insecure system	Living with uncertainty and unpredictability
		"And they just cut my money like that"
Feeling abused by the system	Internalising a stigmatised identity	"I don't think anyone wants to be on benefits for the rest of their life"

		System reinforcing disability stigma
	“How can I survive?”	“Scrounging off family or scrounging off friends”
		“No money in the kitty for me”
		Being thrown into debt
		“Scrimping and saving”
	Being caught in an emotional whirlwind	Angry at the system
		“If you got a learning difficulty, you’re frightened, you’re scared”
		Denial
		“Mind state of worries”
		Feeling devastated by the system
	Being mistreated	
Responding to the system	Being consumed by the system	Adopting the scrounger narrative
		Losing a bit of yourself in the process
		Having a smaller life
	Having support buffers against the system	Getting help from family
		Having professional help
		Having supportive friends
		“If they don’t have the support, then what happens?”
	Surviving the system	Eliciting third sector support
		Resisting the system
		Trying to accept the system

Figure 1.

Grounded theory model



Being stigmatised and excluded in society

PWLD do not claim benefits in a vacuum; rather experiences in society influence their experiences in the benefits system, which in turn reinforce wider experiences. The model captures the multi-layered and embedded nature of these through highlighting that the wider context surrounds all other aspects of the model. The categories "Facing disability stigma" and "Some people look down on you when you've got benefits" were constructed within this concept.

Figure 2.
"Being stigmatised and excluded in society" concept

Facing disability stigma

Participants described implicit and explicit disability stigma. The following sub-categories represent the experiences described: "Being dehumanised, cast out and treated like dirt", "Feeling excluded from the workforce" and "Being denied a life with choices".

Being dehumanised, cast out and treated like dirt. Participants were aware of being ascribed a stigmatised label, impacting how others interacted with them.

> *“I think it’s quite hard having a disability because…people treat you really differently...” (Josh)*

Participants felt segregated from the wider public who were perceived to be *“casting us out” (John).* Participants described mistreatment (e.g. hearing slurs about PWLD in public or being harassed) which left them feeling dehumanised.

> *“Having a learning disability, it's like … you're not part of this world or this community, it’s just feels like … we’re a different species to other people.” (Mary)*

Feeling excluded from the workforce. Participants felt that the workforce was not accessible or welcoming. Traditional employment support was not felt to cater to their needs. This impressed on participants that they *“may never … be able to join the sort of like conventional world of work and earn their own living” (Patricia)*.

Being denied a life with choices. Several participants implied a denial of agency, having their choices limited by family, by staff who support them and by lack of accessible opportunities.

> *“...at nights… they tell me I have to come home early.” (Leon)*

These sometimes subtle and tolerated ways in which choices were limited link to the wider stigma and exclusion experienced by participants.

“Some people look down on you when you’ve got benefits.”

Participants were aware of perceptions of benefits claimants as ‘scroungers’.

> *“... sponging, you’re sitting on the benefit system ‘cause you don’t wanna go to work...” (Katie)*

Some participants were exposed to negative media about benefits users and described the judgements that they felt implicated by.

> *“I’ve seen it on TV ... people [on benefits] just sit there and they just drink booze and just watch the Gogglebox and sit there do sweet F.A., sitting on their a**e doing nothing.” (Mary)*

Participants felt looked down on, feeling their authenticity was questioned by virtue of being on benefits. The stigma and exclusion participants described set the context for their experiences navigating the benefits system.

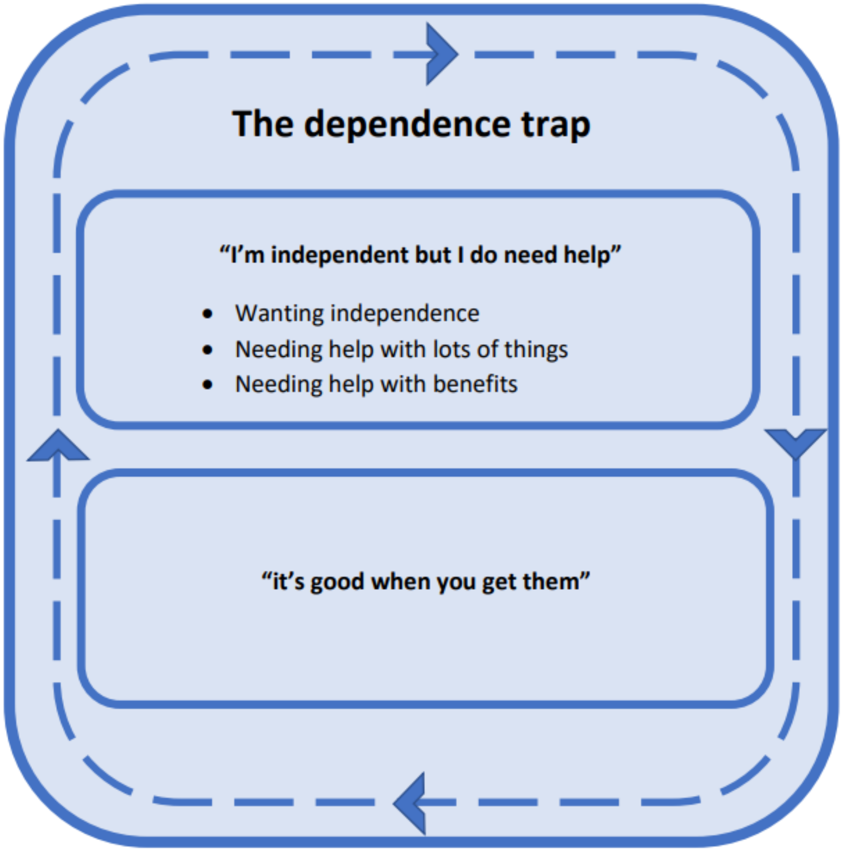
The dependence trap

This concept accounts for the circular processes which lead people to the benefits system and keep them within it. While the trap accounts for PWLD’s relationship to the system, the experiences within the system feed back into the trap, maintaining a sense of stuckness.

> *“... want to get away from that system and you have to get it otherwise ‘cause you won’t be able to ... pay your bills...” (John)*

The categories “I’m independent but I do need help” and “It’s good when you get them” were constructed in this concept.

Figure 3.
“The dependence trap” concept



“I’m independent but I do need help”

Participants described desires for increased independence, but a reality of needing additional support. This could be perceived as a conflict between the sub-categories, “Wanting independence”, “Needing ‘help for lots of things’” and “Needing help with benefits”.

Wanting independence. Participants dreamt of future independence, which they hoped to achieve through accessing education, living alone and working.

“...one day, you can’t wait to become your own independent person.” (Mabel)

Some participants described being deemed *“too able” (Christopher)* by benefits assessors, leading to payments being reduced to *“nothing” (Adam)*, which meant they needed to elicit additional help from others with activities previously managed independently.

Needing "help for lots of things". The reality of living with a LD meant that participants reported needing *"help from friends and family to get [finances] set up." (Adam)* as well as *"with letters, reading" (John)*, "*writing" (Josh)* and daily living tasks.

Needing help with benefits. Inevitably, participants described various aspects of the benefits system they required help with, including *"to know which benefit I'm on" (Michael)*, *"filling in the … form" (Christopher)*, reading information about benefits and communicating with the benefits system.

"It's good when you get them"

Participants reported ways that receiving benefits positively impacted their lives, including being able to *"get out the house." (Julie)* and access activities.

> *"… it helps me do a lot more things than what I would've been able to do." (Craig)*

However, participants shared many experiences that jeopardised these positives, leaving them feeling *"lucky" (Adam)* to have benefits at all or feeling that *"it turned it from something that's ideal to have to something that's not worth getting anymore." (Yusuf, FG)*

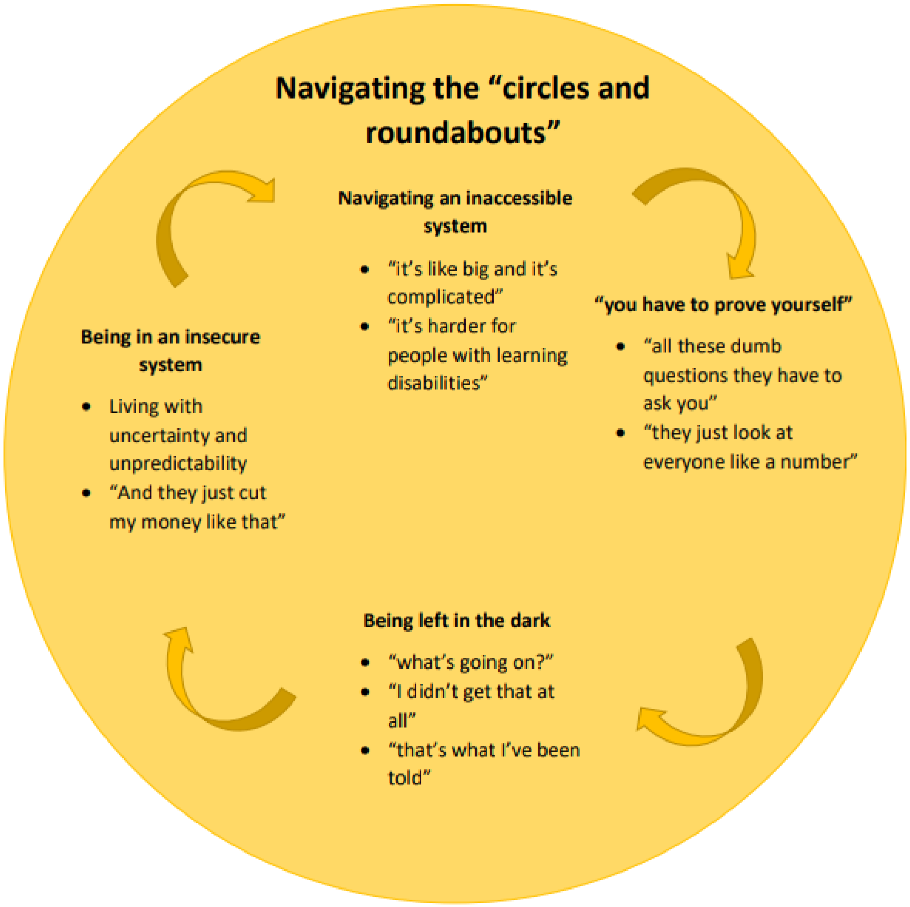
> *"I think benefits nice, but it can cause a lot of problems…" (John)*

The dependence trap exists with the implicit assumption that PWLD require benefits and help and that benefits support independence. Many participants had experiences of the system supporting more opportunities, reinforcing the idea that it increases independence and quality of life. However, being perceived as more independent could result in benefit cuts, resulting in participants becoming more reliant on external systems, making them more dependent.

Navigating the "circles and roundabouts"

This concept relates to the processes by which PWLD navigated the "*stumbling blocks" (John)* encountered within the benefits system. The following interacting categories were constructed: “Navigating an inaccessible system”, “Being left in the dark”, “Being in an insecure system” and “You have to prove yourself”.

Figure 4.
“Navigating the ‘circles and roundabouts’” concept



Navigating an inaccessible system

Participants encountered a *“complicated” (Josh)* system, full of *“gibberish” (Mary)* communication. Adjustments were not made to meet their needs, leaving them wanting adaptations for PWLD.

> *“...everything needs to be put in easy read. Easy to understand, not just easy read...” (Tara, FG)*

“It’s like big and it’s complicated”. Participants highlighted the futility of sending jargon-filled letters to PWLD.

> *"...sometimes when letter come to the house, me and me girlfriend, 'cause we both can't read, and we do find it hard..." (John)*

Participants relied on others to *"check it" (Julie)* and in some cases, failed to recognise the importance of letters, until they suffered consequences. However, some found letters reassuring *"to know how much I've got" (Michael)*.

"It's harder for people with learning disabilities". Participants perceived the benefits system as more difficult for PWLD than people without disabilities.

> *"...it's easy for people who don't have disabilities to get it, and I don't understand why people with disabilities, they make it impossible..." (Josh)*

It was felt that the system was often geared towards those with physical disabilities, leaving participants feeling disregarded.

> *"...that's all they care about, people with physical..." (Mary)*

Being left in the dark

Additional difficulties were described when participants were uninformed about changes to their benefits, the rationale for certain procedures, and changes in the system.

"What's going on?". Participants described discovering benefit cuts when they noticed their money running out. These losses were often a shock to participants.

> *"I thought, money was still coming in, I thought, fine, terrific ... but nah." (Leon)*

This engendered confusion and worry for participants, who had to elicit help to discover what had happened. Leon still didn't know why he had lost his benefits almost a year after they had stopped.

"I didn't get that at all". Participants didn't understand the processes by which they were determined eligible or ineligible for benefits.

"I think that was quite complicated, the points …" (Christopher)

The Department of Work and Pensions (DWP) staff were felt to be *"not very clear" (Julie)* about assessments: *"they don't explain things properly" (Katie)*. This lack of transparency was felt by some participants to have an insidious quality.

"... they will smile and act nice, but they're not." (Daisy, FG)

Participants felt that the system had become *"so confusing" (Adam)* that even people who supported them didn't understand.

"That's what I've been told". Participants heard about potential benefits changes indirectly, making it difficult to understand what changes might happen. The government were perceived to hold the knowledge about this, leaving participants feeling powerless.

"I don't know, because the politicians, they keep arguing about this, blah, blah, blah." (Michael)

Being in an insecure system

Participants described the precarity of the benefits system which left them feeling *"like walking a tightrope…" (Adam)* or as if they were *"on this flaming rollercoaster ... up, down, up, down ... going round and round" (Mary)*. There was an awareness that *"they can stop your money" (Bob)* abruptly without warning.

Living with uncertainty and unpredictability. Participants reflected on the difficulties of a system where *"they keep on changing the rates and the amount they sent you" (Josh)*. Participants felt that the system was increasingly changeable, leaving them managing the uncertainty of potential future changes. Participants noted the unpredictability of how interactions with the benefits system could go.

"...it's potluck … it all depends what person you get … what mood they're in." (Katie)

Some participants noted instances where they *"didn't quite qualify" (Christopher)* when being reassessed for benefits they had previously claimed or having different outcomes at assessments for the same benefit.

"And they just cut my money like that". Participants spoke about having sudden, sometimes repeated cuts to their benefits (e.g. as a result of not responding to a letter). This had a knock-on effect if it impacted other benefits (e.g. housing benefits): *"...the whole thing spirals out of control" (Patricia).* Many described the difficult process to get their benefits back, highlighting the contrast with how readily cuts were made.

> *"...they can shut it down fast, but it takes a long time to get it re-reinstated." (Josh)*

"You have to prove yourself"

Participants were required to prove their eligibility for benefits through repeated assessments, which felt futile *"when really what they need to know is the actual disability" (Josh)*. They felt annoyed and confused by assessment questions, feeling their personal circumstances were unaccounted for.

"All these dumb questions they have to ask you". Participants noticed that some questions were assessing whether they could *"do the most basic thing" (Adam)*, indicating a tightening of eligibility criteria. However, others were surprised by the questions, answering in earnest, which led to later cuts.

> *"I thought, pssh, yeah, I can do most things, I said, I can do that ... And, ah, can you wash yourself? I said, yeah, wash myself, do all that things and ... go out independently and do different stuff." (John)*

The potential for questions to *"humiliate" (Patricia)* participants was raised.

> *“I couldn’t answer them. I mean, because, like, they’re really complicated maths questions ... how is somebody who struggles with numbers going to know what they are?” (Josh)*

“They just look at everyone like a number”. Participants noted that *“they always like to reassess” (Mabel)* despite the fact that for someone with a LD, *“my disability is not going to get any better” (Craig).* They felt that the system did not consider the impact of having a LD.

> *“…they look at it and shrug it off. They don't ask does that impact your life?” (Katie)*

Participants were frustrated by having to travel far to assessments without consideration of the support they might need to get there. For participants who went to tribunal, the lack of adjustments left them being treated like criminals.

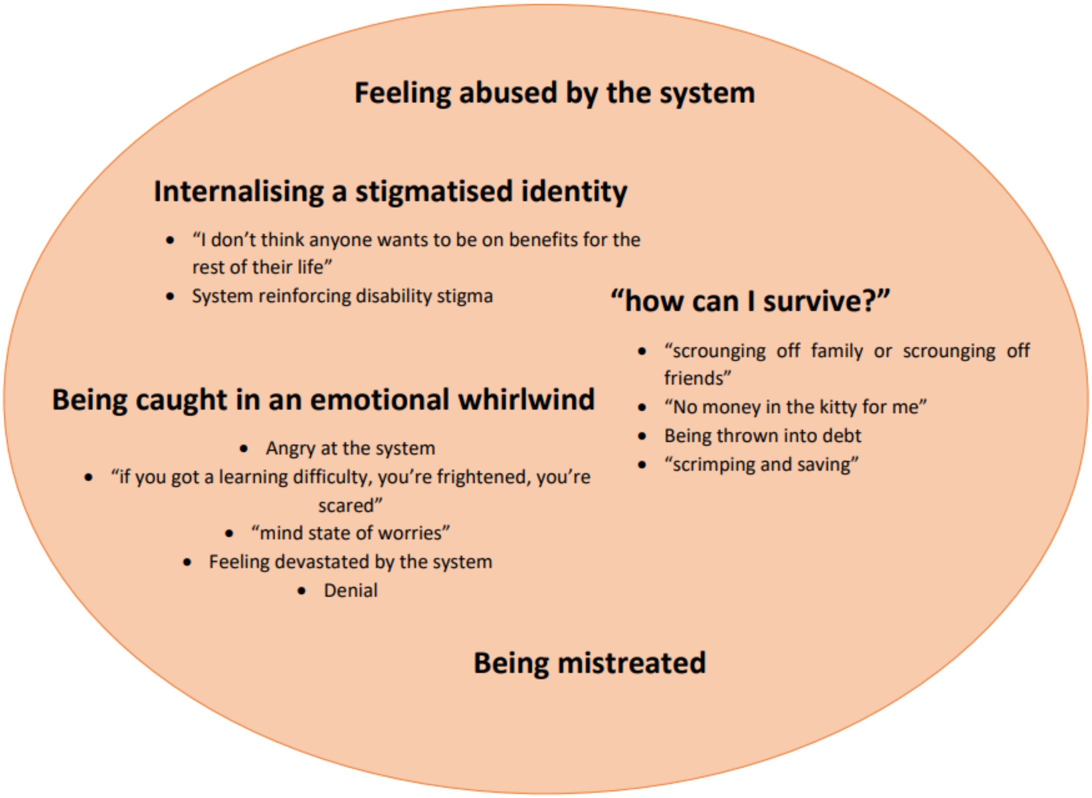
> *“It was scary though because when you went tribunal, you had to be searched…” (Julie)*

The “circles and roundabouts” of the benefits system left participants navigating seemingly endless confusing and demoralising obstacles, leaving an impression of a punitive system.

Feeling abused by the system

The experiences of navigating the system left participants feeling *“that you are abused by it” (Mabel)*. This was compounded by stigma and exclusion in wider society. The interacting categories “Internalising a stigmatised identity”, “How can I survive?”, “Being caught in an emotional whirlwind” and “Being mistreated” were constructed in this concept.

Figure 5.
“Feeling abused by the system” concept



Internalising a stigmatised identity

Participants appeared to internalise discourses of stigma related to using benefits and having a disability.

“I don’t think anyone wants to be on benefits for the rest of their life”. Participants spoke of the shame they felt claiming benefits, leading them to become wary about disclosing this, for fear of judgment. Those in employment felt this eased some of the shame around claiming benefits and imagined feeling worse if they were not fulfilling their perceived capability to work.

> *“I suppose getting benefits now don't make me feel bad. But if I was just getting benefits on its own... Suppose I would feel a bit guilty, ‘cause I think that I’m quite able man and I can do more things.”* (John)

Unemployed participants reported a desire to work to escape feeling *"worthless" (Mabel)* or *"embarrassed" (Adam)* for claiming benefits.

> *"…everyone thinks, yeah, I'm just getting money for nothing and … I wanna work for my money." (Mary)*

System reinforcing disability stigma. Some participants noted that their difficult experiences in society and in the benefits system left them wanting to not have a disability at all.

> *"I just want to be God damn normal. What is wrong with the whole world? Why can't I just be a normal person and have a normal life?" (Mary)*

Participants reflected on how having a disability was not what they would have chosen, they would have rather had a 'normal' life. Experiences in the system and the rhetoric around benefits claimants brought these feelings to the surface.

> *"Because I didn't want to be like as I am in the first place." (Michael)*

Benefits assessments highlighted their disability, potentially reminding them of past assessments which had left them feeling inadequate and as though they had *"failed" (Julie)*.

"How can I survive?"

Participants described financial hardship, particularly following cuts. Some survived on benefits by being extremely careful with money and with support from their network, however, were often left without money for anything enjoyable.

"Scrimping and saving". Participants described how managing their money payment-to-payment took great effort. Participants were constantly conscious of how much they could spend.

> *"Because like you have to… count every penny ... have you got enough money for this, have you got enough money for that." (John)*

"Scrounging off family or scrounging off friends". When they experienced cuts, participants had to *"borrow money off people" (Julie)*.

> *"...my friend helps me out with buying my food and that so I just give her the money back, so. That's another way that I had to survive..." (Mary)*

Having to borrow money from others left participants feeling less independent, *"uncomfortable" (Adam)*, *"embarrassed" (Christopher)*, *"stupid" (Mary)* and *"guilty" (Anika, FG)*.

"No money in the kitty for me". Participants prioritised food and bills but had no money for enjoyment. One participant highlighted the devastating potential consequences of being unable to save for emergencies.

> *"...I could've gone to my dad's funeral, many years ago ... But I didn't have the money to travel." (Michael)*

Being thrown into debt. Some participants fell into debt because of financial difficulties, which negatively impacted on their mental and physical wellbeing.

> *"I just don't know how it got up to £20,000." (Bob)*

Participants described getting an overwhelming amount of *"red letters" (John)*.

> *"I'm sitting on letters ... all I see is letters coming in..." (Leon)*

Being caught in an emotional whirlwind

Participants described various emotional reactions to the benefits system and, in some cases, appeared to engage in denial to protect themselves against difficult feelings associated with using benefits.

Angry at the system. Participants felt angry, "*like I just want to lose my temper" (Mary)*, about the difficulties they encountered within the system which they felt were *"just not right"*

(Fatima, FG). Some participants felt unable to express this anger but imagined how things could have been if they had less support or if there were future changes.

> *“…might have gone down the actual office and might have had a right go at them about them shutting it down...” (Josh)*

“If you got a learning difficulty, you’re frightened, you’re scared”. Participants described being fearful of interactions with the benefits system, not knowing whether they might misstep and consequentially be left destitute.

> *“…whenever one of these assessments comes up … I'm scared … that it's going to be taken away.” (Adam)*

Participants were concerned that they might not know *“the answer to that question” (Mary)* and felt *“really frightened” (Julie)*, thinking *“if I don't get it, what’s gonna happen here?” (Craig).*

“Mind state of worries”. Participants described consistent stress and worry. They *“worried they might cut my benefits down” (Bob)*, leaving them without *“enough money to help me” (Michael*). Those who had support felt that the system was *“stressful for all the people involved” (Josh)*. Some participants noted that they *“hear [about benefits] all around” (Josh)* which added to their sense of threat about what might happen.

Participants worried about how many hours they worked impacting on their benefits. For one participant, getting paid work was felt to be *“not actually a good idea” (Adam)* due to concerns about benefits being cut; further excluding participants from the workforce.

Feeling devastated by the system. Participants reported feeling *“horrible” (Leon)* because of their interactions with the benefits system, sometimes losing hope amidst cuts or reassessments.

> *“I thought to myself … is this what my life is gonna be like?” (Christopher)*

Something going wrong in the system could exacerbate mental health difficulties and was felt to completely disrupt participants’ lives.

> *“...it just made me depressed worse, my anxiety worse … ten times worse than it is now.” (Mary)*

Four participants described feeling suicidal in the past following cuts or while in debt.

> *“I was really bad, I was really – I was threatening to kill myself.” (Bob)*

While most participants reported improvements in their mental health once these difficulties had been rectified, the *“memories” (John)* stayed with them.

> *“...it kind of haunts me, that feeling.” (Mabel)*

Denial. Some participants appeared to engage in denial, both in terms of trying to suppress emotional reactions or of denying the uncertainty of the future.

> *“Interviewer: ...you see things about cuts. How does that make you feel?*
>
> *Bob: Not worried ... ‘Cause I know it won’t affect me.”*

Being mistreated

Participants described receiving *“unfair” (Josh)* and *“cruel” (Mabel)* treatment within the benefits system where staff *“talk down to you” (Tara, FG)*, regarding participants as *“piece(s) of dirt” (Craig)*. Participants were left feeling as though staff were *“trying to slip you up” (Katie)* and felt suspicious about their intentions.

> *“... it sounds like they want less people to be on benefits.” (Adam)*

This mistreatment was felt to be worse for PWLD.

> *“...they seem to mess people about with learning disabilities more…” (John)*

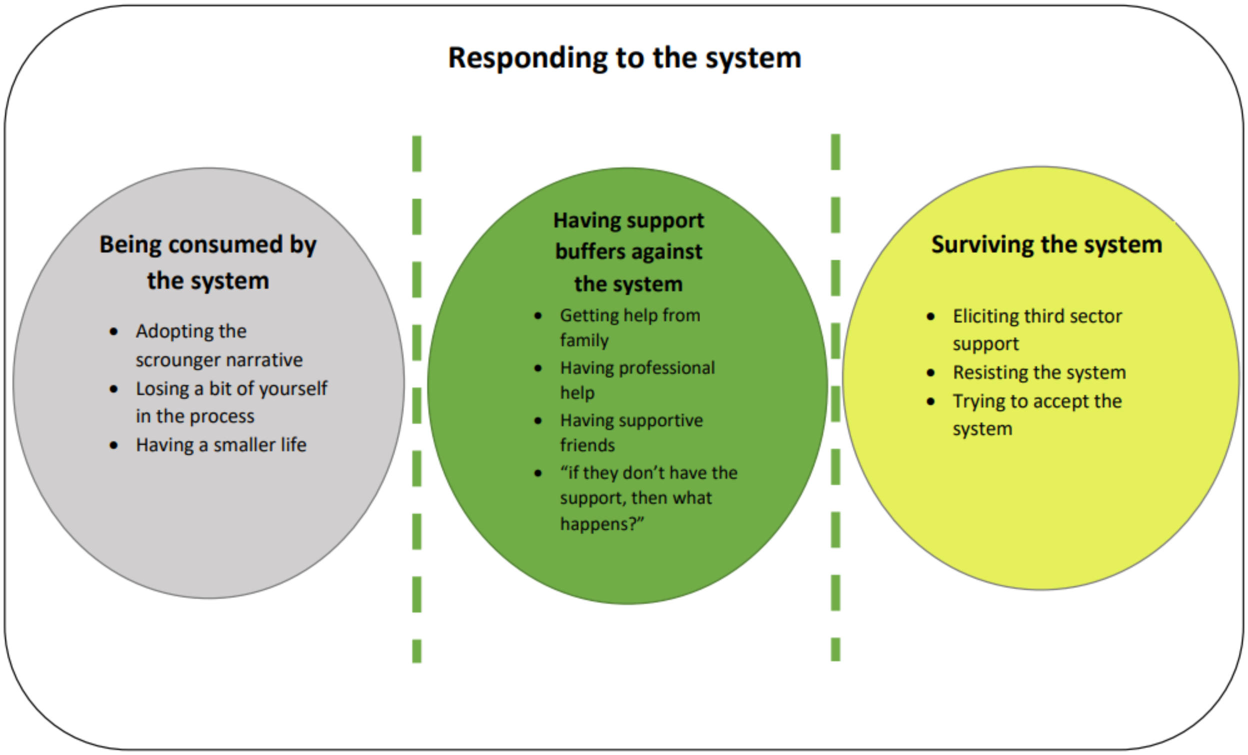
One family member noted that participants seemed to just be *“tolerated by society” (Patricia)*.

Participants described a system which felt abusive, financially and emotionally, which mistreated them and left them internalising wider narratives of stigma, reinforced in the system.

Responding to the system

The final concept relates to the processes by which participants responded to the system. This concept remains within "The dependence trap", highlighting that responses do not remove participants from the trap, but rather are ways of negotiating their lives within the system. The following categories are constructed in this concept: "Being consumed by the system", "Having support buffers against the system" and "Surviving the system". Although represented as separate categories, they are not mutually exclusive, and participants may move between them. Additionally, while the "buffer" of support can protect against some of the harmful effects of the system, it does not alleviate all negative experience.

Figure 6.
"Responding to the system" concept



Being consumed by the system

Participants described how interactions with the benefits system and wider society left them adopting the language of the system, and the ways in which their lives were reduced.

Adopting the scrounger narrative. Some participants attempted to distinguish themselves as ‘genuine’ benefits claimants by adopting the rhetoric around ‘scroungers’. The system was considered easy for fraudulent claimants, leading participants to conclude who was and wasn’t worthy of receiving benefits.

> *“…it shouldn’t be that way, it should only be people with disabilities or people who are, like, in wheelchairs ... or who can't manage ... people shouldn't make it that easy for them...” (Josh)*

Losing a bit of yourself in the process. Participants described how the benefits system *“obstructs your day and your life” (Mabel)*, leaving little energy for their own lives. Some participants’ physical health suffered, or they seemed to tie their sense of self-worth to overcoming the difficulties they encountered in the system.

> *“But if I don't ... come out of it, I'm nothing.” (Leon)*

A family member noted how navigating the system was *“almost like a full-time occupation” (Patricia)*.

Having a smaller life. Participants noted that their lives seemed smaller as a result of navigating the benefits system.

> *“...when me b-benefits stopped, you couldn't go out and have fun...” (John)*

For some participants this felt like a self-fulfilling prophecy as they embodied the stereotype they felt stigmatised by.

“... you’re stuck at home doing sweet F.A., sitting there watching the Gogglebox...” (Mary)

Participants noted impacts on a range of relationships, feeling unable to pursue romantic relationships, having friendships affected and feeling unable to fulfil their preferred family roles. Participants also described unmet personal dreams and interests.

“I wish I could have travelled to France on Eurostar.” (Michael)

Having support buffers against the system

Well-supported participants found that this could buffer against some of the impact of the system.

Getting help from family. Having family enabled participants to get support with understanding letters, attending assessments, and receiving financial and emotional support.

“...mum have always told me, am, don’t put yourself down ... it’s not your fault. It happens to everyone ... that sort of things he-h-help you feel that you're kind of not worthless, isn’t it?” (Mabel)

Having professional help. Professional support was particularly beneficial to participants when they encountered difficulties with the system or with their finances.

“I owe money on that. That got scrapped. Yeah she contacted them people ... she got it scrapped.” (Bob)

Having supportive friends. Friends and partners who were *“in the same boat” (Julie)* helped participants feel understood and could be a source of *“comfort” (John)*.

“...because they are in that same road, they are very helpful, nice and very understanding...” (Mabel)

"If they don't have the support, then what happens?". Some participants expressed wonder at how PWLD could manage the benefits system without support. For some participants, they experienced losses to their benefits when they were without support at assessments.

> *"...at first it didn't go well, the first time, but when I went the second time* [with mum]*, it went well." (Mabel)*

Surviving the system

Many participants described ways in which they managed to survive the system and maintain meaningful lives despite difficulties.

Eliciting third sector support. All participants had help from third sector organisations, providing practical support, and humanising interactions with professionals. Participants experienced being respected, valued and gained a sense of community.

> *"... there's one thing with Mencap, they talk to you as a person...." (Craig)*

Resisting the system. Many participants identified ways of resisting the system, including by participating in this research which they hoped would *"help people in the future make like people getting benefits less stressful" (Adam)*. They were driven by a desire to *"keep fighting all the time" (John)* for changes in the system and society.

Trying to accept the system. Some participants reported wanting to get on with their lives and not think about the difficulties they had with the system.

> *"I just thought I got to accept the decision that they made..." (Christopher)*

Participants tried to focus on *"the positive things" (John)* and keep busy with their interests.

Discussion

This study aimed to develop a GT of the process of navigating the UK benefits system for PWLD. The resulting model highlights five interrelated processes: being stigmatised and excluded in society, becoming caught in the dependence trap, navigating the "circles and roundabouts" of the benefits system, feeling abused and finding ways of responding to the system. It shows that PWLD had experiences of being excluded and looked down upon in society, setting the context for their navigation of the benefits system. They were attuned to negative discourses around disability and benefits claimants both outside and inside of the system. PWLD typically will have claimed benefits throughout their life, as their disability means that they require additional help and support to develop independence. The support offered through benefits brings opportunity to their lives when the system is working well. However, they can become stuck in a dependence trap when their experiences with the system increase their reliance on the people around them and on the system itself, making independence more difficult to achieve. PWLD encounter multiple obstacles claiming benefits, largely around a complicated and inaccessible system that has become increasingly insecure. Interacting with the system significantly impacted on their lives, highlighting the negative effect on their mental health, their precarious financial situations and on their identity and self-worth. As participants described being unable to remove themselves from the trap, their responses involved feeling consumed by the system or finding ways to resist the effects of the system. Social and professional support were protective although did not negate the negative impacts.

Relation to existing literature

The model is broadly congruous with the findings of Saffer et al. (2018). In both models, key difficulties in navigating the complexity of the benefits system and its changes interacted with a wider context, where disability and claiming benefits are disparaged. Both highlight the impact of these difficulties on mental health and identity, as well as the financial strain put on participants.

The increased psychological distress related to claiming benefits has been well established (e.g. Barnes et al., 2016; Cheetham et al., 2019). This is significant for PWLD, already at a greater risk of developing mental health problems than the general public (Bates et al., 2017). Additionally, the complexity of the system affected participants in both the current and Saffer et al.'s (2018) studies; however, for PWLD the language and communication of the system was completely mismatched with their needs.

The experiences participants described within the system were perceived to be abusive. Indeed, some participants described difficulties consistent with having experienced a trauma; hypervigilance to threat, fear, shame, avoidance and intrusive *"memories" (John)* (World Health Organisation, 2019). Participants appeared to describe being constantly alert to things that could go wrong, seeking reassurance from benefits letters or keeping a running awareness of their payments and bills as though scanning for *"an unexploded bomb" (Patricia)*. Hypervigilance was noted in benefits claimants in other studies, with the system viewed as a dangerous place to navigate where claimants could lose their livelihood at any moment (Wright et al., 2020).

Participants in this study appeared to become caught in a dependence trap in the benefits system, similar to poverty traps described elsewhere (Duffy, 2011). Cuts left some PWLD fearing independence (Forrester-Jones et al., 2020), as being viewed as independent seemed to leave participants with less support. Loss of autonomy was described by Malli et al. (2018) in the context of austerity, which left individuals feeling less independent. While national policies often focused on increasing choice, independence and inclusion for PWLD (e.g. *Valuing People,* DoH, 2001), the implementation of welfare policies, since 2010 in particular, have led to reduced independence and inclusion. This was evident in participants' encounters with the benefits system that left them reliant on others for support to keep their benefits and on the system to survive, particularly in the context of workforce exclusion. The system itself engendered further workforce exclusion through fear of losing benefits, seen in Hamilton’s (2017) study where one participant described being too worried about losing benefits to pursue employment.

Stigma featured prominently in the model, both in terms of having a LD and claiming benefits. Goffman (1963) theorised stigma as traits attributed to individuals which are socially devalued. The disability stigma faced by PWLD is well-documented (e.g. Jahoda et al., 2010) and, as in this study, can come from the public as well as family and caregivers who reduce choices and opportunities (Pelleboar-Gunnick et al., 2021). Such stigma is perceivable to PWLD, negatively impacting their sense of self-worth and social identity (Logeswaran et al., 2020), with participants in this study expressing desires to be *“normal” (Mary)*. Benefits stigma is also well reported; classed by Baumberg et al. (2012) as falling into personal or self-stigma, social stigma and institutional stigma, engendered through the process of claiming benefits. However, it is a unique aspect of this research that participants with LD explored the impact on themselves of benefits stigma. Participants were aware of being positioned in an out-group (Tajfel & Turner, 1979), as ‘scroungers’, triggering feelings of shame and worthlessness. This shame was often exacerbated by humiliating interactions with the system, leaving them feeling mistreated and conscious of a possible drive from the DWP to reduce numbers of benefits claimants. While PWLD may previously have been understood as “deserving” claimants (Baumberg et al., 2012, p.3), it appears that for many there has been an increased sense that they may be ‘undeserving’, linked to their wider media representation (Briant et al., 2013). Some participants responded by adopting the language of the system and repositioning (Harré & Langenhove, 1999) themselves as ‘deserving’ claimants as opposed to fraudulent claimants.

Social support offered restorative experiences and, as found elsewhere, PWLD relied on family and charity support when navigating the benefits system (Forrester-Jones et al., 2020). Having peers with similar experiences and belonging to self-advocacy groups allowed participants solidarity in their experiences and a shared identity. While being positioned in an out-group can have negative impacts, feeling part of an in-group can foster positive self-esteem (Tajfel & Turner, 1979). This may explain the buffering effect of social support for participants in this study who appeared to find belonging and understanding with peers.

The current grounded theory adds to existing theories of stigma (Goffman, 1963) and social identity (Tajfel & Turner, 1979), highlighting how PWLD become excluded and stigmatised, however situates this within context, emphasising how structures and systems, which are inherently linked to particular political contexts, perpetuate these experiences. It highlights the importance of inaccessibility in fostering the sense of otherness inherent in stigmatised groups.

While the difficulties associated with navigating the benefits system for PWLD were clear from the results, there are existing community-based initiatives that aim to tackle these difficulties. PSC Southwest's (n.d.) Benefits Project supports people with disabilities and people with mental health needs with assessments, tribunals and medical since, as well as training benefits workers and raising awareness and campaigning around the issues that exist within the system. Such initiatives may counteract against some of the negative experiences described as well working towards eradicating some of the difficulties in the longer term.

Limitations

The inclusion criteria for this study sought participants who identified as having a LD or were accessing LD services. It was not within the scope of this study to screen participants' ‘level’ of LD. Such scrutiny may have been perceived as stigmatising and colluded with assessments where services are restricted (McKenzie et al., 2019). However, this may have risked inclusion of participants who would not meet criteria for a LD (Evans & Randle-Phillips, 2018).

This study struggled to recruit younger participants, who may have highlighted experiences with the benefits system specific to those transitioning to adult services. Additionally, participants were recruited from self-advocacy groups, therefore all those represented in the study had some access to services that could support them. It is thus unknown how participants without this resource would experience the system. Recruiting solely from self-advocacy groups also may have meant that those captured were more likely to have had previous negative experiences of the benefits system, possibly biasing the results.

Although initially planned, respondent validation was not achieved in this study due to time constraints. This limited the ability to ascertain whether the final model resonated with earlier participants. However, focus group data highlighted that participants in a separate context were able to see themselves within the model, adding credibility to the findings.

Clinical implications

Participants emphasised the importance of support when navigating the benefits system. It is important for psychologists and services to routinely ask about benefits in assessments and signpost to organisations, such as food banks or financial advocacy, assuring basic physiological needs are met before offering therapy and focusing on higher-order needs (Maslow, 1943). Psychologists can use their power and privileged role to write letters of support for claimants (Hewitt et al., 2017), support them with form-filling and appealing claims (Watts, 2018).

The prevalence of stigma was evident from this study. Considering the detrimental impact of stigma on mental health and the multiple stigmatised identities attributed to PWLD, psychologists should be mindful of this when approaching therapeutic work. Narrative therapy (White & Epston, 1990) may offer a way of working that allows socio-political landscapes to be formulated, contextualising clients’ distress and offering potential to externalise stigmatised identities. Narrative work may “expose normalising judgement(s)” and “resist normalising language” (Ord, 2013, p.26), enabling exploration of dominant understandings of disability and welfare, while being mindful of how power operates within ‘the normalising gaze’ of society and within therapeutic relationships.

As current UK policies suggest that many PWLD should access mainstream mental health services, some PWLD experiencing benefits and disability stigma will be seen in services such as Increasing Access to Psychological Therapies (IAPT; Dagnan et al., 2017). Thus, psychologists can offer training or consultation to colleagues in other services, enabling them to formulate more widely around stigma.

Psychological interventions may occur at the macro-socioeconomic level, working towards sociopolitical change (PSC, 2015). Psychologists advocating policy-level change may have further-reaching impacts than working individually (Browne et al., 2020). Participants emphasised that the benefits system needs to be accessible. Psychologists may work with service-users, professionals and organisations to advocate for system-level changes, through raising awareness of benefits with colleagues (Watts, 2018), lobbying at policy-level to promote wellbeing and prevent further distress and health inequalities (NHS England, 2014.).

Research implications

While a family carer participant was included, little data emerged in relation to carers’ experiences. Future studies may focus specifically on experiences of carers supporting PWLD with benefits, exploring the associated impact and associated stigma related to benefits (Ali et al., 2012). This may be relevant as families where someone has a disability are likely to have been affected by cuts and be living in poverty (Tucker, 2017).

Further research may seek to test the fit of the current model with non-verbal PWLD. Additionally, research including participants without access to self-advocacy groups and those in more rural areas, where third sector organisations may be less accessible, may establish whether similar processes occur in such settings.

The importance of being able to ‘survive’ the system was seen in this model. Additional research exploring the nuances of how and strategies by which PWLD were able to survive would be valuable.

Conclusion

The processes through which PWLD navigate the benefits system are demonstrated in this study. Interrelated to this is the context of stigma and exclusion which PWLD experience in and outside of the system. This study has contributed to research exploring the difficulties encountered with the UK benefits system and its impact on mental health and identity, making a novel contribution by exploring the experiences of PWLD. The findings are consistent with the wider research highlighting the negative impacts of navigating the benefits system and have clinical and research implications.

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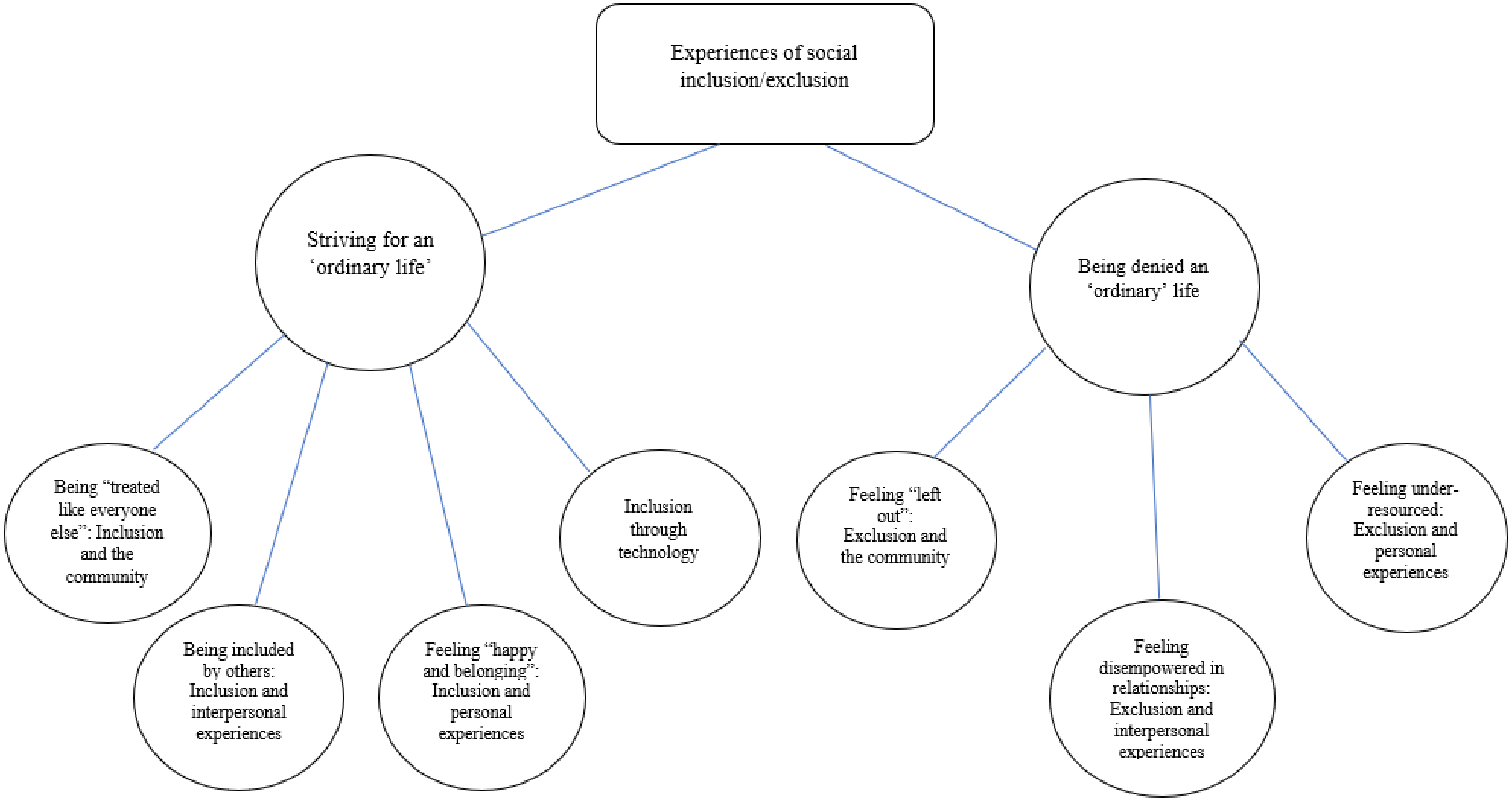
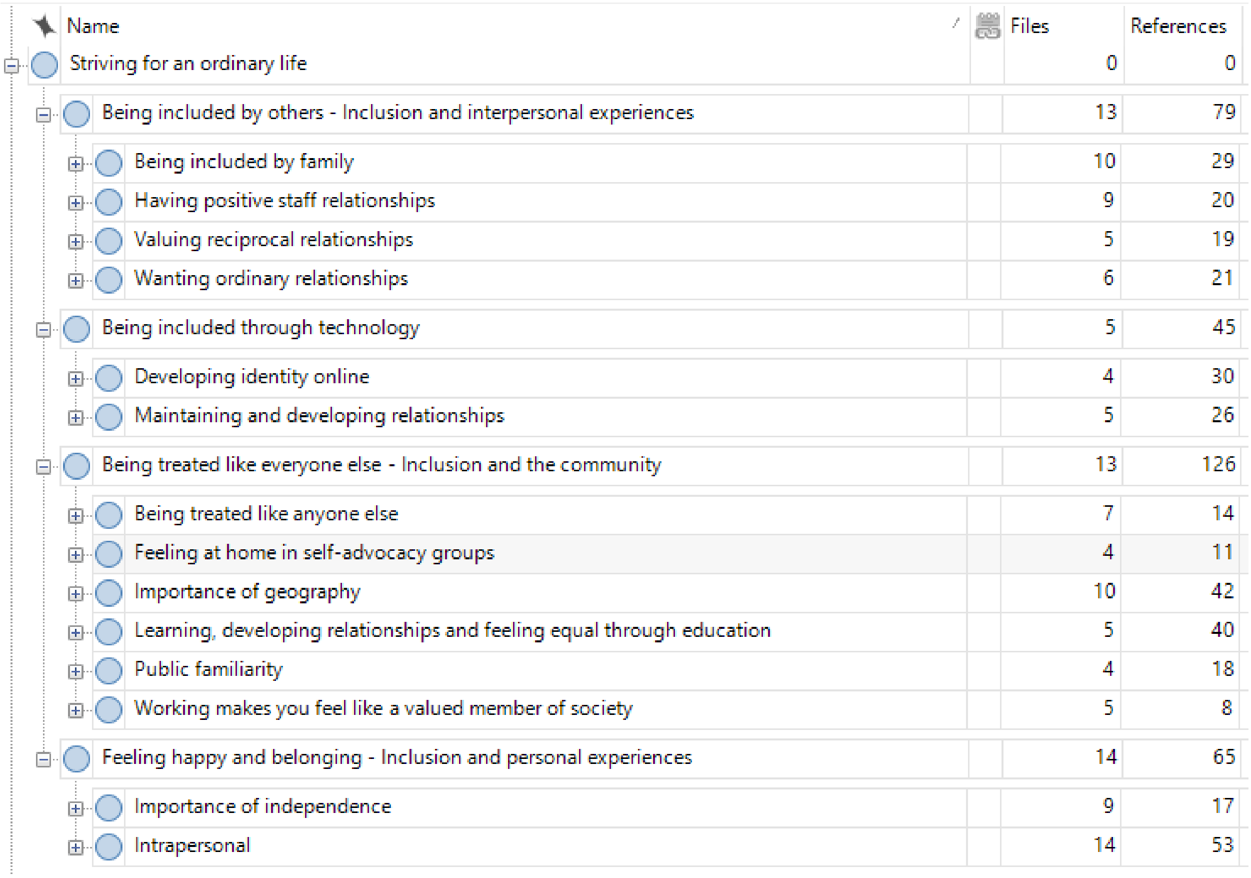
Section C: Appendices of supporting material

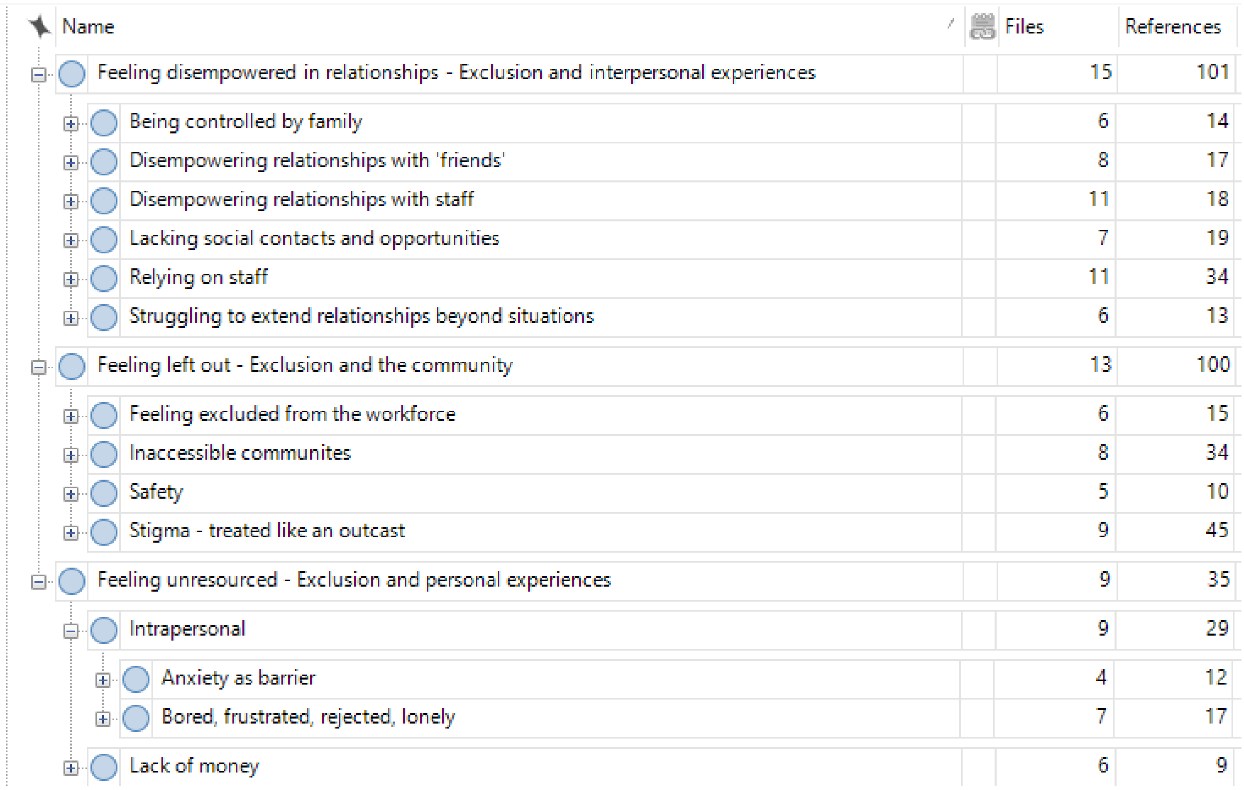
Appendix I: Thematic Map



Appendix II: Inductive Coding Process



Name	Files	References
Striving for an ordinary life	0	0
Being included by others - Inclusion and interpersonal experiences	13	79
Being included by family	10	29
Having positive staff relationships	9	20
Valuing reciprocal relationships	5	19
Wanting ordinary relationships	6	21
Being included through technology	5	45
Developing identity online	4	30
Maintaining and developing relationships	5	26
Being treated like everyone else - Inclusion and the community	13	126
Being treated like anyone else	7	14
Feeling at home in self-advocacy groups	4	11
Importance of geography	10	42
Learning, developing relationships and feeling equal through education	5	40
Public familiarity	4	18
Working makes you feel like a valued member of society	5	8
Feeling happy and belonging - Inclusion and personal experiences	14	65
Importance of independence	9	17
Intrapersonal	14	53



Name	Files	References
Feeling disempowered in relationships - Exclusion and interpersonal experiences	15	101
Being controlled by family	6	14
Disempowering relationships with 'friends'	8	17
Disempowering relationships with staff	11	18
Lacking social contacts and opportunities	7	19
Relying on staff	11	34
Struggling to extend relationships beyond situations	6	13
Feeling left out - Exclusion and the community	13	100
Feeling excluded from the workforce	6	15
Inaccessible communites	8	34
Safety	5	10
Stigma - treated like an outcast	9	45
Feeling unresourced - Exclusion and personal experiences	9	35
Intrapersonal	9	29
Anxiety as barrier	4	12
Bored, frustrated, rejected, lonely	7	17
Lack of money	6	9

Appendix III: CASP Qualitative Checklist (2018)

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Appendix IV: Quality appraisal of identified studies using CASP checklist

Study	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between the researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
1.Abbot & McConkey (2006)	Yes	Yes	Yes, appropriate(Y) but not justified latent content analysis(P)	Yes, (purposive) self-selected sampling(Y), no inclusion/exclusion criteria mentioned although inclusion clear from aim(N), explanation given as to how and why selected(Y), suggestion that others didn't take part as sample self-selected, although no further information given (N)	Yes, setting justified(Y), clear information on data collection(Y) and methods(Y) and focus groups justified(Y), saturation described as being achieved(Y), form of data clear(Y)	Cannot tell, not clear if this was done	Partially, informed consent(Y), confidentiality(Y), right to withdraw(Y), effects of the study not discussed but contact details provided(P), no mention of ethics committee approval(N)	Yes, some description of analysis process but not in-depth(P), clear how themes derived(Y),no explanation of which data was presented(N), there appears to be sufficient data(Y), evidence of contradictory data(Y), some consideration of group facilitators' role in data collection but not sufficient(N)	Yes, more than one analyst involved(Y), findings discussed in relation to the question(Y), noted where expected issues didn't arise in the data(Y), per checking of themes(Y), explicit statement of findings(Y)	Valuable, discussions of service level changes(Y), references to national policy(Y), further research recommendations made(Y)
2.Callus (2017)	Yes	Yes	Yes, qualitative methods justified(Y), thematic analysis	Yes, purposive sampling(Y), inclusions/exclusion criteria	Yes, setting not fully justified(P), clear	Partially, researcher's role was examined in relation to the	Partially, easy read information sheets were mentioned(Y),	Partially, adequate description of analysis process (Y),	Partially, findings are explicitly stated(Y), no evidence for	Some value, discussed in relation to current knowledge(Y),

			partially justified(P)	not outlined(N) but explanation given as to how and why selected(Y), noted that participants self-selected via purposive sampling suggesting others didn't take part, although no further information on non-consent(P)	information on data collection(Y) and methods justified(Y) and explicit(Y), focus groups justified(Y) and modification(Y) explained, saturation not mentioned(N)	research, although potential for bias was not considered, it was discussed as a strength	issues of consent and confidentiality mentioned(Y), effects not discussed (N), no ethics committee approval mentioned(N)	clear how themes derived from data(Y), no explanation of which data was presented(N), there could be more data or longer extracts(N), evidence of contradictory data(Y), facilitator's roles considered in the data collection but not critically examined for bias(P)	and against(N), no credibility discussed(N), findings are discussed in relation to the question(Y)	no further research recommendations(N), some practice-based recommendations(P), lack of generalisability discussed(P)
3.Chadwick & Fullwood (2018)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), thematic analysis not justified(N)	Partially, purposive sampling (Y) in advocacy and social groups(Y), no inclusion/exclusion criteria(N), no info as to why this methods was used(N), no indication of why participants were selected(N), no discussion	Yes, setting not fully justified(P), clear how data was collected(Y), methods justified(Y) and explained what adaptations were available(Y), topic guide included(Y), form of data partially	Cannot tell, some consideration given to rapport building before and after interviews, but no explicit examining of role described in the study	Partially, easy read information sheets were mentioned(Y), issues of consent and confidentiality mentioned(Y), no ethics committee approval mentioned(N), debrief mentioned although no detail given(P)	Yes, in-depth description of analysis evident(Y), categories and themes clear from data(Y), sufficient data presented to support(Y), some contradictory data around frustrations(Y), researchers’ role not adequately	Yes, findings explicitly stated(Y), no adequate discussion of evidence for and against(N), credibility discussed(Y), findings discussed in relation to original question(Y)	Valuable Valuable, discussed in relation to existing knowledge and research(Y), recommendations made for further research(Y) and how to expand on results(Y)

				around people who didn't take up the research(N)	made clear - instant messaging transcripts and suggested that f2f interviews were recorded but not explicitly stated(P), no mention of saturation(N)			considered(N), evidence of triangulation(P).		
4.Corby et al. (2020)	Yes	Yes	Yes, appropriate(Y) and hermeneutic phenomenology justified(Y)	Partially, Sampling strategy(N), inclusion criteria clear (Y), how they were recruited not explained (implied it is from services) but why justified(P), some recruitment issues discussed but not much detail or non-consent(P)	Yes, setting justified(Y), clear how data was collected(Y) and methods explicit(Y), methods justified(Y), form of data clear(Y), saturation not discussed(N)	Cannot tell, some suggestion of researcher using reflective writing but no further consideration evident	Partially, ethics approval granted(Y), no detail given about how research was explained(N), consent not mentioned(N), confidentiality considered(Y), effects not mentioned (N)	Yes, in-depth description of data analysis(Y), some explanation of how data presented(P), sufficient amount of data(Y), some contradictory data(P), role somewhat examined as previous(P)	Yes, findings explicitly stated(Y), rigour mentioned through comparing data and literature but no other discussion on credibility(P), discussed in relation to research question(Y)	Valuable, discussed in relation to existing knowledge(Y), research recommendations made(Y), discussed implications for service providers and education providers(Y)
5.Hall. (2017)	Yes	Yes	Yes, appropriate(Y), justified qualitative(y) and phenomenology(Y)	Yes, criterion (purposive sampling)(Y), inclusion criteria clear(Y), how they were recruited is	Yes, setting not fully justified(P), clear how data collected(Y), methods	Cannot tell, no explicit examining of role described in the study although mention of pre-	Yes, lots of information about how informed consent was gained(Y) and continuously	Yes, adequate description of analysis(Y), sufficient data presented(Y), contradictory data(Y), no	Yes, findings explicitly stated(Y), adequate discussion of evidence for and against(Y),	Valuable, discussed in relation to existing knowledge and research(Y), recommendations made for

				explained(Y), why is partially evident(P), no information around who might have said no but additional information on the recruitment strategy and consent stages given(P)	justified(Y), methods made explicit(Y), form of data clear(Y), no discussion of saturation(N)	interview discussions	monitored, confidentiality acknowledged(Y), approval from ethics committee granted(Y), effects not explicitly mentioned but evidence of briefing and monitoring how they were doing(P)	evidence of own role consideration(N)	credibility discussed(Y), findings discussed in relation to original question(Y)	further research(Y) and implications of the research(Y)
6. Merrels et al. (2017)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), phenomenology justified(Y)	Yes, purposive criterion sampling(Y), inclusion/exclusion criteria(Y), information given as to why people dropped out(Y)	Yes, setting justified(Y), clear how data collected(Y), methods justified(Y), methods made explicit(Y), form of data made clear(Y), saturation not discussed(N)	Yes, research diary kept(Y) and bracketing interviews done(Y)	Yes, ethical approval granted(Y), insufficient details around how explained(N) but known person explained first and there was phased consent processes(Y), confidentiality considered(Y), effects not explicitly discussed but studies piloted and feedback sought and briefing done(P)	Yes, reasonably good description of analysis(Y), not explained how certain data was presented(N) but sufficient data included(Y), some contradictory data(P), use of reflective diary to minimise bias(Y)	Yes, findings explicitly stated(Y), credibility discussed(Y), findings discussed in relation to original question(Y)	Valuable, discussion in relation to existing knowledge and research(Y), recommendations made for further research(Y), lack of transferability recognised but implications discussed(Y)

7.Mooney et al. (2019)	Yes	Yes	Cannot tell, appropriate(Y), justified(N), however, the write-up of this inclusive paper strays slightly from traditional research papers, CASP does not seem to fully grasp the type of write up	Yes, sampling not required as inclusive research group project, clear why they could answer question	Yes, setting justified(Y), clear how data collected(Y), some justification of methods(P), methods and form of data explicit(Y), data saturation not mentioned(N)	N/A – inclusive research design	Yes, ethical approval granted(Y), consent(Y), ground rules(Y), “what's said in the room stays in the room.”(Y), effects considered – option to leave and get support if sad(Y)	Yes, analysis process described(Y), no quotes but descriptive examples provided and clear that themes grounded in data(Y), contradictory examples(Y), dual role so bias not as important although final read through of written paper with the one researcher without LD(N/A)	Yes, findings made explicit(Y), inclusive project with all participants involved in analysis so multiple analysts(Y), findings discussed in relation to research question(Y)	Valuable, Not discussed in relation to existing research(N), research recommendations made and plans to apply for funding for such(Y), lots of practical recommendations made for services and community(Y)
8.Overmars-Marx (2019)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), content analysis not justified(N)	Yes, sampling not stated(N), inclusion criteria(Y), explained how and why(Y), some discussion around why someone might not be eligible(P) and mentioned that someone	Yes, setting justified(Y), clear how collected(Y), justification of methods(Y), methods and form of data explicit(Y), sufficiency made implicit(P)	Cannot tell, some discussion around offering choice to participants about whether to do with/without researcher, however, no discussion of bias in interviews or elsewhere	Partially, no mention of ethics approval(N), sufficient information about how explained and phased consent process evident(Y), consent and confidentiality mentioned(Y),	Yes, analysis process described(Y), clear how themes derived(Y), no explanation of how data was selected(N), sufficient examples(Y), contradictory examples(Y), role not	Yes, findings made explicit(Y), second analyst(Y), findings discussed in relation to research question(Y)	Valuable, discussed in relation to existing research(Y), research recommendations made(Y) and service delivery recommendation made(Y)

				dropped out midway through but no mention of why(P)			effects not discussed(N)	critically examined(N)		
9.Rodríguez Herrero et al. (2020)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), content analysis justified(Y)	Yes, purposive sampling(Y)no inclusion/exclusion criteria mentioned(N), explained how and why(Y), evidence that there were incidences of non-consent but no explanation given(P)	Yes, setting justified(Y), clear how collected(Y), justification of methods(Y), methods and form of data explicit(Y), saturation mentioned(Y)	Cannot tell, no evidence of whether this was considered	Partially, ethics approval not mentioned(N) but APA code of ethics followed(Y), consent and confidentiality mentioned(Y), however, not clear how information was explained(N), but initial contact made through person known to them(Y), effects not considered(N)	Partially, analysis process described but not in-depth(P), clear how themes derived(Y),no explanation of how data was selected(N), sufficient examples(Y), contradictory examples(Y), role not critically examined(N)	Yes, findings made explicit(Y), triangulation mentioned through different graduating classes and different focus groups(Y), findings discussed in relation to research question(Y)	Valuable, discussed in relation to existing research(Y), research recommendations made(Y) and service delivery recommendation made(Y)
10.Shpigelman (2018)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), thematic content analysis not justified(N)	Partially, sampling not explicit(N), inclusion criteria detailed(Y), why and how clear(Y), no further discussion around	Yes, setting not justified(N), clear how collected(Y), justification of methods(Y), methods and form of data explicit(Y), data	Partially, bias discussed in relation to observations but not in other areas	Yes, ethics approval granted(Y), informed consent and confidentiality discussed(Y), not clear how details of the study were explained but this was done	Yes, analysis process described(Y), clear how themes derived(Y), no explanation of how data was selected(N), sufficient examples(Y),	Yes, findings made explicit(Y), triangulation of data through two methods mentioned and second analyst present(Y), findings discussed in relation to	Valuable, discussed in relation to existing research(Y), research recommendations made(Y) and practical recommendations made(Y)

				recruitment e.g. non-consent(N)	saturation mentioned(Y)		through services so phased levels of consent evident(P), effects not considered(N)	contradictory examples(Y), role examined in terms of observational data(P)	research question(Y)	
11.Spassiani et al. (2017)	Yes	Yes	Cannot tell, appropriate(Y), justified qualitative(N), justified Photovoice and Nominal Group Technique(Y)	Yes, sampling not required as inclusive research group project, clear why they could answer question	Yes, setting justified(Y), clear how collected(Y), justification of methods(Y), methods and form of data explicit(Y), data saturation not mentioned(N)	N/A – inclusive research	Cannot tell, ethical approval not mentioned(N), other ethical issues not explicitly discussed, however, the participants were also the researchers which negates many of the ethical issues so they may have been less relevant to describe	Yes, analysis process described(Y), no quotes but clear how many people voted for what and descriptive examples provided(Y), contradictory examples(Y), dual role so bias not relevant in the same way	Yes, findings made explicit(Y), inclusive project with all participants involved in analysis so multiple analysts(Y), findings discussed in relation to research question(Y)	Valuable, discussed in relation to existing research(Y), research recommendations made(Y) and practical recommendations made(Y)
12.Strnadová et al. (2018)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), content analysis not justified(N)	Partially, sampling strategy not explicitly stated(N), no inclusion/exclusion criteria(N), explained how selected and why(Y), no discussion around non-	Yes, setting not fully justified(P), clear how data was collected(Y) and methods explicit(Y), methods justified(Y), form of data clear(Y), saturation not discussed(N)	Cannot tell, no information given	Yes, ethics approval granted(Y), information about the study given in phased ways by organisations first and then info sheets(Y), consent gained(Y), confidentiality of data	Yes, in-depth description of analytic process(Y), clear how themes derived(Y), no explanation of data presented(N), sufficient data presented(Y), contradictory	Yes, findings explicitly stated(Y), credibility discussed(Y), discussed in relation to research question(Y)	Valuable, discussion in relation to existing knowledge(Y), some research recommendations made(Y), transferability discussed(Y), some implications for service provision made(Y)

				participation(N)			mentioned(Y), effects of study not discussed but briefing done(N)	data(Y), multiple analysts discussed(Y) but no examination of role(N)		
13.Sullivan et al. (2016)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), IPA justified(Y)	Yes, Purposive sampling(Y), inclusion/exclusion criteria outlined(Y), explained how selected and why(Y), no discussion around non-participation(N)	Yes, setting justified(Y), clear how data was collected(Y) and methods explicit(Y), methods justified(Y), form of data clear(Y), saturation not discussed(N)	Yes, evidence of reflective journal and supervision during data collection and analysis, evidence of changes based on participant feedback to themes	Yes, ethics approval granted(Y), detail given about how research was explained(Y) and consent(Y) and confidentiality(Y) and possibility for distress considered(P)	Yes, in-depth discuss of analytic process(Y), no explanation of data presented(Y), sufficient data presented(Y), contradictory data(Y), evidence of using reflective diary and supervision for analysis(Y)	Yes, findings explicitly stated(Y), credibility discussed(Y), discussed in relation to research question(Y)	Valuable, discussion in relation to existing knowledge(Y), some research recommendations made(Y), transferability(Y), some implications for service provision made(Y)
14.Van Asselt et al. (2015)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), thematic analysis not justified(N)	Yes, sampling strategy not explicit(N), inclusion criteria outline(Y), explained how selected and why(Y), evidence of recruitment issues(Y)	Yes, setting justified(Y), clear how data was collected(Y) and methods explicit(Y), methods justified for observation(Y) but not interview(N), modifications made clear(Y),	Yes, evidence of reflexive journal during data collection, steps taken to minimise bias during analysis	Yes, ethics approval granted(Y), detail given about how research was explained(Y) and consent(Y) and confidentiality(Y), effects not discussed(N)	Yes, in-depth discuss of analytic process(Y), clear how themes derived(Y), no explanation of data presented(N), sufficient data presented(Y), contradictory data(Y), evidence of	Yes, findings explicitly stated(Y), credibility discussed(Y), discussed in relation to research question(Y)	Valuable, discussion in relation to existing knowledge(Y), research recommendations made(Y), transferability discussed(Y), some implications for service provision made(Y)

					form of data clear(Y), saturation discussed(Y)			awareness of risk of bias in analysis(Y)		
15.White & McKenzie (2015)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), thematic analysis not justified(N)	Yes, sampling not explicit(N), inclusion/exclusion not explicitly stated but inclusion clear(P), how and why explained(Y), issues with sample size discussed(Y)	Yes, setting justified(Y), clear how data was collected(Y) and methods explicit(Y), methods justified(Y), form of data clear(Y), saturation discussed(Y)	Partially, evidence of consideration of bias through field notes during data collection and analysis	Yes, ethics approval granted(Y), detail given about how research was explained(Y) and consent(Y) and confidentiality(Y), effects not explicitly consider but briefed(N)	Yes, in-depth description of data analysis(Y), clear how themes were derived(Y), no explanation of how data presented(N), reasonable amount of data(Y), some contradictory data(Y), role examined as previously(Y)	Yes, findings explicitly stated(Y), credibility discussed through second analyst and consideration of participant validation(Y), discussed in relation to research question(Y)	Valuable, discussed in relation to existing knowledge(Y), two research recommendations made(Y), discussed transferability(Y), implications for OTs made(Y)

Excluded papers:

Hall (2004)	Yes	Yes	Partially, appropriate(Y), but not justified(N), specific method not clear or justified(N)	Can't tell, how they were recruited is explained(Y), sampling method not made explicit(N), inclusion/exclusion not explicitly stated(N), why	Partially, setting justified(Y), clear how data collected(Y), methods justified(Y), methods not made explicit just unstructured	Can't tell, no explicit examining of role described in the study(N), although mention of supporters helping to build trust and location	No, no mention of ethics(N), no discussion of how explained(N), no issues around effects(N) confidentiality(N) or consent(N)	No, no evidence of whether formal analysis happened(N) or how findings were grouped under subheadings(N), sufficient data seems to be presented(P)	Partially, findings explicitly stated(Y), no adequate discussion of evidence for and against(N), credibility not discussed(N), findings discussed in	Valuable, discussed in relation to existing knowledge(Y) and research(Y), some recommendations made for further research(P) and

				is not evident (N), no information around who said no or recruitment issues(N)	discussion(N), form of data not clear(N), no discussion of saturation(N)	helping with this(P)		but no indication of how this was selected(N)	relation to original question(Y)	how the research might be used(Y)
Welsby & Horsfall (2011)	Yes	Yes	Yes, appropriate(Y), qualitative justified(Y), specific method not justified(N)	No, no information given on recruitment strategy so unclear	Partially, setting unclear(N), clear how data was collected and methods explicit(Y), methods justified(Y), form of data clear(Y), no discussion of saturation(N)	Can’t tell, not enough evidence, some discussion of power in the intro but nothing further, relationship not examined(N)	Yes, ethics approval granted(Y), detail given about how research was explained(Y) and consent(Y) and confidentiality(Y), effects not discussed(N)	No, data analysis not described(N), unclear how themes were derived(N), no explanation of how data presented(N), reasonable amount of data(P), some contradictory data(Y), role not examined(N)	Partially, findings stated but not explicitly(P), credibility not discussed(N), discussed in relation to research question(Y)	Little value, not discussed in relation to existing knowledge(N), one research recommendation made(P)

Appendix V: Easy read information sheet for PWLD

Canterbury
Christ Church
University

Would you like to help find things out about getting benefits?

My name is Emer. I am training to be a clinical psychologist. I am doing my training at Canterbury Christchurch University.

I want to find out about what it is like to get benefits when you have a learning disability.

I would like to ask you questions about what it is like to get benefits.

I will write a report about what we spoke about.

The information you talk to me about is private. In the reports I will not use your name so no one will be able to know it is about you. This means it is 'confidential.'

easy read
made with photosymbols

Made with Photosymbols

Appendix VI: Full information sheet for PWLD

Canterbury
Christ Church
University

Would you like to help find things out about getting benefits?

My name is Emer. I am training to be a clinical psychologist. I am doing my training at Canterbury Christchurch University.

I want to find out about what it is like to get benefits when you have a learning disability.

I want to speak to people who get benefits. I also want to speak to someone if they used to get benefits but don't any more. I also want to speak to someone who helps you get benefits like a family member or carer.

1. What do we want to find out?

People with a learning disability should get benefits if they need them.

This helps them to have enough money to buy the things they need.

Benefits is money from the government.

I would like to hear what it is like to use benefits when you have a learning disability.

An Ethics Committee has said it is OK to find out about this.

An Ethics Committee decides if it is a good idea to find out about things. An Ethics Committee decides if it is safe to find out about things.

We will start to find things out now. We will finish in April 2021.

2. How will we find things out?

If you want to take part, I will visit you one or two times. This is so that I can talk to you more about taking part.

You can ask me questions.

We will make a plan together about how we will find things out.

At our first meeting, I will ask you if you want to take part.

If you have already read the information sheet, you can decide if you want to take part then. Or you can decide to go home and think about whether you want to take part.

If you want to take part then, I will ask you about your benefits. This will be our interview.

Or you can decide to meet a second time. This is so you can think more about whether you want to say “yes”. It is up to you.

At our second meeting, I will ask you about getting benefits. This will be our interview.

We can meet on our own.

Or we can meet with someone you know well. It is up to you.

I want to hear your story. Even if we meet with someone you know well, I will only ask you questions. The questions will be easy.

The information you talk to me about is private. In the reports I will not use your name so no one will be able to know it is about you. This means it is 'confidential.'

3. Saying "yes" or "no" to taking part

You do not have to take part. It is your choice.

You can talk to other people to help you choose.

If you want to say “yes” to taking part, I will ask you to sign a consent form. A consent form is a form that says whether you say “yes” or “no”.

If you do not want to take part, you can say “no”.

Even if you say “yes”, you can say “no” later.

You do not have to give a reason to say “no”. Saying “no” will not change how people treat you.

4. More details if you want to say “yes”

I will interview you by asking you questions. The questions will be easy.

We might also use pictures and questionnaires together to help you answer the questions if you find this easier. A questionnaire is some questions on paper with answers you can choose from.

We might talk for half an hour or one hour. We can take a break.

I will record the interview on a recorder.

I will ask you about your family and friends.

I will ask if they help you with your benefits. I might ask if they would like to talk to me about what it is like helping you with benefits.

The information you talk to me about is private. No one will be able to know it is about you in the reports. This means it is 'confidential.'

But if I am worried about something you tell me I might need to talk to someone else. For example, I might be worried that you are in danger, or that someone else is in danger.

I will try to talk to you about this before I speak to anyone else.

What could happen if you take part?

I will ask you questions about your benefits. You might think about difficult things that have happened to you or people you know.

Sometimes this is hard and you might feel upset, sad or angry.

If you feel upset you can choose not to answer my questions.

You can choose to have a break.

If you feel very upset, we can talk about where else you can find support.

5. What happens after taking part?

I will type up the interviews on a computer. I will then delete the recordings. This means they will be gone forever.

I will keep the typed up interviews for 10 years. My university will keep the typed up interviews for 10 years.

They will be kept in a locked computer. A copy will be kept in a locked cabinet.

Nobody else can look at the typed up interviews.

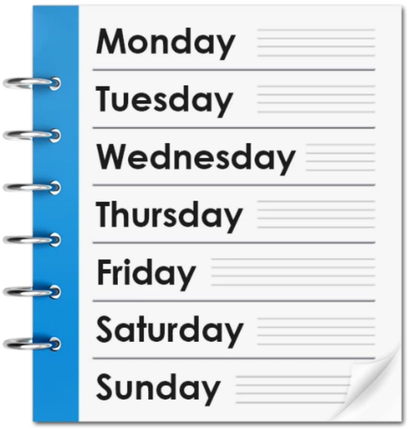
After 10 years, the typed up interviews will be deleted. This means they will be gone forever.

I will change information, like your name. The information will be 'anonymous'– this means no-one will know it is you.

The information on the computer will be kept locked with a password. This means it is 'confidential.'

I will write a report about what we have found out.

I might write things that you have said into these reports. But I will not use anyone's names. No one will know that it was you that said it.



Within two weeks after our interview, you can ask me not to write about the things you told me.

After two weeks it will be too late for the things you told me to be taken out of the reports.

But remember, I will not use your name. So people who read the reports will not know they are about you.

I will ask you to meet me one more time. I will ask you to look at the report with me. I will ask you about what I wrote in the report. I will ask if what I wrote is the same as what we spoke about. If there is a word that you can't read, I will read it to you.

You do not have to do this. It is up to you. You can decide whether to say "yes" or "no" to this meeting.

Lots of people might want to read the report. They might want to know what has been good about getting benefits. They also might want to know what could have been better.

People who want to learn more might be:

People like you who get benefits

Their families and their carers

Social workers

Psychologists

Politicians

If you would like to know more about what we have found out, I will arrange to let you know. I could meet with you or I could write to you.

I will write the reports in Spring 2021.

6. Who can I contact?

Three clinical psychologists, named Tamara, Annabel and Jessica, are helping me find things out. Our contact details are here:

Emer O’Riordan

Phone number: xxx

Email: xxx

Dr. Tamara Leeuwerik

Phone number: xxx

Email: xxx

Dr. Annabel Head

Phone number: xxx

Email: xxx

Dr. Jessica Saffer

Phone number: xxx

Email: xxx

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Appendix VII: Information sheet for families and carers

Information about the research

How do people with learning disabilities navigate the benefits system?

Hello. My name is Emer O’Riordan and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.

(Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?

This study aims to explore what it is like to navigate the benefits system when you have a learning disability.

We want to find out what it is like for someone with a learning disability to navigate that system, particularly in relation to their role in society and their identity. The views of participants will be used to develop a model that could help organisations to support people going through this experience and possibly encourage policy makers to ensure that the system fits the needs of its users.

Why have I been invited?

You have been invited because you are a family member or carer who supports a person with a learning disability to claim their benefits. To really understand what it is like for someone with a learning disability to navigate the benefits system, we think it would be valuable to speak to people who support them to this as well as speaking to the person who receives the benefits.

Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you agree to take part, I will ask you to join me (Emer O’Riordan) for an interview. I will speak to you about the research and check that you have understood everything or this information sheet. You can ask me questions about the research. If you want to take part, I will ask you to sign a consent form. I will then ask you questions about what it is like for the person you support to claim benefits, and what it is like for you to support them with this. This interview may last for up to an hour. I will audio record the interview. This is so that I can transcribe the interview afterwards. Towards the end of the study, I will invite you back to check out what I have written about the interviews I have conducted. I will ask you if this sounds like what we spoke about. You do not have to attend this second meeting, even if you attended the first interview.

Expenses and payments

If you agree to attend, I can pay up £10 for any travel expenses incurred.

What will I be asked to do?

I will ask you to join me for an interview lasting up to one hour. I will ask you questions about your experiences of supporting someone to use the benefits system and the experience of the person that you support. I will invite you back a second time when I have written to report to check that what I have written sounds like what we discussed.

What are the possible disadvantages and risks of taking part?

It is possible that discussing your experiences and the person you support's experiences of claiming benefits might be upsetting. We will be able to take breaks at any point during the interview and we can stop the interviews if you are finding it too difficult. I will also provide you with information about local services where you can get support after your interview if this would be helpful for you.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study could potentially help to improve the process of claiming benefits for people with learning disabilities and the people who support them with this or could better inform other services on how to support people going through this process.

We also hope that the interview may potentially provide you with the space to discuss issues with the process of supporting someone to claim benefits. While this may not benefit you directly, you may find this interesting. I will not be able to provide direct support around issues of claiming benefits, but I may be able to direct you to services that could support you.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don’t want to carry on with the study?

If you choose to withdraw from the study, we can remove any of the information that we have discussed within two weeks after the interview. After this point, it will not be possible to remove the information we have discussed. However, it is important to remember that all of the information we discuss will be completely anonymised.

What if there is a problem?

Although we hope this is not the case, if you have a complaint about any aspect of the study, these will be handled with the utmost importance. Please follow directions below if this is the case.

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me (Emer O’Riordan) and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology –fergal.jones@canterbury.ac.uk

Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the course of the research will be kept strictly confidential, and any information about you which leaves the interview location will have your name removed so that you cannot be recognised. I will audio record our interview so that it can be transcribed. The audio recording will be encrypted and transferred to a password protected laptop and encrypted USB immediately after the interview. It will be deleted from the audio recorder. The transcribed interviews will also be stored on a password protected laptop and encrypted USB. All identifying information will be anonymised, e.g. pseudonyms used, place names removed, interviews stored with a code, etc. I will have access to the recordings and transcribed interviews. My supervisors may also have access to this. Nobody else will be able to access any of this data. The audio recordings will be destroyed at the end of the study. The transcribed interviews will be retained for 10 years in a locked cabinet at the Salomons Institute for Applied Psychology, Canterbury Christ Church University. I will also keep the transcribed interviews on a password protected laptop for 10 years. After this time, all the data will be destroyed.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else.

What will happen to the results of the research study?

When the study is completed, I will write up the findings as an academic research project that will be submitted as part of the requirements of my course. In addition, I will write up an article for publication in a journal. If you want me to send you the results of the study, I can send this to you via email or post. I will ask you what your preference is.

These publications might use quotes from our interviews, but I will ensure the quotes will not identify you to ensure your privacy. If you say something during the interview that you do not want to be used, you can ask me to remove this from the transcript within two weeks after the interview.

Who is sponsoring and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

Further information and contact details

If you would like further information or would like to discuss any details, please get in touch with the researcher by phone or email. Alternatively, you can contact the lead supervisor, Tamara Leeuwerik. Contact details are provided below.

Principal researcher	**Research supervisor**
Emer O'Riordan	Dr Tamara Leeuwerik
Trainee Clinical Psychologist	Clinical Psychologist
Tel: xxx	Tel: xxx
Email: xxx	Email: xxx

Appendix VIII: Full information sheet for focus group

Canterbury Christ Church University

Would you like to help find things out about getting benefits?

My name is Emer. I am training to be a clinical psychologist. I am doing my training at Canterbury Christchurch University.

I want to find out about what it is like to get benefits when you have a learning disability.

I want to speak to people who get benefits. I also want to speak to someone if they used to get benefits but don't any more. I also want to speak to someone who helps you get benefits like a family member or carer.

1. What do we want to find out?

People with a learning disability should get benefits if they need them.

This helps them to have enough money to buy the things they need.

Benefits is money from the government.

I would like to hear what it is like to use benefits when you have a learning disability.

An Ethics Committee has said it is OK to find out about this.

An Ethics Committee decides if it is a good idea to find out about things. An Ethics Committee decides if it is safe to find out about things.

We will start to find things out now. We will finish in April 2021.

2. How will we find things out?

If you want to take part, I will visit your group one time. This is so that I can talk to you more about taking part.

You can ask me questions.

We will make a plan together about how we will find things out.

At our meeting, I will ask you if you want to take part.

You can ask me questions about the information sheet. You can decide if you want to take part.

If you want to take part then, I will ask you about getting benefits. This will be our group interview.

You can come to the group meeting alone. Or you can bring someone you know well. It is up to you.

I want to hear your story. Even if we meet with someone you know well, I will only ask you questions. The questions will be easy.

The information you talk to me about is private. In the reports I will not use your name so no one will be able to know it is about you. This means it is 'confidential.'

3. Saying "yes" or "no" to taking part

You do not have to take part. It is your choice.

You can talk to other people to help you choose.

If you want to say "yes" to taking part, I will ask you to sign a consent form. A consent form is a form that says whether you say "yes" or "no".

If you do not want to take part, you can say “no”.

Even if you say “yes”, you can say “no” later.

You do not have to give a reason to say “no”. Saying “no” will not change how people treat you.

4. More details if you want to say “yes”

I will interview you by asking you questions. The questions will be easy.

We might also use pictures and questionnaires together to help you answer the questions if you find this easier. A questionnaire is some questions on paper with answers you can choose from.

We might talk for half an hour or one hour. We can take a break.

I will record the interview on a recorder.

The information you talk to me about is private. No one will be able to know it is about you in the reports. This means it is 'confidential.'

But if I am worried about something you tell me I might need to talk to someone else. For example, I might be worried that you are in danger, or that someone else is in danger.

I will try to talk to you about this before I speak to anyone else.

What could happen if you take part?

I will ask you questions about your benefits. I will ask you if your story is like other people's stories. You might think about difficult things that have happened to you or people you know.

Sometimes this is hard and you might feel upset, sad or angry.

If you feel upset you can choose not to answer my questions.

You can choose to have a break.

If you feel very upset, we can talk about where else you can find support.

5. What happens after taking part?

I will type up the group interview on a computer. I will then delete the recordings. This means they will be gone forever.

I will keep the typed up interviews for 10 years. My university will keep the typed up interviews for 10 years.
They will be kept in a locked computer. A copy will be kept in a locked cabinet.
Nobody else can look at the typed up interviews.

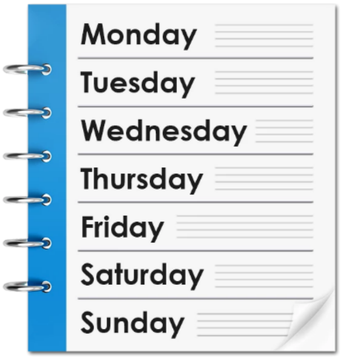
After 10 years, the typed up interviews will be deleted. This means they will be gone forever.

I will change information, like your name. The information will be 'anonymous'– this means no-one will know it is you.

The information on the computer will be kept locked with a password. This means it is 'confidential.'

I will write a report about what we have found out.

I might write things that you have said into these reports. But I will not use anyone's names. No one will know that it was you that said it.



Within two weeks after our interview, you can ask me not to write about the things you told me.
After two weeks it will be too late for the things you told me to be taken out of the reports.

But remember, I will not use your name. So people who read the reports will not know they are about you.

I will ask you to meet me one more time. I will ask you to look at the report with me. I will ask you about what I wrote in the report. I will ask if what I wrote is the same as what we spoke about. If there is a word that you can't read, I will read it to you.

You do not have to do this. It is up to you. You can decide whether to say "yes" or "no" to this meeting.

Lots of people might want to read the report. They might want to know what has been good about getting benefits. They also might want to know what could have been better.

People who want to learn more might be:

People like you who get benefits
Their families and their carers
Social workers
Psychologists
Politicians

If you would like to know more about what we have found out, I will arrange to let you know. I could meet with you or I could write to you.

I will write the reports in Spring 2021.

6. Who can I contact?

Three clinical psychologists, named Tamara, Annabel and Jessica, are helping me find things out. Our contact details are here:

Emer O’Riordan
Phone number: XXX
Email: XXX

Dr. Tamara Leeuwerik
Phone number: XXX
Email: XXX

Dr. Annabel Head
Phone number: XXXX
Email: XXX

Dr. Jessica Saffer
Phone number: XXX
Email: XXX

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Appendix IX: Interview schedule for PWLD

Agree with participant before interview if they want/need to use pictures. Remind participant that we can take a break whenever they need.

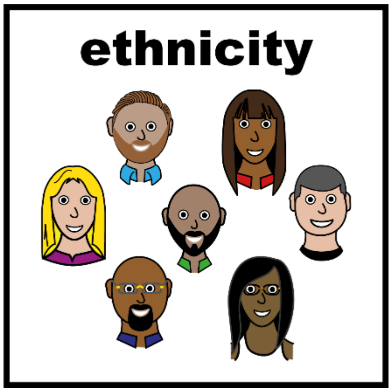
Can you tell me a bit about yourself?

What does having a learning disability mean to you?

Prompts: Why did you say yes to this research?

How old are you?

It’s OK if you don’t want to say.



How would you describe your ethnicity?

It’s OK if you don’t want to say.

Do you live with family? Do you live in a house with staff?

It's OK if you don't want to say.

Can you tell me about your disability benefits?

Prompts: Which benefits do you get? It's OK if you don't know.

What is it like getting benefits?

Prompts: Have you had letters about your benefits? Can you give me an example of a recent time you got a letter about your benefits?

What is it like getting letters about benefits?

Prompts: Do you have to go to the Job Centre? What's that like?

When was the last time you went to the Job Centre? Can you tell me about that?

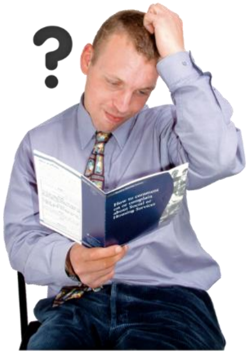
Prompts: Have you had to be re-assessed?

What is it like being told you have to be re-assessed?

How did the assessment go?

Did it make sense?

Do you worry that you might be re-assessed again? How would that be for you?



Prompts: Do you find it easy or hard (or something else) to be using benefits?

Does someone help you with your benefits?

Who are they? Can you tell me about a time when they helped you with your benefits?

Does getting benefits affect what you are able to do every day? Can you give me an example? Does getting benefits help you do to do more? Does getting benefits make you do less?

Does getting benefits affect your physical health?

Prompt: Does getting benefits make you feel ill? Does getting benefits make you feel well? Does getting benefits make you go to the doctor less? Does getting benefits make you go to the doctor more? Does getting benefits affect your body? Can you give me an example?

Does getting benefits affect your mental health?

Prompts: Does getting benefits affect your mood? Does it make you feel happy? Does it make you feel sad? Does it make you feel angry? Does it make you feel safe? Does it make you feel scared? Can you give me an example?

Does getting benefits affect how you get on with your friends? Does getting benefits affect how you get on with your family?

Prompts: Can you give me an example?

Does getting benefits affect your family/carer? Does helping you with your benefits affect your family/carer?

Prompts: Can you give me an example? Is it easy for them to help you? Is it hard for them to help you?

Does getting benefits affect what you do in your community/local area?

Prompts: Does it affect your every day life? Does it affect how much you go out? Do you got out more/less because of getting benefits? Does it affect what you do every day? Can you give me an example?

Do you work? Do you volunteer?

Does getting benefits affect whether you volunteer? Does getting benefits affect whether you have a paid job?

Prompt: Can you give me an example? Is it easier/harder to work because of getting benefits?

Do you study/go to college?

Does getting benefits affect whether you study?

Prompts: Does getting benefits affect whether you go to college? Can you give me an example?

Does getting benefits affect how much you see friends?

Prompt: Can you give me an example? Do you see friends more/less because of getting benefits?

Do you have any hobbies? Can you give me an example of a hobby

Does getting benefits affect whether you do hobbies? Can you tell me about a time when getting benefits stopped you doing a hobby? Can you tell me about a time when benefits helped you to do a hobby?

Does getting benefits affect how you see yourself?

Prompts: Does getting benefits affect your identity? Does it make you feel good about yourself? Does it make you feel bad about yourself?

Prompts: Does getting benefits affect anything else? Can you tell me more about that? Can you tell me about a time when that happened?

Is there anything bad about getting benefits?

Is there anything good about getting benefits?

Was getting benefits like this before? Was getting benefits different before?

Prompts: Is getting benefits harder now? Is getting benefits easier now?

Does getting benefits change what other people think about you?

Prompts: Does getting benefits change how your friends feel about you? Does getting benefits change how your family feel about you? Does getting benefits change how strangers see you? Can you give me an example?

Prompts: Do you hear people talk about benefits on the TV? Do you read about people getting benefits in the newspaper? Do you hear people talk about benefits on the radio? Do you see people talking about benefits on Facebook?

Prompts: How does that make you feel? Can you tell me about a time that happened?

What do other people think about people who use benefits?

Is there anything else you want to tell me about having a learning disability and getting benefits? Is there anything else you would like me to ask you about?

What is the most important thing we talked about today?

How was the interview? How do you feel now? Do you want to ask me a question?

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Appendix X: Interview schedule for families or carers of PWLD

Can you tell me a bit about yourself and your family member/the person you care for?

Why did you say yes to this research?

Can you tell me about the benefits your family member/the person you care for receives? Which benefits do they get? How do you support them with claiming those benefits? What is it like for you to support them with this? What do you notice about what it is like for them to claim benefits?

Have they had to be re-assessed for their benefits? What did you notice about how that was for them? Did you observe whether they understood everything? How was that for you? Did you understand everything? What was it like getting letters for this?

Did they go to the Job Centre? Did you go with them? How was that?

Have you observed whether they find it easy/hard claiming benefits? Do you find it easy/hard to support them?

Do you think that claiming benefits affect what they're able to do every day? How have you noticed that? Have you observed if they do anything more/less as a result of claiming benefits?

Have you observed if claiming benefits affects their physical health? Can you tell me more about that?

Have you observed if claiming benefits affects their mental health? Can you tell me more about that? Does it impact on your mental health?

Have you observed whether claiming benefits impacts on their relationships? With friends? Family? Partners? Does it affect how much they see friends/partners?

Does claiming benefits/supporting them with benefits affect your relationship with them? Does it affect your ability to support/care for them? Can you tell me more about that?

Have you observed if claiming benefits impacts on their ability to participate in their community?

Have you observed if claiming benefits impacts on whether they work/volunteer/study?

Have you observed if claiming benefits affects whether they do any hobbies?

Do you think claiming benefits affects how they see themselves? How have you observed that? Have you seen anything to suggest that it impacts on their identity? Can you tell me more about that?

Have you observed any good/bad things about claiming benefits for them? What do you think is good about claiming benefits? What do you think is bad about claiming benefits? How have you observed that?

Has claiming benefits always been like this? Has it changed over time? Does it get easier/more difficult? Can you tell me more about that?

Have you observed whether claiming benefits change how other people see them? Their friends/family/strangers/society/the media? Can you tell me more about that?

Is there anything else that claiming benefits impacts for you or that you have observe to impacts for them? Is there anything else you want to tell me about what you have observed about having a learning disability/supporting someone with a learning disability and claiming benefits? Is there anything you wish I'd asked about?

What is the most important thing you've told me today?

How was taking part in this interview? Any questions?

Appendix XI: Excerpt from an open-coded transcript

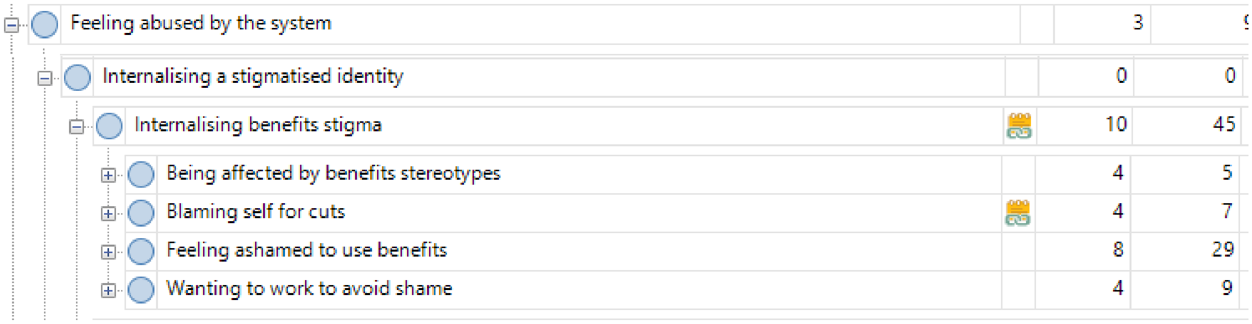
This has been removed from the electronic copy

Appendix XII: nVivo coding examples

Subcategory – Being in an insecure system

Navigating the circles and roundabouts		0	0
Being in an insecure system		1	2
And they just cut my money like that		9	20
Cuts to the system ##WIDER CUTS		1	2
Having a long, difficult journey getting benefits reinstated		9	31
Having benefits cut		10	26
Third sector funding issues ##WIDERCUTS		1	1
Getting less social care support ## WIDER CUTS		4	5
Living with uncertainty and unpredictability		0	0
Being in a changing system		15	61
circles and roundabouts		3	9
Going backwards and forwards		3	10
it can still sometimes feel like walking a tightrope as to whether you can keep them		10	28
it's pot luck ... who you get		7	12
Living with uncertainty		10	14
So it can put a lot – can put a lot of stumbling blocks in your way, benefits sometimes.		3	5
Up and down process		5	15

Subcategory – Internalising benefits stigma



Feeling abused by the system		3	9
Internalising a stigmatised identity		0	0
Internalising benefits stigma	🔗	10	45
Being affected by benefits stereotypes		4	5
Blaming self for cuts	🔗	4	7
Feeling ashamed to use benefits		8	29
Wanting to work to avoid shame		4	9

Appendix XIII: Examples of memos during theoretical coding

21.04.2021. Open code: Blaming self for cuts, I wonder whether this code relates to the broader concept (or potential broader concept) of being consumed by the system where it becomes to the extent that you're internalising things or whether it is more to do with being abused by the system? It’s interesting how there seems to be lots of *messiness* or overlap between the concepts that are emerging, it makes me think of the system itself which feels messy and sticky and unclear.

25.04.2021. I think I'm going to recode this from "not wanting disability" to "System reinforcing stigmatised identity" because X seems to be carrying shame and stigma around his disability and here he seems to suggest that using benefits and all that entails reminds him of this stigmatised identity, brings it into light and reinforces it. It makes me think of his emphasis on achieving and independence and work and the loss he must feel as a result of this childhood accident. Would this loss be as pronounced if stigma was not prevalent and he had more opportunities? There might still be the loss of a particular life but perhaps X wouldn't feel this as keenly if it was easier for him to have his own flat and access education and if he didn't have to worry about surviving on benefits.

29.04.2021. I’m wondering about the idea of “denial”. X seems to be active in his use of denial as a strategy but I think I’m seeing evidence of more subtle denial elsewhere and I’m not sure where it fits. I’ve coded “Not receiving letters” for someone but it’s quite interesting because there is a subtle indication that he probably *is* getting letters, but he is avoiding *discovering* these letters, which seems a denial of the uncertainty of the system through avoiding things that might shake the belief that life is stable now. Actually, X doesn't know what those letters say, but he still struggles with debt and repayments on a lesser level and he has no control over what happens with his benefits which I imagine makes him very anxious and angry. But X chooses to say that things are fine and deny (this is *my* perception of what is happening) this because I imagine it's quite unbearable for him to envisage being faced with thousands of pounds of debt again and being faced with the desperation and suicidality he felt back then. When you have so little control over your life, why wouldn't you deny that?

10.05.2021. I wonder whether 'Being left in the dark' is a link between the inaccessibility of the system and the insecurity of the system? Both of these things result in people feeling confused, not knowing what is going on and not having had anything explained. It feels like a kind of neglect that all of these things happen and then people aren't even being told what's going on. It makes me wonder about the sense of 'Feeling abused by the system' which I'd imagined as a subcategory under the insecurity but maybe this idea of an abusive system is bigger than that.

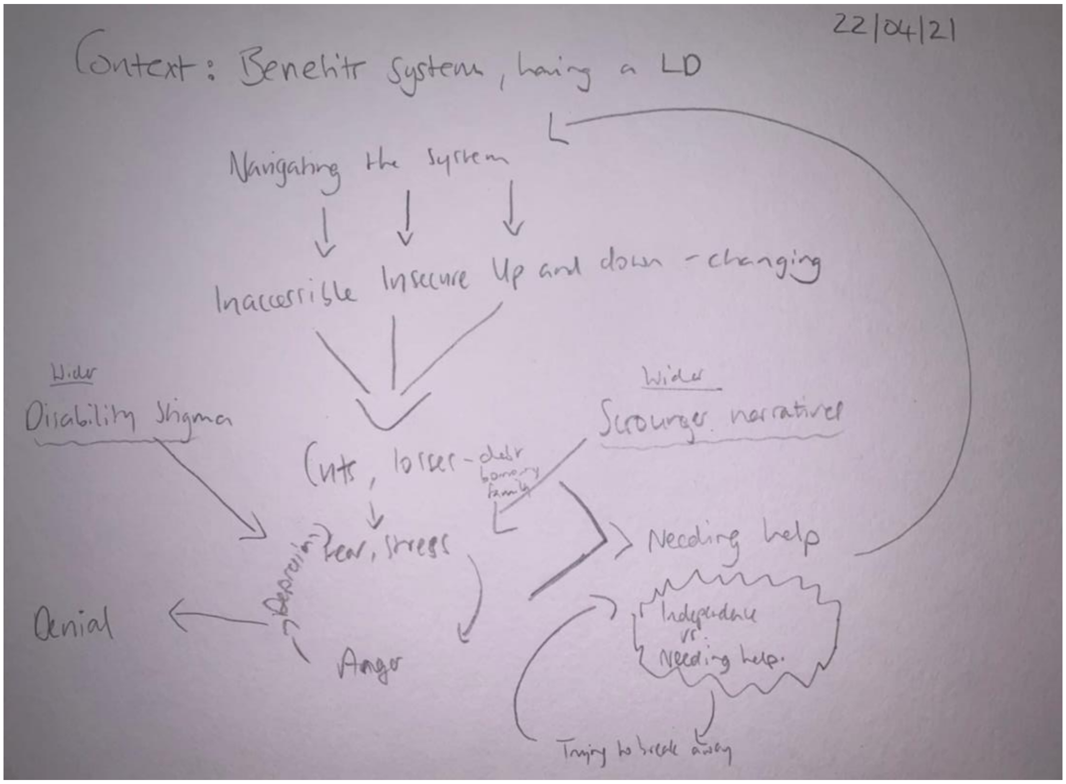
20.05.2021. PWLD are in the position where if they want to move closer towards independence in terms of living and work, they are always faced with the fear of reduction of support and benefits. I wonder how many people are additionally disabled by this catch-22? I am starting to recognise that the fact that people *need help* but *want independence* are possibly closely tied together whereas previously I hadn’t seen this. There is an incongruence at benefits being something that enables independence (financially – or not really for most of the participants I spoke to) but if you can't fit into the system or be understood by the system then your dependency is highlighted and pulled on. But not just pulled on, pulled back? It makes you dependent and reduces independence? POWER. It feels like power is at play, PWLD are being made to feel powerless. Or having their powerlessness exposed? It also makes me think of the implicit threat in “it’s good when you get them”. Yes, benefits could and can enrich someone’s life and make them more independent **but** this is not the current system according to my participants. I am reminded of reading something about ‘poverty traps’ and welfare. Is this a different kind of trap, keeping PWLD dependent and powerless?

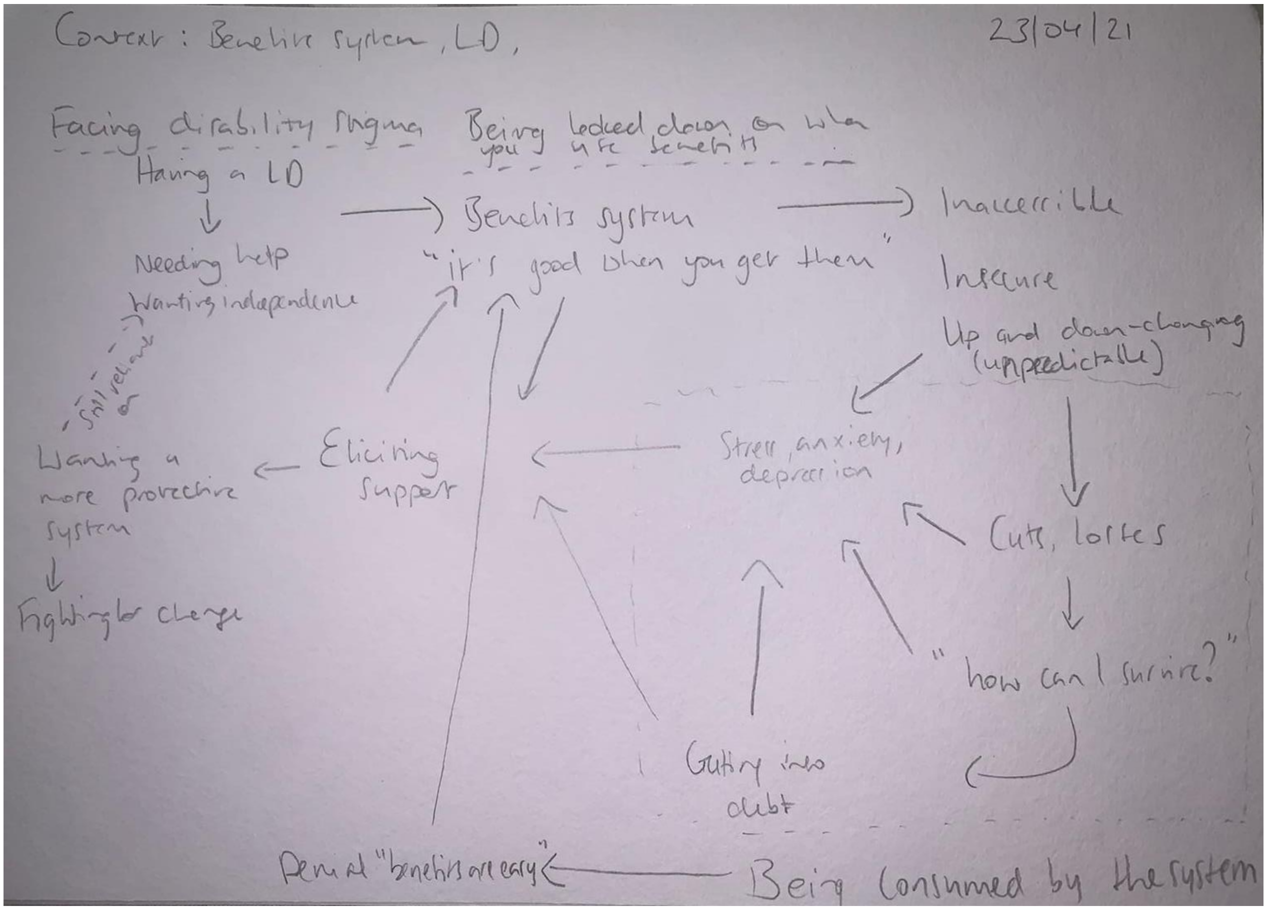
01.06.2021. I’m back to “Feeling abused by the system”. I’m seeing this emerge as a bigger concept and recognising how things I have previously put elsewhere may fit better under the abuse of the system. For example, I had “how can I survive?” under “Being consumed by the system”. “Internalising a stigmatised identity” was not a category, rather the codes which make up the sub-categories were all held within “Being stigmatised and excluded in society”. I had failed to see the more insidious self-stigma that was occurring *within* the system, rather than outside of it. For me, these fit with an abusive system as it conjures to my mind financial abuse/deprivation and how abuse may leave you blaming yourself or *internalising* the abuse or, in this case, the stigma.

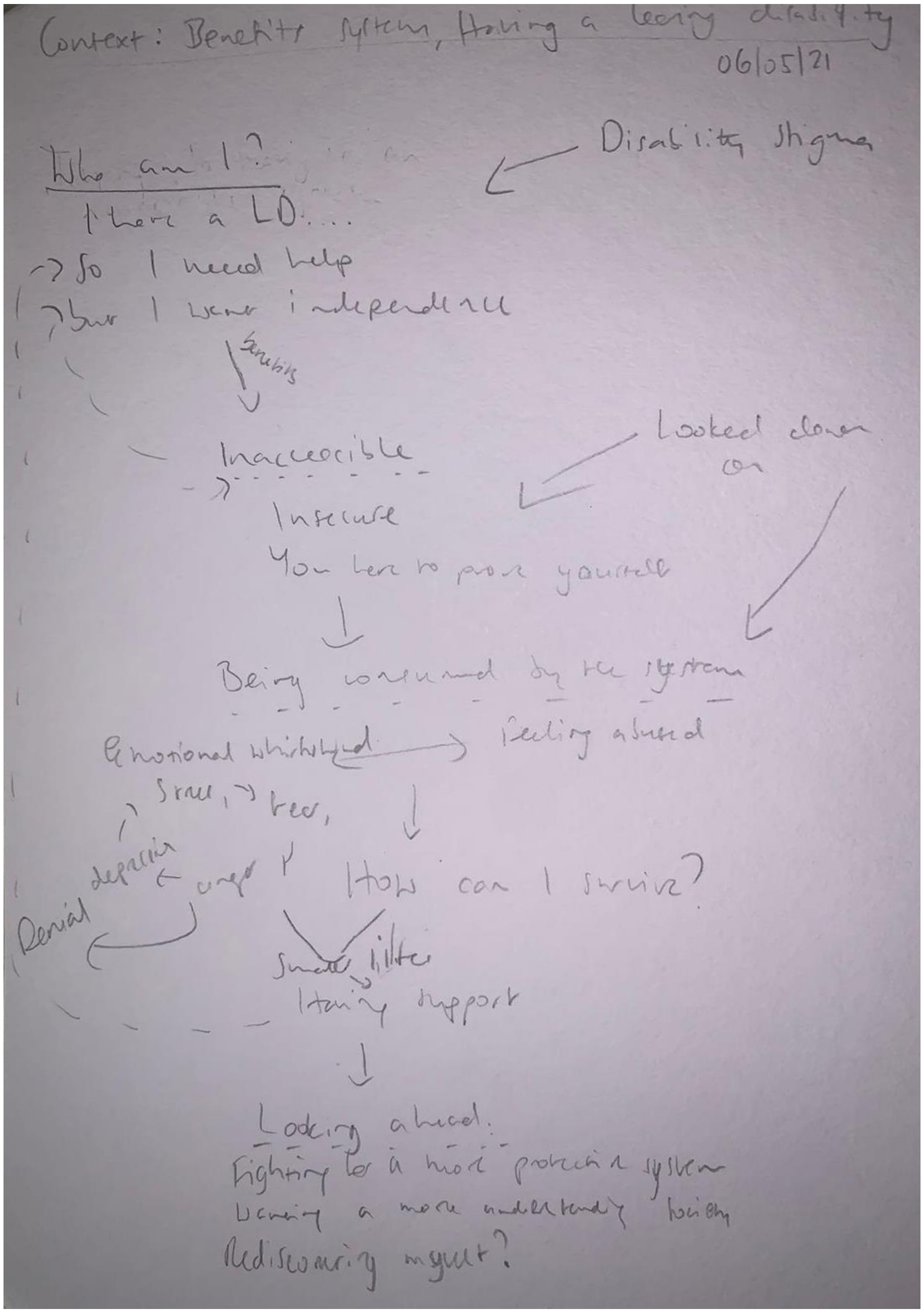
11.06.2021. I’ve named my final concept as “Living within the system” but it doesn’t seem right to me. The *living within* aspect is supposed to account for the fact that they are stuck in “The dependence trap”, it is not linear, they are not moving away from it and while it is a concept of outcomes, it doesn’t necessarily change much. However, *living within* isn’t capturing it either. There are three parts to this, there is the more negative outcome, “being consumed”, and the more positive “survival”. There is also the role of support which acts as a buffer for some people. Part of me wants to call it all “Surviving the system” but there is something very active and optimistic to me about survival and I’m not sure all of the categories capture that sense of finding a way forwards that feels beneficial or hopeful. I’m struck by the idea of the abusive system again and whether responses would better capture that these experiences are ways that people have reacted to/negotiated a life in the system? “Responding to the system” may broadly capture them all together and implicitly follow on from the idea of responding to abuse/trauma. I’m not fully happy with this name either but I wonder if it is the best fit? It makes me reflect on an earlier memo where I stated: “This idea of a strong response just makes me think of traumatic responses and I wonder about the traumatising nature of these assessments. They are not just simple conversations where someone gets a sense of the help you need, they seem to be grueling…” Maybe responding is an apt fit for these experiences.

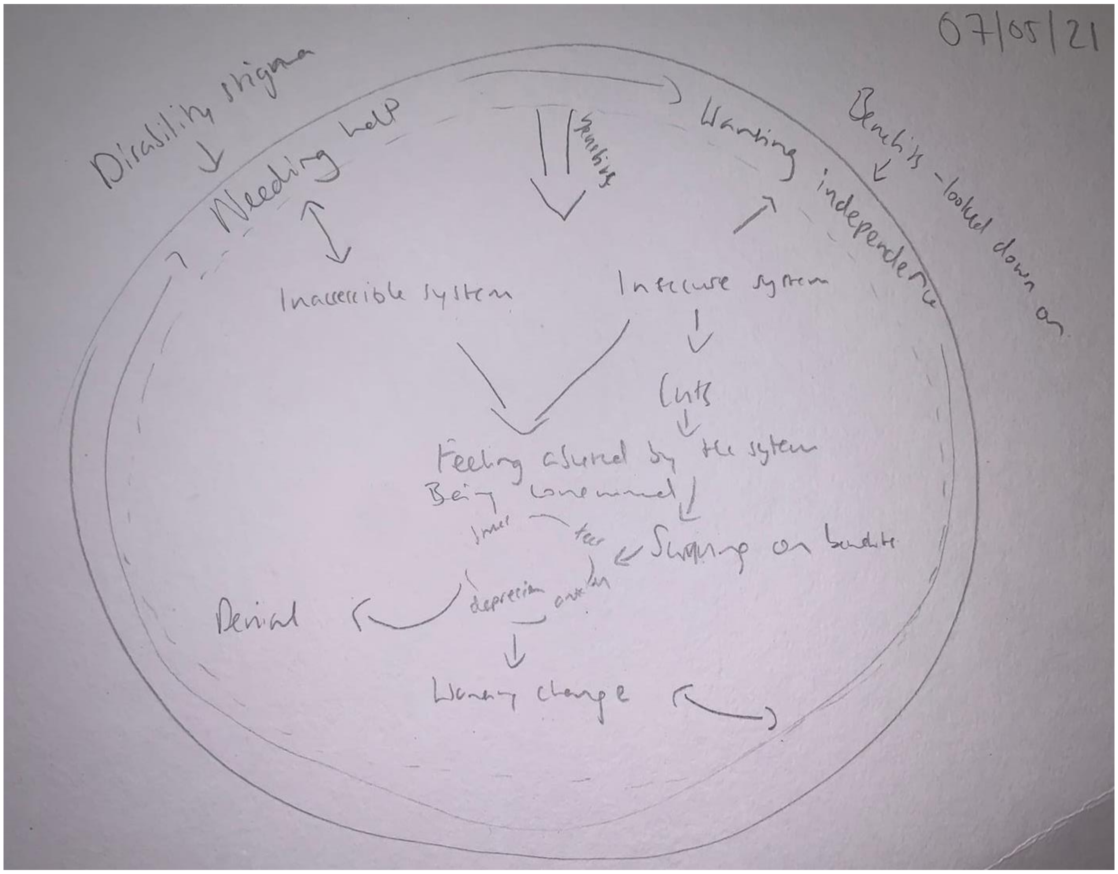
Appendix XIV: Examples of theory development through diagramming

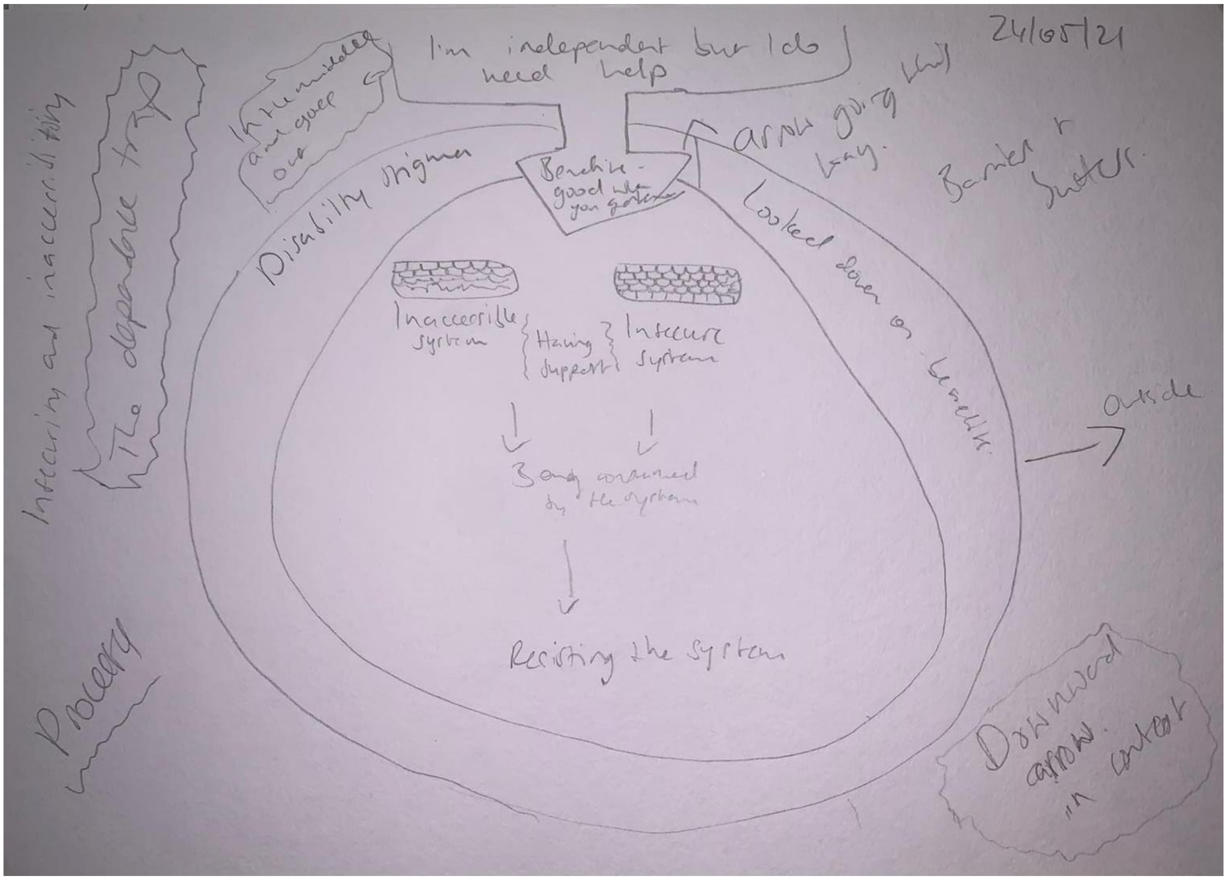
Diagramming used to develop the theory, from initial line drawings connecting codes to more coherent models.

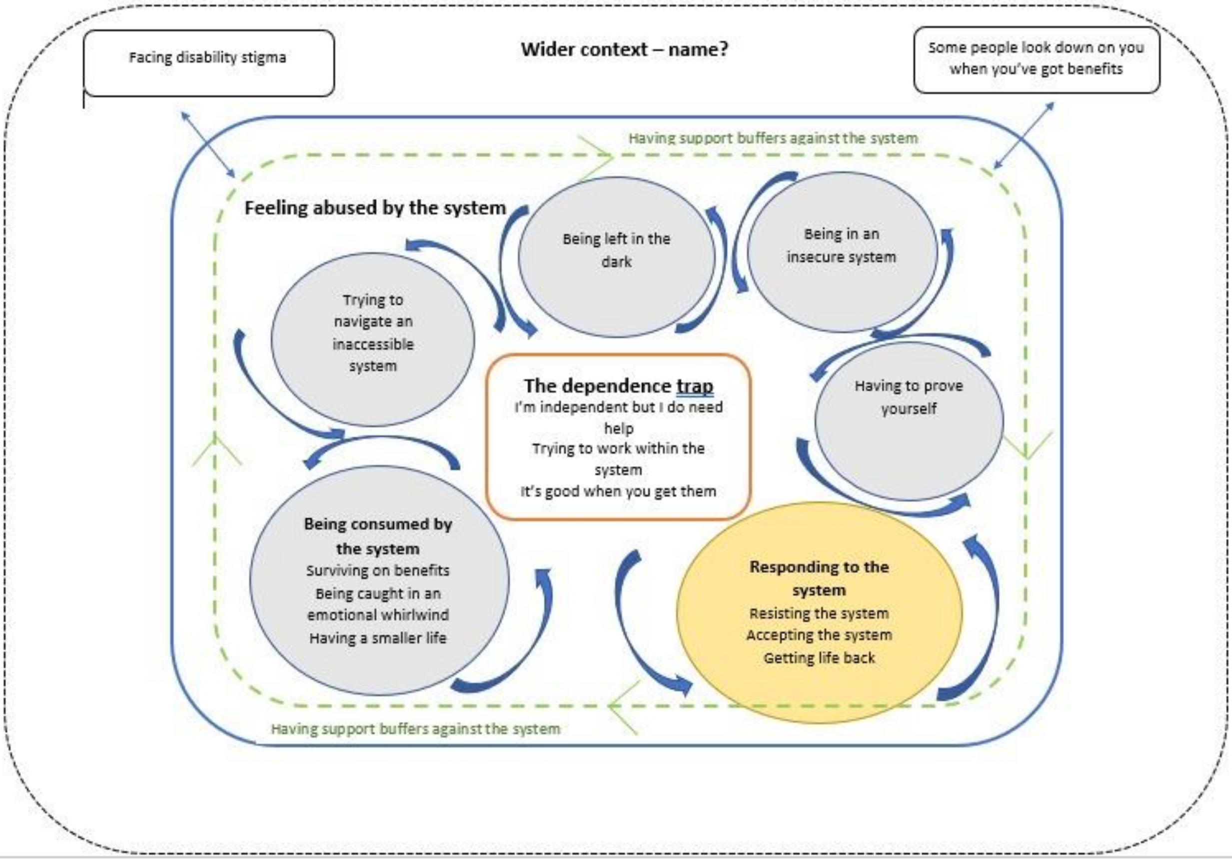



Context : Benefits system, LD,
23/04/21
Facing disability stigma
Being looked down on when you are on benefits
Having a LD
Needing help
Wanting independence
Still reliant or
Benefits system
"it's good when you get them"
Inaccessible
Insecure
Up and down-changing (unpredictable)
Stress, anxiety, depression
Eliciting support
Wanting a more protective system
Fighting for change
Cuts, losses
"how can I survive?"
Getting into debt
Denial "benefits are easy"
Being consumed by the system


Context: Benefits system, Having a learning disability
06/05/21
Who am I?
I have a LD....
-> So I need help
-> But I want independence
Sensitivity
Disability Stigma
Inaccessible
Insecure
You have to prove yourself
Looked down on
Being consumed by the system
Emotional whirlwind
Feeling abused
Stress, -> fear,
depression
anger
Denial
How can I survive?
Small little
Having support
Looking ahead:
Fighting for a more protective system
Wanting a more understanding society
Rediscovering myself?


07/05/21
Disability stigma
Needing help
Sanctions
Wanting independence
Benefits - looked down on
Inaccessible system
Insecure system
Cuts
Feeling abused by the system
Being consumed
shame
fear
anxiety
depression
Surviving on benefits
Denial
Wanting change


24/05/21
I'm independent but I do need help
Intermediate and goes out
The dependence trap
Insecurity and inaccessibility
Disability stigma
Benefits - good what you got
arrow going that way.
Barriers & Shutters.
Looked down on benefits
Inaccessible system
Having support
Insecure system
Being contained by the system
Resisting the system
Outside
Poverty
Downward arrow in context


Facing disability stigma
Wider context – name?
Some people look down on you when you've got benefits
Having support buffers against the system
Feeling abused by the system
Being left in the dark
Being in an insecure system
Trying to navigate an inaccessible system
Having to prove yourself
The dependence trap
I'm independent but I do need help
Trying to work within the system
It's good when you get them
Being consumed by the system
Surviving on benefits
Being caught in an emotional whirlwind
Having a smaller life
Responding to the system
Resisting the system
Accepting the system
Getting life back
Having support buffers against the system

Appendix XV: Abridged reflective diary

November 2019

My ethics application came back fully approved! I feel so relieved considering how it took longer than I was expecting to get my research proposal approved when I first submitted it. I have that nervous excitement about getting started with my interviews. I care about doing this well and creating a space where people with learning disabilities' voices might be elevated and heard. This feels even more important as I'm on my learning disability placement at the moment. I'm aware of the struggle for many people with learning disabilities to have their wishes and difficulties understood or acknowledged by some of the people closest to them who know them well and have the best intentions for them. If their support network can get it wrong without meaning to, how can I be sure that I'm creating a helpful, validating space? I'm hoping that my experiences on placement, supervision and using this diary can help me keep my values fully in line with the interview process so that I don't replicate some of these interactions.

I was involved in an eligibility assessment on placement today for a man in his 40s who had gone by in mainstream services until this point with the help and support of his family. He was accepted into the service and it seemed clear to me and my colleague after meeting him and going through the assessment that he had a learning disability. He spoke during the assessment about being reassessed for his benefits and having these stopped. He couldn't understand what had happened and found the whole process confusing. His brother tried to help him but was finding it difficult too. I'm reminded by how difficult it can be for anyone to understand some of these processes, but how bewildering it can be to just one day be told your benefits have been stopped when you've always had them and never had to deal with that. I really feel like this will be a valuable piece of work to do, to give people to space to tell these stories. Even more so because it the context of our assessment, we didn’t get to listen to that story fully. I wonder how many people mention their difficulties with benefits in services but get told it’s not the right person to speak to or get redirected elsewhere without much support.

December 2019

I went to an event today to begin recruiting for my project the morning after the General Election 2019. I was anticipating there to be so much anger and disappointment, which was how I was feeling, and while that was definitely around, I felt struck by how optimistic and determined people can be despite the odds not being in their favour and having multiple disadvantages. It reminded me that while I’m expecting to hear stories of difficulty and struggle, I am also likely to hear stories of community action, strength and resourcefulness by virtue of where I am recruiting from.

January 2020

I have just had my first interview. It was nerve wracking! It went well, although I think I need to work more on being as adaptable as possible in the moment. I felt so sad hearing that X couldn’t attend his dad’s funeral due to his financial difficulties. I wondered how many other people have had losses like this made worse by their own situation. But I also reminded myself about how enabling the welfare system can be when it works well. X appreciated the money he got and what it allowed him to do, but he struggles with the confusion and anxiety that it provokes when it changes constantly, and he doesn’t have enough money to plan a holiday. Even though I felt sad hearing about some of the difficult things seemingly made worse by struggling to get enough benefits to get by comfortably, I did feel hopeful that maybe things can change, maybe these stories can make people listen to what needs to change.

February 2020

My interview style is slightly frustrating me transcribing! I feel like I am a bit overly focused on zooming in on participants’ moods and internals experience which may be reflective of my role as a therapist most days in the week. This might be more difficult for someone with LD to articulate and I might need to be more conscious about adapting to explore more what is behaviourally or environmentally different when times are hard.

March 2020

Coronavirus has suddenly become very much a reality in the UK. I spent my last week on my learning disability placement watching the service go into disarray in one sense, with appointments cancelled and people feeling scared, and also watching a huge amount of planning what would happen. I had two interviews earlier this month and coronavirus was on the minds of my interviewees who were also feeling anxious but I don’t think any of us expected this to happen. We are getting emails from the uni about what we can do in terms of research and the general sense is that we need to move to interviewing remotely where possible. I’m going to apply for an amendment, but I wonder how this is going to impact my research where people with learning disabilities generally have less access to technology and the internet and whether benefits will even be such a concern for them when all of this happening! I also can’t help but think of how frightening and confusing it must be for people with learning disabilities right now – I certainly feel that way myself.

May 2020

Coding is definitely bringing out strong reactions in me to the data. I am struck by a sense of punishment vs protection in the system. The welfare system is set up to be something supportive, protective, that helps people in need, but my participants are describing a system that seems to actively punish vulnerable people instead. There is something very wholesome and hopeful about one of my participant’s view of how society should work, but maybe the punitive view is the correct one? I wonder how much these interviews add to my growing cynicism at the state of the welfare system, at the government. I need to remind myself that there is hope, this participant holds hope, people who are offering up their time and experiences for interviews hold hope and I need to try and carry that hope with them.

January 2021

Today in an interview, a participant spoke about the word ‘assessment’ having negative connotations. I was surprised to hear her say this, maybe because in my role, we also regularly talk about assessment but of course assessment is something that happens in school, something that happens when you receive a diagnosis of a LD, something she may have experienced through the care system as her son was removed for her, so, of course, even this word can be enough to reinforce the stigma she experiences for having a LD. It makes me think of how I maybe sometimes feel different (morally 'better'?) than those who are part of the DWP but of course, the NHS and psychology can be damaging to PWLD too and historically have been. Assessment is our bag after all! It makes me think of what may have been held back in my interviews, what may have felt unsafe to say. I hope I have created a facilitating, safe environment for participants but of course they may have, understandably, complex relationships to help.

February 2021

The benefits system is just one part of a range of institutional issues which exploit and take advantage of PWLD. What must it be like to face constant threats like this? And again, what happens when PWLD don't have families or staff to support them? What do we do as a profession to help?

March 2021

I feel so angry! How is it that, for participants, if you have someone to go to the assessment with you, you get the benefits, if you go alone, you get denied? How many people does this happen to? How many people never manage to get benefits back because of this? How is this just?

April 2021

I just had a really useful Zoom meeting with a researcher colleague who is also doing grounded theory where we were beginning to think about theoretical memos and pulling our models together. We also thought about how much we’ve missed over the last year and a bit though as our planned monthly grounded theory workshops have suffered as people have had a variety of delays with their projects and we’ve not been able to meet at uni in all that time. Instead, we’ve had much smaller meetings, less frequently with those who are at a similar level of progress as ourselves. While these have been invaluable in my grounded theory journey, I do feel sad for not having the opportunity to be able to do these in person and in larger groups where we might have been able to benefit from a wider range of perspectives. I imagine it might have meant a much richer experience, however, I’m grateful that we’ve managed to continue this peer researcher support despite the challenges.

June 2021

Model development feels like a challenge. I want to do justice to what my participants have told me. Their experiences are nuanced, and perhaps I won’t pick up every thread exactly as they said it but I’m reminded that the model is a *co-construction*, and that that I will undoubtedly privilege and respond to certain aspects of the data, but I have been using supervision and memoing and journaling to monitor this and raise my awareness of my perspective. I am due to meet with my focus group shortly and I really welcome the opportunity to see if this resonates with others. Due to time constraints, I've felt sad not to be able to complete participant validation at this time but this feels like a valuable step for me to feel that the model is useful.

Appendix XVI: Ethics approval

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Appendix XVII: Consent forms

Consent form for individual interviews for PWLD

Canterbury
Christ Church
University

Consent Form:

Finding out about getting benefits

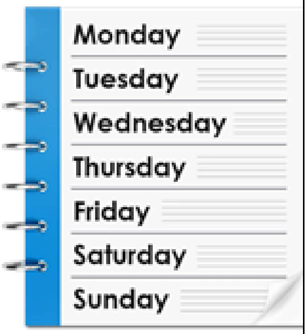
My name is ……………………………………………………..

Please circle			
	**I have read the information sheet.**	**YES** 	**NO** 
	**I have met with Emer to talk about the project.**	**YES** 	**NO** 

	**I have been able to ask questions about the project. I know what I will be asked to do to help find out about what it is like to get benefits when you have a learning disability.**	**YES** 	**NO** 
	**I know that I can say "no" to taking part at any time in the project.**	**YES** 	**NO** 
	**I know that this means I can stop at any time in the interview. I can also call Emer at any time to tell her I don't want to take**	**YES** 	**NO** 

	part any more.		
	**I know that information about me will be anonymous – this means that Emer will not use my name. However, I know that if Emer is worried about me or someone else she might need to talk to someone else.**	**YES** 	**NO** 
	**I know that Emer will use a voice recorder to record my interview.**	**YES** 	**NO** 

 	I know that Emer might contact my friend/family. I say "yes" to this.	**YES** 	**NO** 
	I know that Emer will type things up. They might be things that I saw, or questionnaires that I answer. I know that Emer will not use my real name. I know that no one will be able to know it is about me.	**YES** 	**NO** 
 	I know that Emer will use the interviews to write a report. I know that the report might be published.	**YES** 	**NO** 

	**I know that Emer will ask me to look at the report with her. I know that she will ask me if the report sounds like what we spoke about. I know that I can say "no" to this.**	**YES** 	**NO** 
	**I know that for two weeks after my interview, I can ask Emer not to write about the things I talked about with her.**	**YES** 	**NO** 
	**I know how to contact Emer, Tamara, Annabel or Jessica.**	**YES** 	**NO** 

	**I know that Emer will ask me if I would like her to get in touch to explain more about what we have found out.**	**YES** 	**NO** 
	**I say "yes" to taking part in the project.**	**YES** 	**NO** 

Signed here (participant): …………………………………………

Signed by researcher: ……………………………………………….

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Consent form for families and carers

Canterbury Christ Church University

Finding out about getting benefits: How do people with learning disabilities navigate the benefits system?

My name is ……………………………………………………..

Please circle		
I have read and understood the information sheet.	**YES**	**NO**
I have met with Emer to talk about the project.	**YES**	**NO**
I have been able to ask questions about the project. I know what I will be asked to do to help find out about what it is like to support someone with a learning disability who gets benefits.	**YES**	**NO**
I know that I do not have to consent to taking part at any time in the project.	**YES**	**NO**
I know that this means I can stop at any time in the interview. I can also	**YES**	**NO**

call Emer at any time to tell her I don't want to take part any more.		
I know that information about me will be anonymised. However, I know that if Emer is worried about me or someone else she might need to talk to someone else.	**YES**	**NO**
I know that Emer will record my interview.	**YES**	**NO**
I know that Emer will type up the interview. I know that all names and information about me and the person I support with be anonymous.	**YES**	**NO**
I know that Emer will use the interviews to write a report. I know that the report might be published. I know that what I said might be in the report – but that it will be confidential.	**YES**	**NO**
I know that Emer will ask me to look at the report with her. I know that she will ask me if the report sounds like what we spoke about. I know do	**YES**	**NO**

not have to consent to this.		
I know that within two weeks after my interview, I can ask Emer not to write about the things I talked about with her.	**YES**	**NO**
I know how to contact Emer, Julie, Annabel or Jessica.	**YES**	**NO**
I know that Emer will ask me if I would like her to get in touch to explain more about what we have found out.	**YES**	**NO**
I consent to taking part in the project.	**YES**	**NO**

Signed here (participant): ………………………………………………

Signed by researcher: …………………………………………………

Consent form for focus group

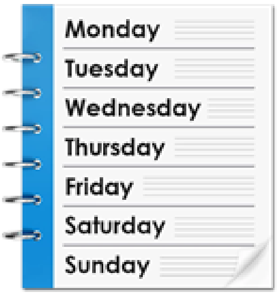
Consent Form:
Finding out about getting benefits

My name is …………………………………………………..

Please circle			
	**I have read the information sheet.**	**YES** 	**NO** 
	**I have met with Emer to talk about the project.**	**YES** 	**NO** 
	**I have been able to ask questions about the project. I know what I will be asked to do to help find out about what it is like to get benefits when you have a**	**YES** 	**NO** 

	learning disability.		
	**I know that I can say "no" to taking part at any time in the project.**	**YES** 	**NO** 
	**I know that this means I can stop at any time in the group interview. I can also call Emer at any time to tell her I don't want to take part any more.**	**YES** 	**NO** 
	**I know that information about me will be anonymous – this means that Emer will not use my name. However, I know that if Emer is worried about me or someone else she might need to talk to someone else.**	**YES** 	**NO** 

	**I know that Emer will use a voice recorder to record the group interview.**	**YES** 	**NO** 
	**I know that Emer will type things up. They might be things that I say, or questionnaires that I answer. I know that Emer will not use my real name. I know that no one will be able to know it is about me.**	**YES** 	**NO** 
	**I know that Emer will use the group interview to write a report. I know that the report might be published.**	**YES** 	**NO** 
	I know that Emer will ask me to look at the report with her. I know		

	that she will ask me if the report sounds like what we spoke about. I know that I can say "no" to this.	YES 	NO 
	I know that for two weeks after the group interview, I can ask Emer not to write about the things I talked about with her.	YES 	NO 
	I know how to contact Emer, Tamara, Annabel or Jessica.	YES 	NO 
	I know that Emer will ask me if I would like her to get in touch to explain more about what we have found out.	YES 	NO 

	**I say "yes" to taking part in the project.**	**YES** 	**NO** 

Signed here (participant): ………………………………………………………

Signed by researcher:………………………………………………………

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Appendix XVIII: Record sheet for assessing consent

Participant ID:...xxxx..........Record for assessing consent

Date: xxxx First information meeting

What are the signs that the person has understood information?

Signs that the person is listening / has understood	**Was this happening (please tick)**	**Details**
Does the person seem engaged? Does their body language / eye contact suggest they are interested?		
Is the person elaborating verbally – for example, comments that they		

would be interested in taking part?		
Any non-verbal signs they are interested – for example, nodding?		

What are the signs that the person has not understood the information?

Signs that the person is not listening / has not understood	**Was this happening (please tick)**	**Details**
Is the person unengaged with the researcher or conversation?		
Are there concerns that the person is acquiescing		

with the researcher? Do they agree to things without clearly understanding?		
Do they appear to be ambivalent or disinterested? Any negative non-verbal signs, such as facial expressions?		

Appendix XIX: Screening tool to assess distress

Record for Risk Assessing Appropriateness for Inclusion in the Study

Non-verbal indicators of distress to be assessed alongside these questions. Understanding of questions to be assessed. Consult with any trusted persons who may be with the participant.

Questions:

Have you had a meeting or assessment about benefits in the last 6 months that has made you very upset? Have you had a loss of benefits in the last 6 months that has made you very upset?

(If yes continue to the next questions. If yes to the following, the person is not eligible for the study)

Does thinking about the meeting/assessment/loss ever make you think about taking your own life?

Does thinking about the meeting/assessment/loss ever make you think about hurting yourself?

Does thinking about the meeting/assessment/loss ever make you think about hurting other people?

Does thinking about the meeting/assessment/loss make you feel really sad? Prompt: Does it make you stop wanting to see people, do things, or leave the house?

Appendix XX: Signposting information

Who to Contact if You Are Worried About Your Mental Health

	Sometimes talking about difficult things can make you feel sad or worried. If you want to talk to someone about this, please read this leaflet.
	You can go to you GP. They talk to you about why you are sad or worried. They can help you to get more support.

	You can also phone NHS 111. You can phone them 24 hours a day. You can tell them if you have a learning disability.
	Phone the Samaritans for free in confidence – they will listen to you if you want to talk: 116 123
	You can phone the Crisis Team/Single Point of Access Team xxx. They can help if you

	are sad or worried. You can phone them 24 hours a day. You can tell them if you have a learning disability.
	If you feel like hurting yourself or someone else you can go to the Hospital: Xxx Phone 999 and tell them you think you will hurt yourrself.

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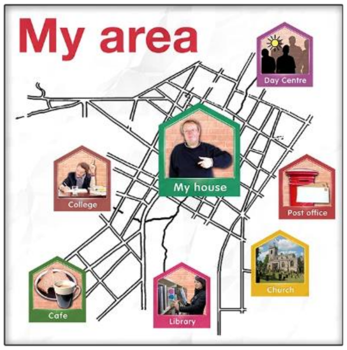
Appendix XXI: Sample visual aids for use in interviews

Example pictures from Photosymbols website which were available to be used in interviews

 Happy	 Community	 Lunch with friend
 Art	 Ill	 Music
 Meet friend	 Work	 Hobbies

Appendix XXII: British Journal of Learning Disabilities' author guidelines

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Appendix XXIII: Summary report for ethics panel

Dear ethics panel members,

Re: "How can I survive?": A grounded theory of people with learning disabilities' experiences of navigating the UK benefits system

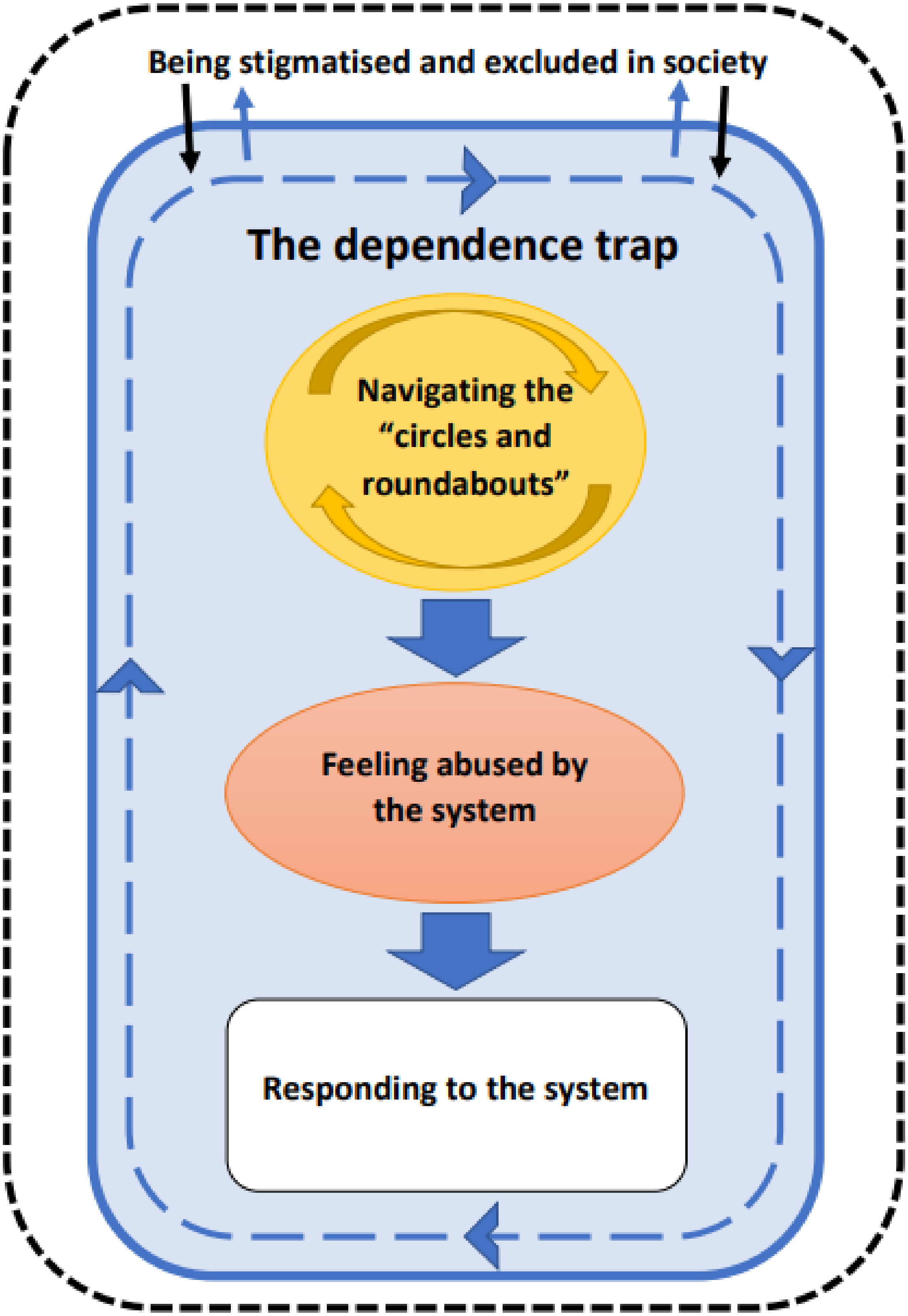
I am writing to inform you that this research study has been completed and submitted in partial fulfilment of the requirements of Canterbury Christ Church University Doctorate in Clinical Psychology. I am enclosing a summary of the project.

The study: This grounded theory sought to illustrate the processes by which people with learning disabilities navigated the UK benefits system, their experiences of this in terms of their lives, wellbeing, personal and social identity. 12 people with learning disabilities and one family carer participated in semi-structured interviews. Five people with learning disabilities partook in a focus group. A constructivist grounded theory methodology was employed to construct a theory grounded in the experiences of participants.

The model summary: Findings were constructed across five concepts: "Being stigmatised and excluded in society", "The dependence trap", "Navigating the 'circles and roundabouts", "Feeling abused by the system" and "Responding to the system". A table outlining each of the categories and subcategories and diagrams of the model and categories are presented below, alongside a brief summary.

Concept	Category	Sub-category
Being stigmatised and excluded in society	Facing disability stigma	Being dehumanised, cast out and treated like dirt
		Feeling excluded from the workforce
		Being denied a life with choices
	“Some people look down on you when you’ve got benefits”	
The dependence trap	“I’m independent but I do need help”	Wanting independence
		Needing help “for lots of things”
		Needing help with benefits
	“It’s good when you get them”	
Navigating the “circles and roundabouts”	Navigating an inaccessible system	“It’s like big and it’s complicated”
		“It’s harder for people with learning disabilities”
	“You have to prove yourself”	“All these dumb questions they have to ask you”
		“They just look at everyone like a number”
	Being left in the dark	“What’s going on?”
		“I didn’t get that at all”
		“that’s what I’ve been told”
	Being in an insecure system	Living with uncertainty and unpredictability
		“And they just cut my money like that”
Feeling abused by the system	Internalising a stigmatised identity	“I don’t think anyone wants to be on benefits for the rest of their life”
		System reinforcing disability stigma
	“How can I survive?”	“Scrounging off family or scrounging off friends”

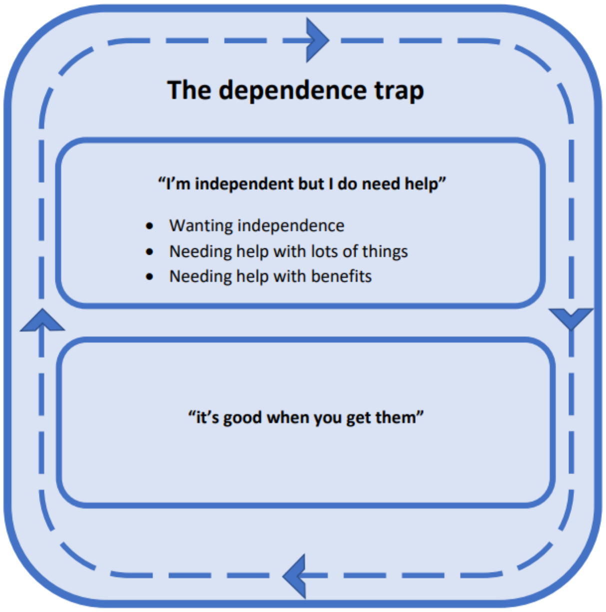
		“No money in the kitty for me”
		Being thrown into debt
		“Scrimping and saving”
	Being caught in an emotional whirlwind	Angry at the system
		“If you got a learning difficulty, you’re frightened, you’re scared”
		Denial
		“Mind state of worries”
		Feeling devastated by the system
	Being mistreated	
Responding to the system	Being consumed by the system	Adopting the scrounger narrative
		Losing a bit of yourself in the process
		Having a smaller life
	Having support buffers against the system	Getting help from family
		Having professional help
		Having supportive friends
		“If they don’t have the support, then what happens?”
	Surviving the system	Eliciting third sector support
		Resisting the system
		Trying to accept the system


Being stigmatised and excluded in society
The dependence trap
Navigating the "circles and roundabouts"
Feeling abused by the system
Responding to the system

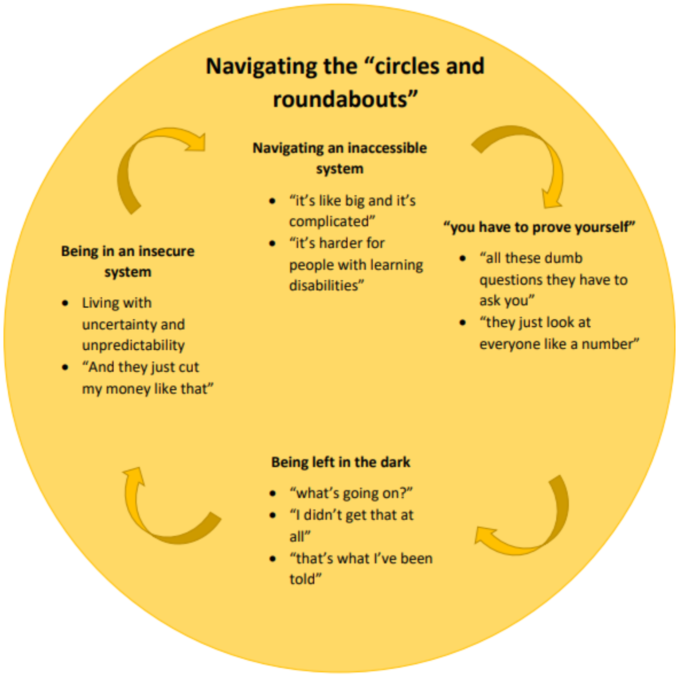
The constructed model identified 15 interacting categories organised across five concepts: “Being stigmatised and excluded in society”, “The dependence trap”, “Navigating the ‘circles and roundabouts”, “Feeling abused by the system” and “Responding to the system”.

Summary: The emergent theory highlighted the embedded, multi-layered nature of participants’ experiences of wider society and the benefits system. Five key interrelated processes were outlined: being stigmatised and excluded in society, becoming caught in the dependence trap, navigating the “circles and roundabouts” of the benefits system, feeling abused and finding ways of responding to the system. It shows that people with learning disabilities had experiences of being excluded and looked down upon in society, setting the context for their navigation of the benefits system. They were attuned to negative discourses around disability and benefits claimants both outside and inside of the system.

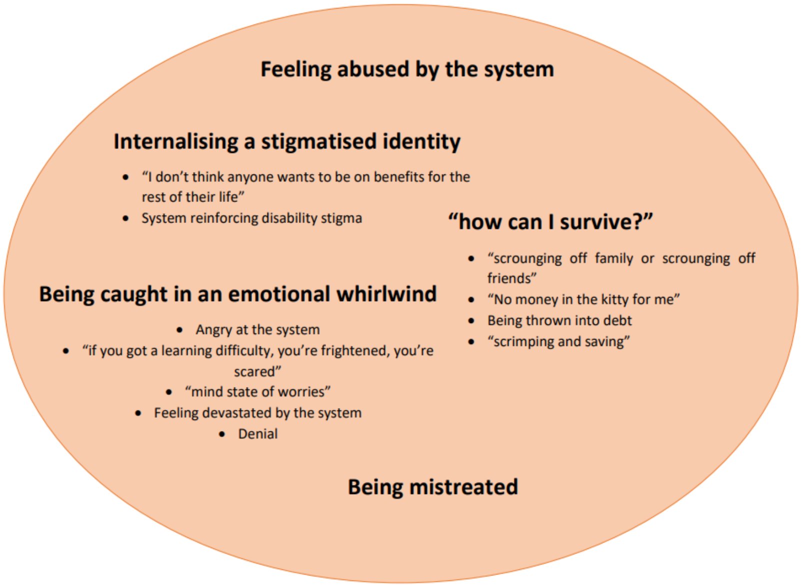
People with learning disabilities typically will have claimed benefits throughout their life, as their disability means that they require additional help and support to develop independence. The support offered through benefits brings opportunity to their lives when the system is working well. However, they can become stuck in a dependence trap when their experiences with the system increase their reliance on the people around them and on the system itself, making independence more difficult to achieve.



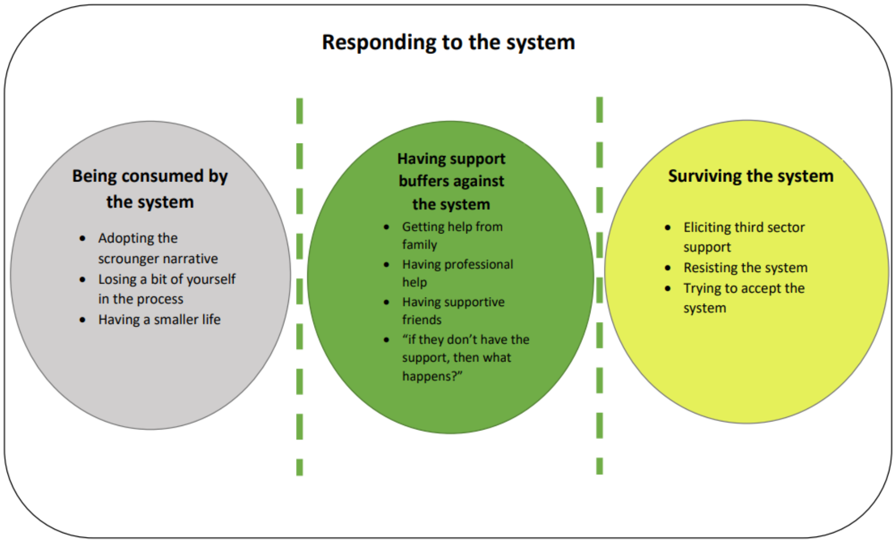
People with learning disabilities encounter multiple obstacles claiming benefits, largely around a complicated and inaccessible system that has become increasingly insecure, requiring multiple reassessments for benefits.



Interacting with the system significantly impacted on their lives, leaving participants feeling abused. Their mistreatment and the negative effect on their mental health, their precarious financial situations and on their identity and self-worth were highlighted.



As participants described being unable to remove themselves from the trap, their responses involved feeling consumed by the system or finding ways to resist the effects of the system. Social and professional support were protective although did not negate the negative impacts.



These findings highlight the negative impacts of navigating the benefits system on people with learning disabilities' mental health, identity, and potential for independence. Ways of responding to the system are considered. Implications for clinical practice and research were outlined, particularly for ways clinical psychologists can work with and support clients with learning disabilities.

An accessible summary of this research will be sent to participants and it is anticipated that the results of the study will be presented to the self-advocacy groups involved. It be submitted for publication in The British Journal of Learning Disabilities.

Please get in touch if you have any questions about this study.

Best wishes,

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Appendix XXIV: Summary report for participants

The summary report for participants will be completed following submission of this Major Research Project. Due to the time constraints of project, and the summary needing to be made accessible for participants with learning disabilities using Easy Read, it will take additional time to complete. A copy can be made available at a later date if required.