Facilitating Healthcare Access for Adults with Learning Disabilities: The Challenges and Experiences of Community Support Workers in England, the United Kingdom

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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Abstract

People with learning disabilities (PWLDs) suffer disproportionately higher levels of morbidity and mortality in comparison with the non-disabled population in the United Kingdom. Despite the improved longevity in the rest of the population in recent decades, the lives of men and women with learning disabilities are still shorter than those of non-disabled people. In addition, when PWLDs seek access to healthcare, they face healthcare systems that do not readily accommodate their specific and varied impairments. Most PWLDs access healthcare with the support of other people such as paid carers. Supported access to healthcare facilities brings with it unique challenges and opportunities for PWLDs and those who support them. Among these challenges is the capacity to communicate healthcare needs to healthcare providers. The aim of this study is to explore the experiences and challenges of community support workers (CSWs) as they facilitate healthcare access for PWLDs. This aim is achieved in two ways. Firstly, the challenges and facilitators that CSWs experience when they facilitate access to healthcare for PWLDs are identified. Secondly, the role of CSWs in the coordination of healthcare needs for PWLDs is examined. The aim and the objectives are underpinned by the research question: How do community support workers construct the challenges and experiences they encounter in facilitating healthcare access for people with learning disabilities?

This is a qualitative study using Critical Realism (CR) as its theoretical approach in conjunction with the Social Model of Disability (SMD). The two approaches are used in tandem to complement each other.

A literature review was conducted to identify the role of CSWs in the facilitation of healthcare access for PWLDs. The review identified a gap in the literature regarding the unique barriers and facilitators to healthcare for PWLDs from the perspective of CSWs. However, the review's contribution is in the use of CR and SMD in the identification of structural issues which act either as enablers or hindrances in the facilitation of healthcare. In addition, the review situates the role of CSWs as communicators, advocates, ardent learners and collaborators of healthcare access for PWLDs,

The key findings of this study are: the CSWs were assertive and proactive in ensuring the provision of reasonable adjustments for PWLDs; healthcare provision by healthcare providers can be an obstacle to healthcare access for PWLDs; CSWs' were willing to be assertive in advocating for PWLDs; CSWs were aware of their roles in health care facilitation; CSWs were willing to collaborate with other agencies; CSWS were effective communicators with health care providers; additionally, CSWs were able to identify their own staffing and training needs as well as those of health care providers.

This study highlights the vital role of CSWs in the facilitation of healthcare access for PWLDs. CSWs bring to their role skills in advocacy, collaboration, and assertiveness. Beside enablers, the study has highlighted serious barriers to healthcare access and facilitation such as CSWs' lack of skills in early identification of signs of ill-health. In addition, the lack of awareness of key legislation such as the Mental Capacity Act (2005) in some HCPs remains an obstacle to both access and facilitation for PWLDs and CSWs respectively.

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List of abbreviations

A & E	Accident & Emergency
CASP	Critical Appraisal Skills Programme
CLDP	Community Learning Disability Programme
CINAHL	Cumulative Index of Nursing and Allied Health
CR	Critical Realism
CSW	Community Support Worker
GP	General Practitioner
HCP	Health Care Provider
IMCA	Independent Mental Capacity Advocate
IQ	Intelligence Quotient
LD	Learning Disability
MCA	Mental Capacity Act
MeSH	Medical Subject Headings
NICE	National Institute for Health and Care Excellence
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PWLD	People/Person with Learning Disabilities
SMD	Social Model of Disability
TA	Thematic analysis.
UK	United Kingdom
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organisation

Tables and Figures

Chapter One: Introduction

1.1 Overview

People with learning disabilities (PWLDs) experience disproportionate morbidity and mortality due to unequal access to healthcare (Flynn & Hatton, 2021; Regmi & Mudyarabikwa, 2020). Community Support Workers (CSWs) provide a vital link in facilitating timely healthcare access for PWLDs, particularly for PWLDs living in staff-supported accommodation (Clifford et al., 2018). However, despite this, CSWs are usually marginalised by healthcare providers at the point of facilitating healthcare access for PWLDs (McShea et al., 2016). CSWs working with PWLDs are professionals responsible for day-to-day support. The type of support rendered by CSWs ranges from facilitating the activities of daily living, such as feeding, to the promotion of health and the facilitation of healthcare access (Bell, 2012; Gregson et al., 2022). This study explores the role and experiences of CSWs in relation to healthcare access for PWLDs in England.

The term 'learning disability' is ascribed to a person who has reduced capacity to learn new and complex information and skills as well as reduced capacity to function independently in a social setting; the manifestation of these characteristics occur before attainment of adulthood (Emerson & Heslop, 2010). The population of PWLDs is diverse in relation to the severity of the learning disability and the level of dependency; PWLDs are therefore not a homogeneous group and their support needs are equally varied (Cluley et al., 2020).

It is estimated that there are over 1.5 million adults with learning disabilities in the United Kingdom (UK) (Scherer et al., 2023). Within the broader category of learning disabilities, it is currently estimated that there are three to six people per 1,000 who have a severe learning disability (Gates & Mafuba, 2016), some of whom are also physically impaired. People with a severe learning disability can find it difficult to access healthcare without the help of others (Cluley et al., 2020); without this help, many of them experience diseases that are preventable or treatable (Doherty et al., 2020). Enabling access to treatment and instituting preventive measures therefore requires support from other people such as family

members or CSWs (McShea et al., 2016). CSWs have the potential to make a difference to the health of PWLDs and to facilitate their access to prompt healthcare because they are always in close contact with PWLDs for 24 hours constantly (especially those in staffed accommodation). This level of interaction contrasts with the level of contact that health care providers (HCPs) such as GPs and nurses have with PWLDs (Weissman-Fogel et al., 2015). On account of this, CSWs are in a position to know PWLDs' day-to-day variations in behaviour as well as alterations in bodily functions (McShea et al., 2016).

Despite UK government policy measures in the past to improve PWLDs' access to healthcare, as outlined in the White Paper titled *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001), there has not been a corresponding increase in access (Doherty et al., 2020; Ryan et al., 2017). In fact, a recent survey found equity of access to healthcare for PWLDs worsened during the pandemic (Flynn & Hatton, 2021). This highlights the ongoing intractability of healthcare access for PWLDs.

'Healthcare access' has a diversity of meanings (Thomas, 2017); however, in this research, access is defined as enabling physical entry into a health facility as well as successfully enabling utilisation of a service that meets one's healthcare needs, such as treatment for a specific ailment (Alborz et al., 2005). In respect to people with impairments like PWLDs, access includes making reasonable adjustments for them as they seek healthcare (MacArthur et al., 2015). This implies that achievement of physical access alone does not necessarily denote full access to a desired service. In cognisance of this, CSWs do not just facilitate physical access but they also provide the communication and observation skills necessary for successful utilisation of a service.

Researchers exploring access issues for disabled people have devoted more attention towards studying physical access issues than other forms of hindrances to access, particularly those experienced by PWLDs (Nind & Seale, 2009). Moreover, Nind and Seale (2009) observe that for each study conducted into PWLDs' healthcare access, there was thirty times more research conducted exploring the physical barriers encountered by physically disabled people.

1.2 Purpose of the Study

The purpose of this qualitative study is to explore the experiences of CSWs in facilitating healthcare access for PWLDs in England. The experiences explored include opportunities, facilitators and barriers to, the provision of accessible and equitable healthcare for PWLDs. In exploring these, aspects of interaction, collaboration, and power relationships of CSWs with other agencies such as doctors, nurses and social workers are investigated. Exploration of interactions with other agencies recognises that provision of healthcare, as well as access to healthcare, is a multi-agency as well as multidisciplinary set of activities (Talbot et al., 2010).

CSWs may be referred to as paid carers (Meagher, 2006), care workers (Razavi & Staab, 2010), social care staff (Manthorpe & Martineau, 2010) and support workers (Monaghan & Cumella, 2009). The focus of this study is on paid CSWs because they serve a larger pool of PWLDs, and, as such, their experiences are likely to be more varied and complex than family carers. This research is undertaken on the recognition that CSWs make a positive difference in the healthcare access and subsequent health outcomes of PWLDs (McShea et al., 2016).

1.3 Definition and concept of learning disability

The conceptualisation of a learning disability (LD) has evolved over the years (Scanlon, 2013; Talbot et al., 2010). The term 'learning disability' is commonly used in the UK in preference to 'learning difficulty', as is used in other countries (Cluley et al., 2020). The other term used is intellectual disability (Newton & McGillivray, 2019b). The distinction between learning disability and learning difficulty is that the latter is broader in scope, in that it encompasses other conditions such as dyslexia, which may not fit within the criterion of a learning disability (Gates & Mafuba, 2016). Although there is no unanimity on the universal definition of a learning disability (Büttner & Hasselhorn, 2011), the term selected for this study is the one commonly used in the UK (Gates & Mafuba, 2016; Webb & Whitaker, 2012). The current definition of a learning disability is premised on

three criteria: an intelligence quotient (IQ) of less than 70; poor social functionality; and childhood onset usually before 16 years of age (Rapley, 2004). The implication is that these three criteria must be met before a diagnosis is made (Slowie & Martin, 2014). However, these criteria are not universally applicable; instead, some researchers prefer to use only the criteria of social functionality and childhood onset before age 16 (Büttner & Hasselhorn, 2011; Spaul et al., 2020). PWLDs have further been classified as having profound (IQ less than 20), severe (IQ 20-35), moderate (IQ 35-50) or mild (IQ 50-70) (Russell et al., 2017) learning disabilities. The differences among different groups of PWLDs demonstrate that they are not a homogenous group either intellectually or functionally (Ziviani et al., 2004); consequently, the provision of support must be tailored to their specific needs (Carnaby et al., 2010).

Although IQ has been the major criterion for determining the diagnosis of a learning disability, this has been questioned (Mayes & Calhoun, 2005). The controversy relating to the unacceptability of IQ as the main criterion in the definition of LD arises on account of discrepancies observed between high IQ test performance, academic achievement and social adaptability (Büttner & Hasselhorn, 2011; Scanlon, 2013; Spaul et al., 2020; Webb & Whitaker, 2012). As observed in Scanlon (2013), some students with high IQ do not have a higher academic achievement and neither do they adapt socially in a way that enables them to live independently. In view of this, a precise assessment of a learning disability is significant in determining the appropriate type of support. An incorrect assessment has an impact on the support a PWLD can receive from government agencies such as social services (Russell, 2003). Russell (2003) further argues that a correct assessment of disability translates into finding appropriate support that has a bearing on the quality of a person's life for a long time. Lack of a diagnosis for a person who has a learning disability disadvantages them regarding their access to healthcare (Palucka et al., 2008; Russell et al., 2017).

1.4 Equity of healthcare access for PWLDs and the role of CSWs

The supporting role of CSWs in relation to PWLDs' healthcare and general wellbeing emerged prominently in the period beginning from the late 1950s up to the mid-1980s (Ingham & Atkinson, 2013). This period was associated with the closures of long-term institutions that catered for people with mental illnesses and PWLDs (Ingham & Atkinson, 2013; Killaspy, 2007). The closures of these facilities resulted in PWLDs moving into smaller, staffed residential units in the community. The closure of long-term institutions for PWLDs was based on the theory of normalisation (Davis, 2013), and later the related theory of valorisation (Windley & Chapman, 2010), which advocated for the integration of PWLDs within wider society, by providing support and reasonable adjustments for them to be able to live independently and equitably.

The requirement for the provision of equity and reasonable adjustments is enshrined in the Equality Act 2010 (Heslop et al., 2019). This legislation is designed to prevent and address discrimination against disabled people, and is grounded in the Social Model of Disability (Barnes, 2019). Reasonable adjustments in relation to health and social care are measures expected from service organisations to accommodate the specific needs of disabled people so that they can access services without any barriers (Pearce, 2022). A further consequence of the theories of valorisation and normalisation has been an increase in research focusing on PWLDs (Walmsley, 2001).

The extent of the disparity in the morbidity and mortality of PWLDs in comparison with non-disabled people is highlighted in Heslop and Marriott (2015), who argue that PWLDs are often diagnosed too late for HCPs to make a substantial difference to their health outcomes (Heslop & Marriott, 2015). On average, men in England with learning disabilities had a life expectancy of 66 years in 2018 compared with 80 years in men without a learning disability, and women with learning disabilities had a life expectancy of 66.5 years, and died on average, 18 years earlier than their counterparts without a learning disability (Thornton, 2019). Heslop and Marriott (2015) observed that the two major factors contributing to higher mortality among PWLDs as compared to the general population are the points at which a diagnosis and treatment are instituted. A retrospective cohort study by Brameld et al. (2018) highlighted that when PWLDs presented at Accident and Emergency (A&E) Departments, they were on most occasions not properly examined. Where

assessments were undertaken, 29% of PWLDs were sent home without any treatment even when they had presented with similar symptoms to non-disabled people. It was further observed that admissions of PWLDs were much lower and they tended to stay longer in hospital when they were admitted (Brameld et al., 2018).

The facilitation of healthcare is among the key responsibilities CSWs carry out as part of their duties towards PWLDs (Murphy, 2017). According to the National Institute for Health and Care Excellence (NICE) guidelines (2018), providers of services to PWLDs are expected to involve CSWs in the healthcare delivery for PWLDs (Murphy, 2017). The CSWs are in a position to identify early signs of ill-health in some diseases, due to their daily direct interactions with the people in their care and their knowledge of the people they are responsible for (Tuffrey-Wijne et al., 2016). Given this, CSWs are considered key frontline workers in the healthcare of PWLDs who live in supported staffed housing in the UK (Emerson, 2004).

Little attention has been paid towards exploring the experiences of CSWs in the facilitation of access to healthcare for PWLDs (Robertson et al., 2015). Research into the challenges faced by PWLDs and their CSWs highlights that health care providers do not always provide PWLDs with adequate healthcare (Tuffrey-Wijne et al., 2016). In addition, research into the attitudes of nurses suggests that some have little consideration for the opinions of PWLDs and their CSWs (Michael & Richardson, 2008; Tuffrey-Wijne et al., 2016). When PWLDs consult with health care professionals, the views of their accompanying CSWs regarding the history of symptoms are often ignored (Heslop et al., 2013). The inability of HCPs to view CSWs as potential partners in healthcare may suggest issues of awareness, power relations or misunderstandings of each other's roles (Tuffrey-Wijne et al., 2016).

Research into how HCPs view their position on medical issues highlights that they perceive themselves to have greater epistemic authority on matters pertaining to PWLDs than CSWs (Tuffrey-Wijne et al., 2016). Additionally, HCPs consider themselves to have privileged knowledge on matters pertaining to illness in comparison with non-medical professionals in general (Heritage & Raymond, 2005; Smirthwaite & Swahnberg, 2016). These stances have implications for collaboration and communication with non-medical professions such as CSWs.

1.5 Research Problem

Evidence of inequality in access to healthcare by adults with learning disabilities is documented in several studies (Emerson & Hatton, 2014; Emerson et al., 2016; Kavanagh et al., 2021). However, the role of CSWs in the facilitation of healthcare for PWLDs has not received much research attention (Campbell, 2010). Equally unexplored are CSWs' experiences and challenges in facilitating healthcare access and the impact of their input on the health outcomes of PWLDs (Campbell, 2010; Tuffrey-Wijne et al., 2016). Rousseau et al. (2020) argue that by involving CSWs in early disease identification, mitigation measures can be implemented in time to avert further deterioration of treatable conditions. This translates into timely referrals for PWLDs to a healthcare provider. Although CSWs have been identified as key in the early identification of ill-health, their skill sets vary and are sometimes limited (McKenzie, 2011). A lack of sufficient skills (in relation to fully understanding the healthcare needs of PWLDs) has consequences for the quality of healthcare support given (Wyatt & Talbot, 2013). Willis (2015a) highlights that some CSWs often fail to recognise early symptoms of serious illness.

Liberati et al. (2016) observed that HCPs such as nurses and doctors treat CSWs in the same way as they treat adults with learning disabilities; both are regarded as of lower intellectual capacity and social status. This in turn has an impact on the quality-of-service HCPs provide to PWLDs; some HCPs ignored the CSWs' knowledge of PWLD. In the case of CSWs, this power relationship manifests itself in poorer inter-professional cooperation between HCPs and CSWs (Liberati et al., 2016)..

Emerson and Hatton (2014) argue that there is a relationship between improved health promotion in the general population and the average longevity among PWLDs. There has been a significant improvement in the life span of PWLDs over the years. For example, in the case of Down syndrome, the life span shifted from nine years in 1929 to over 50 years by 2000 (Rafii et al., 2019; Torr et al., 2010).

This suggests that the disparity in life expectancy between PWLDs and non-disabled people could be reduced further given the right environment for health promotion and support. However, this improvement remains much lower than in the non-disabled population (Emerson & Hatton, 2014). Emerson and Hatton (2014) further argue that the success of any health promotion for PWLDs is dependent in part on other people such as CSWs.

The significance of this study is based on Glover and Emerson's (2013) assumption that CSWs have the potential to make a difference to the current poorer health outcomes of PWLDs**.** The multifaceted role of CSWs in the general health and wellbeing of PWLDs provides an opportunity for making an impact. By bringing to light any positive experiences which have a bearing on the health outcomes of PWLDs, it is expected that a modest contribution could be made to the quest to address the current inequalities in healthcare access for PWLDs; this could be through the identification of barriers and opportunities and consequently shape opportunities for policy interventions.

Health statistics have consistently presented a higher number of preventable deaths and diseases among PWLDs in comparison with the rest of the population (Spaul et al., 2020). This highlights the fact that the underlying contributing factors may either have been inadequately explored or dealt with insufficiently to reverse the health outcomes for PWLDs. Spaul et al. (2020) observe that the attendant factors contributing to the high morbidity and mortality of PWLDs remain largely under-researched. Similarly, research into the facilitative role of CSWs in the healthcare of PWLDs remains largely limited to what HCPs expect of CSWs, rather than the other way (Manthorpe & Martineau, 2010; Spaul et al., 2020). The lack of extensive research into the facilitative role of CSWs seems inexplicable, given that CSWs are expected by NHS Public Health England policy to have a major input into the health of adults with learning disabilities (Davies, 2021; Ptomey et al., 2017).

Previous studies on CSWs have focused on the perception of their role and training needs (Windley & Chapman, 2010). However, given the closer contact, and the potential role that CSWs could play in promoting the health of PWLDs, little has been documented on the challenges, opportunities, and experiences of CSWs in facilitating healthcare access for PWLDs. While there have been limited studies which have explored some experiences of CSWs in areas such as work-related

stress (Judd et al., 2017; Nyashanu et al., 2022), the scope of their focus was not targeted towards the exploration of the challenges and experiences directly related to CSWs' role in the facilitation of healthcare access. In addition, while much research has been devoted towards promotion of physical access to healthcare for disabled people in general, very few studies have been dedicated to exploring the unique access needs of PWLDs which might lead to reasonable adjustments being made for their emotional and psychological needs (Nind & Seale, 2009).

Despite UK government policy expectations of the role of CSWs in relation to the healthcare of PWLDs, this has not been matched with adequate organisational support; this is highlighted in research into staff coping during the Covid-19 pandemic (McMahon et al., 2020). McMahon et al. (2020) observed that CSWs were subjected to high levels of stress without adequate skills training to enable them to cope with a very demanding event. However, this lack of adequate organisational support is not unique to the pandemic period (Whittington & Burns, 2005). McMahon et al. (2020) emphasise that CSWs work in the most challenging of environments (this includes behaviour that challenges others from PWLDs) arising from the nature of their work. However, only limited research to explore these challenges – and how they impact the healthcare access of PWLDs - has been undertaken.

With the increasing life span for PWLDs, diseases associated with older age have been noted among them, including breast and prostate cancers (Martean et al., 2014). Due to the inability of some PWLDs and CSWs to identify early signs and symptoms of ill-health, there is a risk of losing some of the modest achievements in promoting the health of PWLDs. The loss of momentum in the improvement of the healthcare of PWLDs may arise due to the inability to address the challenges in the facilitation of, and access to, healthcare for this group.

Position and role of the researcher: The researcher worked as a CSW throughout and prior to the research project. In addition, the researcher worked for one of the organisations from which ten of the participants were recruited (the ten were managers of CSWs). The researcher's position as an employee of that organisation was disclosed during ethics applications with both Lancaster University and the organisation which the researcher worked for. In addition, the researcher had previously worked as a healthcare provider and educator in the healthcare sector.

The experiences of having worked both as CSW and healthcare provider shaped the researcher's interest in the research topic. One aspect that influenced his research interest were ongoing day-to day challenges he met in the facilitation of healthcare for PWLDs**.** These challenges led the researcher to explore from the literature what was known on the topic of access to healthcare for PWLDs. This in turn led to the desire to explore the topic at hand in a more systematic way in the form of this research study.

Research Approaches: This study explores the experiences of CSWs in the facilitation of healthcare access for PWLDs in England. The exploration of the experiences of CSWs was undertaken through qualitative methodology using the theoretical approaches of Critical Realism (CR) and the Social Model of Disability (SMD). Qualitative methodology was specifically selected as it facilitated articulation of experiences in a manner that enabled the research question, aim and objectives to be met.

CR and SMD approaches were selected because they highlight inequalities and issues associated with disadvantaged groups and the barriers they face (Bogna et al., 2020; Costa & Magalhães, 2020; Winance, 2016). The SMD in particular focuses on the inequalities experienced by disabled people (Winance, 2016). The philosophical ethos of SMD is that it is society and its structures that disable rather than the impairments that disabled people have. The quest of the researcher is to explore the presence and nature of those barriers and how they affect healthcare access through the eyes of those who support them to gain that access.

In the framing of the research question and design of data collection instruments, the researcher sought to explore the barriers and facilitators to healthcare access. The purpose of exploring facilitators in addition to barriers was to determine the challenges and opportunities in relation to healthcare facilitation for both CSWs and PWLDs. SMD was used to identify the barriers. In turn, identified barriers through SMD were interrogated at three levels of CR, namely empirical, actual and real. Similarly, facilitators identified by participants were subjected to the same level of scrutiny using the three levels of CR both during field interviews and during data analysis.

A theoretical position is stated to provide a reader with the lens through which they can view the philosophical underpinnings of the research. The SMD together with CR have been adopted to provide the philosophical basis upon which the study is premised due to their shared ethos in identifying social barriers. CR is also concerned with the identification of facilitators. A detailed exploration of both CR and SMD is provided below.

Critical Realism: Critical realism (CR), as developed by Bhaskar (2008), is an epistemology that recognises causality of reality as permeating throughout the social world. In its quest for a fairer social world perspective, CR is concerned with the structures that give rise to the inequalities that prevail within society (Bryman, 2012). This is evident when CR asserts that phenomena are not just a product of human labels or perceptions (Groff, 2004). Instead, the social world exists irrespective of whether human beings experience it or not. CR divides truth into two categories: the transitive and intransitive (Fletcher, 2017). Transitive truth belongs to the empirical domain, and is based on the observer and their interpretation of a given phenomenon (Hartwig, 2015). As this knowledge is observable, it belongs to the empirical realm of CR. In contrast, intransitive truth is not based on the observer; its events are not premised on human interpretation (Fletcher, 2017). The intransitive truth belongs to the actual domain as it determines the observable events. Transitive truth, unlike intransitive truth, can be challenged by new and better explanations of a given phenomenon (Fletcher, 2017).

Although at first glance the stance of CR regarding transitive truth appears closer to that of relativistic epistemology, there are, however, significant differences, especially regarding the relativistic claim that all truth claims are valid (Fletcher, 2017; Groff, 2004). Other authors argue that the two theories (relativistic and CR) intersect at some points, particularly when both theories admit that knowledge claims and meaning are not static but dynamic (Al-Amoudi & Willmott, 2011). Al-Amoudi and Willmott (2011) argue that the transitive aspect of CR appears to accommodate the relativistic nature of knowledge.

CR cuts across the quantitative and qualitative divide in its application (McKeown & McKeown, 2017). CR's utility value lies in its ability to facilitate the researcher

in providing plausible explanations which underlie the superficial facts, as advanced by McKeown and McKeown (2017) who consider it essential in qualitative research. CR facilitates the understanding of underlying explanations by interrogating the facts at its three levels or domains: the empirical, the actual and the real (as explained above) (Fletcher, 2017).

The justification for selecting CR as the epistemological position of choice arises from its claims to highlight causal social structures with the view to highlighting prevailing inequalities and consequently negating them (Bryman, 2012). In addition, due to CR's epistemology of recognising external reality as a valid mode of perceiving phenomena it sits well as a theory for studying experiences.

Public health as a discipline is not only concerned with disease prevention and health promotion in a given population group; it is also concerned with structural factors which have a bearing on the health outcomes of populations (Petrini, 2010). Both CR and public health are concerned with structural issues which have a bearing on the wellbeing of society. Furthermore, both CR and public health focus on societal inequalities. However, it ought to be acknowledged that CR is not the only theory which espouses equity in social structures and social inequalities; other theories do lay claim to aiming to challenge inequalities. Feminist theory, for example, lays claim to addressing social inequalities, particularly the historically disadvantaged role of women and minority groups (Cluley et al., 2020). In fact, some feminist theorists view disability in similar terms to gender inequalities (Wendell, 1989). Wendell (1989) explores the relationship she noticed between being a female and being disabled when she acquired a life changing illness. Wendell observed that the inequalities of physically disabled people, and women's struggle for gender equality are related. She noted that both were concerned with the removal of social barriers created by society (Wendell, 1989). CR goes beyond challenging inequalities; it is also concerned with issues of causality (Groff, 2004); in this respect, there is a plausible connection between viewing public health issues from the perspective of CR in a study focusing on access to healthcare. Moreover, public health is concerned with the social determinants of health such as equitable access to healthcare.

Public health as a discipline is concerned with other determinants of health inequalities such as learning disabilities, communication difficulties and reduced

health literacy (Atkinson et al., 2013). The majority of these determinants of health inequalities are inherent among PWLDs, the very population which is the focus of this study (Atkinson et al., 2013).

MacFarlane and O'Reilly-de Brún (2012) highlight the view that the application of theory to every aspect of the research process facilitates the elicitation of those aspects of the findings which could otherwise have been neglected. In this study, CR was used to highlight health inequalities associated with PWLDs by interrogating the factors underlying them.

In selecting CR as the theory underpinning the study, the researcher is seeking to demonstrate that the experiences of CSWs supporting PWLDs are based on real experiences borne out of the interactions that take place within the realm of space and time.

CR recognises that reality can be accessed through gathered evidence (Fletcher, 2017); in this instance, that reality is accessed through the data gathered through interviews. In this respect, CR's ontological position on the construction of reality contrasts with the constructivist position which argues that the existence of reality is almost entirely a product of the explanatory capacity and reasoning skills of the person perceiving a phenomenon (Fletcher, 2017). A common thread can be evident in experiences that may appear to be a tangled mess of disparate voices. The picture formed by these nuanced perceptions when critically analysed facilitates the understanding of the phenomenon being explored. From a CR approach, the experiences of participants belong to the empirical realm. However, a critical realist does not just take these experiences at face value; instead, the experiences are explored further to determine the underlying mechanisms in the realm of the actual and the real (the causal factors).

It has been argued that research that seeks to explore the issues of the marginalised must have for its starting point a number of decisions, one of these being to be either neutral or on the side of those who are marginalised (Moore et al., 1998). Moore et al. (1998) argue that research that seeks to highlight the challenges of disabled people cannot take a neutral stance, as this would gloss over their issues. The starting point therefore, is to take into consideration that PWLDs and the people who provide support are already a marginalised group (Moore et al., 1998).

The Social Model of Disability: The philosophical position that a service provider takes has an impact on how a service is provided to a disabled person; this observation is applicable to both CSWs as well as HCPs (Smart, 2004). In turn, it determines how the actions undertaken for and with those who are marginalised or stigmatised are performed (Scambler, 2009). In addition, Cluley et al. (2020) observe that the paradigm through which a given individual views disability has an impact on the actions they will undertake to mitigate any challenges.

SMD advocates argue that there is a distinction between having an impairment and being disabled (Owens, 2015; Smart & Smart, 2006); the former may be genetic, congenital or acquired while the latter is a product of society (Owens, 2015). The selection of SMD as a model underpinning this study is based on the fact that this model addresses the current social, environmental, legal, and structural issues that disabled people currently face (Owens, 2015). This is not a declaration that the SMD is a panacea addressing all the outstanding challenges facing disabled people. Prior to the introduction of the SMD, the medical model had been the main framework through which much research related to disability was undertaken (Smart, 2004).

A persistent preoccupation of the SMD has been the quest to define and eliminate major barriers to the full participation of disabled people within society. Advocates of SMD argue that it is society with its structures and systems which disable; rather than the bodies of those who have impairments (Barnes, 2007). The SMD was formulated to highlight and address those social structural barriers that disabled people perceive to have been created by the ableist society (Barnes, 2007). The term ableist is defined as an attitude that favours non-disabled people in various spheres of life such as education, employment and other areas, at the expense of disabled people (Hammell, 2004). To be precise, the SMD under discussion is the UK Social Model of Disability (Thomas, 2008).

The ontological basis of SMD: The SMD is distinguished from other models of disability by the elements that constitute its definition as well as the shared characteristics of its developers, namely that all the original contributors were disabled people (Barnes & Mercer, 2004). From an epistemological perspective,

the SMD is a collective recognition by many disabled people that their impairments are not the primary source of their difficulty in functioning optimally; rather it is society's limiting environmental, social, and legal structures which are disabling. Although the sole focus on disability at the expense of impairments in the UK model has been questioned by some sectors within the disability movement (Shakespeare, 2014b) (as discussed below), there has been a consensus among most disabled people that there are elements within society which are disabling (Shakespeare & Watson, 1997).

From an ontological perspective, the creation and enactment of laws within the UK, such as the Mental Capacity Act (2005) and the Equality Act (2010), which guide how disabled people are to be supported, is a recognition of the existence of the barriers and oppressions that disabled people encounter. However, the existence of the barriers that disabled people face have not always been recognised by those in power (Dodd, 2014). The enactment of new laws and policies in recent years as well as the keen interest in academia to explore issues affecting disabled people demonstrates a marked shift (Barnes, 2019).

Contestation of the SMD concepts: Over the years, since the adoption of the SMD, some of its foundational concepts have been challenged and criticised. Among the reasons for the criticism has been the need to revisit some key concepts as they have been considered misleading and not sufficiently accommodating of a wide spectrum of disabilities (Shakespeare & Watson, 1997). In response to these criticisms, some of the early authors of the SMD have sought to clarify, reify, and define some of the earlier concepts and the language used in the initial stages of the SMD. Among the concepts challenged is the current definition of disability according to the UK model of SMD and its application. Equally, the concept of separating impairment from disability has been questioned.

Criticisms of the SMD have come from disabled scholars as well as from non-disabled academics. Among disabled scholars who have raised issues with some tenets of the SMD is Shakespeare (2014a). Despite recognising the achievements of the SMD, he argues that the SMD should redefine the relationship between professionals and disabled people by suggesting that there ought to be a mutually supportive relationship between HCPs and disabled people, rather than one that fosters dependence and antagonism. He further argues that there is unnecessary

separation between impairment and disability. In response to these issues, Thomas (2008) argues that Shakespeare destroyed the foundational concepts of SMD, namely, the separation of disability from impairment and this stance may have been taken without providing a well-researched basis for such a radical paradigm shift.

SMD and the concept of care: One of the concepts where there has been a paradigm shift is that of care. Care has been perceived by some disabled researchers and activists as being rooted in the medical model rather than in the SMD (Barnes, 2007; Shakespeare, 2014a). The medical model of disability views disability as a mainly biological issue (Terzi, 2004; Tregaskis, 2004) and focuses on deviation in bodily anatomy in comparison with the non-disabled population. The medical model of disability is perceived as being paternalistic by disabled people, based on the notion that medical personnel view themselves as providers of care and solutions to what they consider as medical anomalies without considering the lived experiences of disabled people (Lalvani, 2015). Besides being viewed as being paternalistic, the concept of care is also considered to infringe on the quest for equality by disabled people (Barnes, 2007).

By viewing themselves as objects of care rather than support, disabled people perceive that they are not accorded equal rights as other citizens and, consequently, that they are not treated as full members of society (Barnes, 2007). The concept of care for disabled people is considered dehumanising as it places their health outcomes in the hands of professionals, thereby taking away their independence and dignity (Barnes, 2007; Shakespeare, 2014a). In addition, the concept of care is perceived by disabled people as equating their impairments with diseases that need a cure (Barnes, 2007). It is in view of this that those who facilitate the activities of daily living for disabled people are in many cases expected to play a supportive role rather a caring one (Barnes, 2007).

In response to the concerns of activists for disabled people, the UK government passed the Care Act (2014) to provide person-centred care focusing on disabled people's needs (Gant, 2017). The underlying principle of the Care Act (2014) is to give a disabled person as much freedom and level of decision-making power over their care or support as possible (Feldon, 2017). The goal of the Care Act (2014) is to ensure that the wellbeing of a person in receipt of care or support is either "improved" or "maintained" (Feldon, 2017). Even though the Care Act (2014)

meets most of the aspirations of disability activists and the SMD, some disability activists are still unhappy with the use of the term "care". The word "care" is used side by side with the word "support" in the Care Act (2014) (Feldon, 2017). From an ontological perspective, in as much as the word "care" could be considered demeaning among the disability activists (Shakespeare, 2014b), the reality is that some disabled people will need care while others will need both support and care (Halvorsen et al., 2020). The delicate balance between provision of care and support could be navigated at the individual level, considering that even in one person there are dynamics between support and care needs (Halvorsen et al., 2020).

According to Shakespeare (2014a), care is defined in terms of dependency, need and deficiency on the part of a disabled person. He argues that the picture of dependency, need and deficiency leads to a culture in which disabled people are viewed as 'helpless' and in need of rescue. Such a view, it is argued, has an impact on both disabled person and the provider of care: disabled persons perceive themselves as oppressed, in 'failed bodies'; and carers, meanwhile, view themselves as 'helpers' who must do good for the person considered as 'helpless' (Shakespeare, 2014a).

In seeking to reconcile the expectations of the SMD with its emphasis on empowerment and the need for various professionals to play supportive and enabling roles, the necessity for CSWs to be sensitive is imperative. Such sensitivity could take the form of treating each disabled person as an individual in accordance with their specific needs, as stipulated in the Care Act (2014). Given the wide spectrum of impairments, some disabled people have a higher level of dependency, whereas others have lower dependency levels. In view of this, the boundary between support and care must be navigated with due diligence by CSWs when dealing with highly dependent disabled people.

SMD in relation to PWLDs and CSWs: This thesis seeks to bring to the fore concepts of SMD as shared between CSWs and PWLDs with a view to demonstrating how these impact healthcare facilitation and access. Among such concepts is the issue of marginalisation of both groups by both HCPs and non-disabled persons (Shakespeare, 2014a). This is both in terms of how society perceives support staff, but also in terms of how such staff are expected to perform their roles in the light of current legislation (Feldon, 2017). Shakespeare (2014a)

argues that CSWs have lower status in relation to power dynamics in comparison with other caring professionals such as nurses and doctors. Shakespeare (2014a) further highlights that the perception of CSWs as 'low status' care providers has an impact on their work output; this perception affects how disabled people are supported when CSWs collaborate and communicate with HCPs on their behalf (Tuffrey-Wijne et al., 2016). The negative perception of support work is also aligned to its long tradition as a predominantly female-dominated occupation (Twigg, 2000). This in turn is as result of patriarchal attitudes that consider support work carried out by females as 'inferior' and 'dirty' (Glaister, 1998; Twigg, 2000, p.127). Twigg (2000, p.130) states that society further views CSWs as 'servants' rather than professionals governed by standards.

In seeking to situate the positive role of CSWs in relation to care, one must fit them within the understanding of the SMD rather than the wider society's perception (Webber et al., 2010). The expected, and possibly acceptable, understanding in the SMD is that CSWs for PWLDs are not expected to play a caring role in the conventional sense, but more of a supportive and facilitative role that is empowering to PWLDs (Webber et al., 2010).

SMD and its leverage in advancing the cause of disabled people: In view of the varying degrees to which categories of disabled people are affected by societal barriers and discriminations, there is room for the SMD to be more heterogenous in respect to specific disabilities as it develops and advances further. There are certain categories of disabled people for whom societal barriers regarding access have largely remained unchanged, despite improvements which have accrued to other groups. One such group are PWLDs, who still face barriers when it comes to healthcare access (Ali et al., 2013; da Rosa et al., 2020; Dern & Sappok, 2016a; Gregson et al., 2022).

1.6 Aim, Objectives, and Research Question

This section highlights the aim, objectives and research question which have

guided the study

1.6.1 Aim and Objectives

To explore the experiences of CSWs in facilitating healthcare access for PWLDs.

Objectives

1. To identify the challenges and facilitators that CSWs experience when they facilitate access to healthcare for PWLDs.

2. To examine the role of CSWs in the coordination of the healthcare needs for PWLDs with other agencies.

1.6.2 Research question

How do CSWs construct the challenges and experiences they encounter in facilitating PWLDs' access to healthcare?

1.7 Study Structure

The thesis consists of five chapters. Chapter one provides an overview of the research area, the overview to the subject, and the purpose of the study. Chapter two is a systematic review of the literature on the role of CSWs in the facilitation of healthcare access for PWLDs. The literature review findings are used to identify what is known about the study topic as well as to identify any gaps in knowledge. Chapter 3 consists of two parts: part one consists of a brief recap of the theoretical approaches already discussed in detail in chapter 1 and the methodology underpinning the study; part two consists of the study methods namely, the study design, the recruitment of participants, methods of data collection, data management, data analysis, data interpretation, and ethical issues. Chapter four presents the study findings. Chapter five includes a discussion of the key findings of the study and the conclusion. The discussion includes the contribution of the study to the literature and the study's strengths and limitations. The conclusion also outlines the implications of the findings and provides recommendations for further research.

Chapter Two: Literature Review

Introduction

This chapter presents a systematic review of the literature exploring how CSWs are involved in the facilitation of healthcare access for PWLDs. The specific focus of the review is on looking at the CSWs' role in various settings such as in residential settings for PWLDs and GP surgeries, and in secondary care provision, and at how CSWs collaborate with other agencies in facilitating healthcare access.

The disproportionate morbidity and mortality rates among PWLDs have been a subject of much research over the years. One of the major contributing factors to premature deaths within this population group is a delay in early diagnosis of illness (Heslop et al., 2014). Compounding the health care needs of PWLDs is their dependency on others to access health care (Redley et al., 2012). Consequently, the health outcomes of PWLDs are linked to the support they receive from others (Redley et al., 2012). While some key healthcare providers (such as doctors and nurses) and non-health care professionals (such as social workers) have been acknowledged as key to facilitating access to healthcare, other professionals such as CSWs have been less likely to be perceived as playing an important role in the day-to-day healthcare of PWLDs (Najafizada et al., 2015).

The greater frequency of contact which CSWs have with PWLDs in the community makes them a critical component in healthcare delivery (Webber et al., 2010). CSWs are usually the first line of paid staff that a person with a learning disability will encounter if they live in community-based staffed accommodation. Consequently, CSWs have a significant role in the day-to-day care of PWLDs. CSWs on many occasions act as 'substitute decision makers' for PWLDs; this is especially the case for those who have been assessed as lacking capacity to make their own decisions according to the Mental Capacity Act (2005) (Dunn, Clare, & Holland, 2010). CSWs, in addition, must make many key decisions with PWLDs on a day-to-day basis. These are related to recognition of early signs of ill health, promotion of health and prevention of disease (Emerson & Hatton, 2014). Recent reviews on the experiences of CSWs in relation to barriers to access of healthcare by PWLDs have failed to recognise and highlight the critical role of CSWs in facilitating the healthcare of PWLDs. In addition, primary studies have mainly focused on the

perceptions of PWLDs but have paid little attention to the study of the experiences of support staff (Ali et al., 2013; Hutchison & Kroese, 2016). The dearth of both primary studies and systematic reviews focusing on the experiences of CSWs (Nijhof et al., 2024) and their central role in healthcare facilitation has been acknowledged (Hastings, 2010; Nijhof et al., 2024).

2. 1 Review Question

How are community support workers involved in the facilitation of healthcare access for people with learning disabilities?

2.2 Literature Review Methodology and Methods

This section covers the design underpinning the review, search strategy and the framework defining the search strategy.

2.2.1 Design

This review focused on qualitative research studies and qualitative data extracted from mixed methods primary research. Due to a qualitative paradigm being better suited for highlighting participant experiences, in contrast with the quantitative paradigm which focuses on quantifying phenomena (Krauss, 2005), it was deemed a better fit for this review. Thematic synthesis was chosen as a tool to synthesise the selected studies based on its three-stage analysis, which provides a thorough systematic process of heterogenous studies (Thomas & Harden, 2008). Thematic synthesis is suitable for primary studies exploring people's experiences and perspectives (Thomas & Harden, 2008) and has been used in reviews focusing on healthcare, experiences, needs and preferences of carers of stroke survivors (Luker et al., 2015), and factors affecting diabetes prevention in primary care settings (Messina et al., 2017).

Critical Realism (CR) is designed to explore underlying mechanisms which may explain the observed phenomena in the primary studies (Krauss, 2005).

This review was initially undertaken in June 2019 and was updated in 2023 to include an expanded selection of databases as well as to add hand-searched references.

2.2.2 Search strategy

An informal scoping of the literature was initially conducted to determine the sources, type and quantity of literature available on the review question (Booth et al., 2016) and to enable the refining of the review methods. The initial review utilised two databases CINAHL and PubMed; the updated review included the following additional databases: MEDLINE, Google Scholar, APA PsycINFO and Academic Search Complete. Reference lists from previous studies and previous systematic reviews were also searched.

2.2.3 Framework defining the search

A framework known as CoCoPop (**Co**ndition, **Co**ntext, **Pop**ulation) was used to guide the search and focus the review question (CASP, 2023). A CoCoPop framework is advisable for reviews which are not focusing on an intervention or making group comparisons (CASP, 2023). The components of the CoCoPop framework are provided in Table 1 below.

Table 1: CoCoPop framework

Condition	Healthcare facilitation and access for PWLDs
Context	Healthcare facilities and residences of PWLDs
Population	Community Support Workers

2.2.3.1 Condition

This review focuses on CSWs' experiences of facilitating PWLDs' access to and usage of healthcare services, including how they interact and collaborate within organisations and with other agencies to facilitate access. The review includes evidence from primary qualitative and mixed methods studies which focus on PWLDs and their CSWs. Studies focusing on family members with caring responsibilities were excluded, as were studies which did not demonstrate a clear design and population of interest. However, studies which highlighted the role of CSWs, but whose main study population were other healthcare professionals such as nurses, doctors, and dentists were included.

2.2.3.2 Context. Healthcare in this review is viewed as a comprehensive system that encompasses curative, preventive, and promotive aspects of health. From that perspective, healthcare provision has varied participants and settings, including GP surgeries and hospitals (Bains et al., 2018).

2.2.3.3 Population: The primary study population of this review are CSWs involved in day-to-day healthcare facilitation and access for PWLDs.

2.3. Inclusion and exclusion criteria

Table 2 highlights the inclusion and exclusion criteria used in the selection of the studies.

Table 2: Inclusion and exclusion criteria

Inclusion criteria		**Exclusion criteria**
Item	**Criteria**	**Criteria**

Population	CSWs aged 18+ providing care to adults with learning disabilities.	Family carers
Period	Studies published 1984 -2023	Studies before 1984
Study design	Qualitative studies Qualitative data from mixed method studies	Quantitative studies Reviews
Countries	All countries	N/A
Language	English language studies or studies translated into English	Studies without any English translation.

2.3.1 Search terms

The search process involved free text, MeSH (Medical Subject Headings) terms, truncations, Boolean operators, adapted subject headings, scoping searches, and use of the thesaurus. The following terms were used: caregivers, health personnel, social care, personal assistant, healthcare personnel, support worker, care worker, caregiver, carer, healthcare, primary care, community care, intellectual disability, intellectual impairment, learning disorder, and learning disability. The terms were developed with the help of a specialist subject librarian. The process of how the search terms were applied is demonstrated in the sample searches shown in appendices 1a and 1b.

2.4 Study selection and procedure

Data Management: All the identified studies were saved in Endnote to facilitate the process of checking for duplicates as well as making retrieval of studies more efficient.

Selection of studies: Qualitative and mixed methods studies that met the selection criteria were selected. To provide evidence for the search process, detailed documentation of the search was undertaken. The methodological requirements of PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) formed the main basis for reporting the search process of the review (see figure 1).

Reference lists: Reference lists from included studies were checked to identify other studies relevant to the review question.

2.4.1 Data extraction and quality screening of the studies

Data from the included studies were extracted into a data extraction form (see Appendix 4), an adapted version of the Joanna Briggs Institute qualitative data extraction tool (Lockwood et al., 2017). The data extraction form was piloted in two studies to ensure its suitability. Data extracted from each study included author names, journal title, year of data collection and publication, the country where the primary study was undertaken, the aim of the study, study design, sampling methods,

results including the key themes, conclusions and recommendations description of study setting and participants. The summaries of selected studies is presented in Table 3 below.

Each selected article went through a two-stage screening process. The first screening was to determine whether a given article was potentially relevant to answering the review question based on its title and abstract. If an article was deemed potentially relevant, it was selected for the second stage of assessment which was the reading of the full text. The full texts of all the articles which were deemed to be relevant were explored further. Any studies which were excluded after the full text had been read through were recorded and the reasons for the exclusion stated.

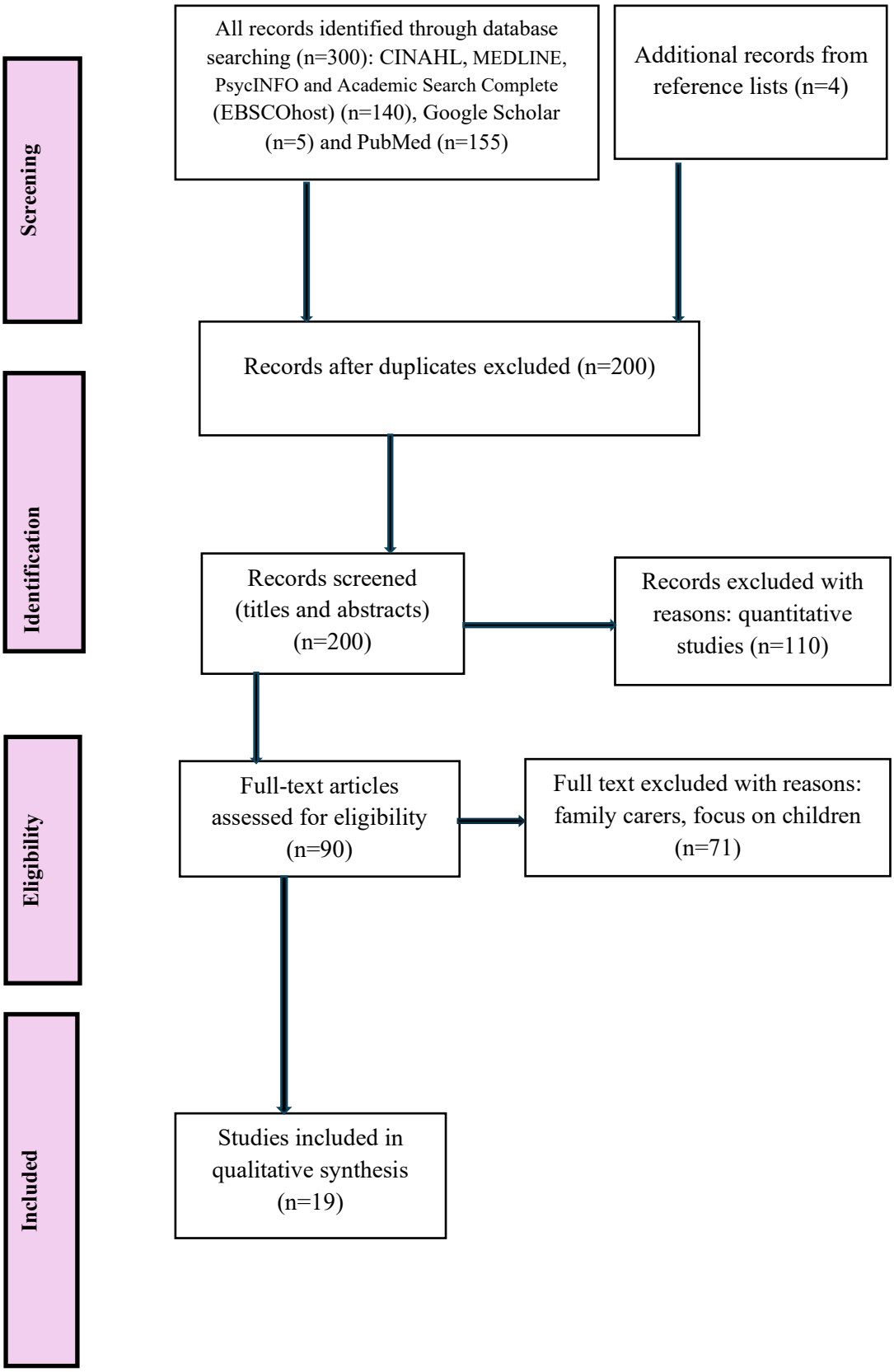

Screening
Identification
Eligibility
Included
All records identified through database searching (n=300): CINAHL, MEDLINE, PsycINFO and Academic Search Complete (EBSCOhost) (n=140), Google Scholar (n=5) and PubMed (n=155)
Additional records from reference lists (n=4)
Records after duplicates excluded (n=200)
Records screened (titles and abstracts) (n=200)
Records excluded with reasons: quantitative studies (n=110)
Full-text articles assessed for eligibility (n=90)
Full text excluded with reasons: family carers, focus on children (n=71)
Studies included in qualitative synthesis (n=19)

Figure 1: Prisma flow chart

2.5.2 Search outcome

Nineteen studies met the inclusion criteria (see Table 3: Summaries of studies identified for the literature review) and were drawn from the UK (n=15), Australia (n=2), Netherlands (n=1) and USA (n=1).

Table 3: Summaries of studies identified for the literature review

Authors and country	Sample and setting	Aim, design, and analysis	Summary of relevant findings
1. Burton, H., & Walters, L. (2013). Australia	18 doctors and, people with learning disabilities and their carers in rural Australia.	To gain a better understanding of whether and how people with learning disabilities access annual comprehensive health assessments (ACHAs). Sub-questions were: Which rural general practice characteristics affect access? and how is the role of general practice in delivering (ACHAs) viewed by PWLDs and by doctors. Design: qualitative using semi-structured interviews. Analysis: thematic analysis	The role of the CSW is crucial in the health assessment process and can improve the transfer of information about a PWLD between the disability and health sectors and within the health sector.
2. Kruger, B., & Northway, R. (2019).	9 Behavioural Specialists	Aim: to understand Behavioural Specialists' experiences of involving	Cooperation and collaboration with CSWs were key to the

UK.		service users in the development of the Positive Behaviour Support plan. Research question: ‘what is going on here?’ A qualitative design, using semi-structured interviews in 3 focus groups. Analysis: thematic analysis	development of positive behaviour support in managing behaviour that challenges
3.Wullink, M., Veldhuijzen, W., Lantman-de Valk, H. M. J., Metsemakers, J. F. M., & Dinant, G. (2009). Netherlands	10 people with learning disabilities	Research question: 'What are the similarities and differences between the communication preferences of people with learning disabilities and the professional criteria for doctor-patient communication by GPs? Design: qualitative, using semi-structured interviews and focus group. Analysis: content analysis	CSWs’ manner of communication during GP consultation was below the expectations of people with mild learning disabilities. CSWs spoke without the PWLDs’ permission during GP consultations.
4.Wilkinson, J., Dreyfus, D., Bowen, D., & Bokhour, B. (2013). USA	49 participants (n=27) women with learning disabilities, (n=22) doctors.	Aim: to explore barriers to mammography for women with LDs and to understand how these women access and experience medical care. A qualitative design using semi-structured interviews. Analysis: grounded theory	Physicians felt that patients with LD took too much time and said that they preferred communicating with the support worker. The interviews also revealed unconscious biases about people with LD. Patient participation is encouraged for PWLDs

			but is limited because of both physician and patient factors.
5. Jones, M. C., McLafferty, E., Walley, R., Toland, J., & Melson, N. (2008). UK	25 participants consisting of (n=6) people with learning disabilities, (n=19) social care staff	Aim: to gain service user and social care staff perspectives on the barriers facing people with intellectual disabilities when accessing primary healthcare. A qualitative design using focus groups and semi-structured interviews. Analysis: thematic analysis	CSWs identified the attitudes and behaviour of primary healthcare staff' as sometimes problematic. Getting to know a PWLD is an important first step in improving access to primary healthcare.
6. Powrie, E. (2003). UK	107 Practice nurses	Aim: To inform the learning disability service of the role of primary care in current service provision for people with learning disabilities. Qualitative design using both and quantitative qualitative methods for data collection. Analysis: descriptive statistics for quantitative data and content analysis for qualitative data.	Communication barriers exist and they prevent access to health screening and treatment for some PWLDs. Training and support is required for practice nurses and CSWs. Effective communication and co-operation between carers and practice nurses, enhances primary care provision.
7. Thornton, C. (1999) UK.	6 Multidisciplinary community learning disability teams (CTLD) and 11 managers of small homes for	Research question: **1** How community teams working with people with learning disabilities and managers of small homes (MSH), whose residents	There was poor collaboration between CTLD and managers of homes for PWLDS.

	residents with learning disabilities	are people with learning disabilities, perceive the primary health care needs of their clients? **2** What degree of collaboration occurs between the CTLD, the MSH and the primary health care trust (PHCT)? **3** Are the GPs, as the coordinators of primary health care, effective in meeting the needs of their clients? **4** Would they welcome the introduction of a community learning disability nurse working within the primary health care setting to facilitate the health care of people with learning disabilities? Design: qualitative using focus groups and semi-structured interviews. Analysis: thematic framework	
8. Antaki, C., & Chinn, D. (2019) UK	75 doctors, people with learning disabilities, unpaid and paid carers	Aim: how the companion designs their talk - how they manage their claim to know information over which the patient has prior rights of entitlement. Do they use their greater epistemic	CSWs had a tendency of intervening unnecessarily during GP consultations. Interventions by CSWs varied from occasional intrusions to complete

		status to simply over-ride the patient, or do they adopt different epistemic stances to manage the matter with more delicacy? Design: qualitative using conversational analysis using video for data collection	usurping of the role of PWLDs.
9. Chinn, D., & Rudall, D. (2019). UK	24 Patients with learning disabilities and their companions (carers: paid or unpaid	Aim: to establish, within naturally occurring health consultations, who HCPs select to answer their questions during health checks – Is it patients with ID or their companions (CSW)– and who actually answers. Design: Qualitative Analysis: conversational analysis	HCPs in most primary health care consultations solicited information about from the patient rather than the accompanying support person. The support person was only selected in fewer cases.
10. Messent, P. R., Cooke, C. B., & Long, J. (1999). UK	24 Adults with moderate and mild learning disabilities, managers of residential homes and carers.	Aim: to establish whether a group of 24 adults with mild and moderate learning disabilities receive adequate support to be able to make choices to lead a physically active lifestyle. Method: qualitative interviews. Analysis: content analysis	Organisational barriers as well as inadequacy in resources prevent CSWs from supporting PWLDs to engage in physical activity.
11. Murphy, J. (2006**).**	38 participants consisting of GP staff,	Aim: to explore consultation between	HCPs felt frustrated when communicating

UK	people with aphasia and people with learning disabilities.	people with communication disability and General Practice (GP) staff from the perspectives of both patients and staff. Analysis: progressive thematic analysis	with PWLDs for not being understood. HCPs relied mostly on CSWs to communicate to PWLDs. PWLDs were unhappy with HCPs for speaking through CSWs to them.
12. Young, A. F., Chesson, R. A., & Wilson, A. J. (2007). UK	40 Participants consisting of people with learning disabilities with their paid and unpaid carers.	Aim: to elicit the perceptions of people with learning disabilities, family carers and CSWs regarding risk factors associated with cardiac disease. Design: qualitative using semi-structured interviews. Analysis: thematic framework	CSWs recognised the risk factors associated with cardiac disease in PWLDs but lacked knowledge on how to mitigate these factors.
13 Findlay, L., Williams, A. C. d. C., Baum, S., & Scior, K. (2015). UK	11 Caregivers (paid and unpaid)	Aim: to explore in-depth, the experiences of paid (formal) and unpaid (informal) caregivers supporting adults with intellectual disabilities who were possibly and/or definitely in pain. Aims: to investigate: (i) how caregivers respond to possible or actual pain; (ii) if and how they recognize pain and (iii) what emotional impact these processes have on caregivers. Qualitative design using semi-	CSWs had difficulties recognising and managing pain in PWLDs.

		structured interviews. Analysis: Interpretative Phenomenological Analysis.	
14.Willis, D. S., Wishart, J. G., & Muir, W. J. (2010). UK	69 Carers	Aim: through one-to-one interviews, to (1) explore knowledge and understanding of the menopause in these women's carers, (2) gather their experiences of supporting the women under their care through the menopause, and (3) identify what additional help might assist carers in providing better support over this important transitional period in the lives of women with ID. Design: qualitative using interviews. Analysis: thematic analysis.	CSWs had difficulty in understanding the emotional and physical changes that women with a learning disability and going through menopause
15. Windley, D., & Chapman, M. (2010). UK	8 Support workers	Aim: how Community Learning Disability Teams (CLDTs) can best carry out their role of providing support and training to CSWs for adults with learning/intellectual disabilities, by understanding how support workers perceive their role, training and support needs. Areas of	CSWs viewed their role as maximising quality of life for PWLDs. CSWs were of the view that they learnt by 'trial and error'.

		enquiry included the following: • Support workers' motivation and perception of their role • Support workers' perception of their own and others' performance • The value of training and its application • Power relationships between support workers, service-users, and professionals • Leadership and guidance Design: qualitative using focus groups and semi-structured interviews. Analysis: thematic framework	
16. Willis, D. S. (2015). UK	12 Women with learning disabilities	Aim: to understand what influenced women with intellectual disabilities to participate in breast screening and to explore their experience of having mammography. Design: qualitative ethnographic study using semi-structured interviews and observations. Analysis:	Women with learning disabilities attending mammography were of the view that CSWs were very important in supporting them during breast screening. CSWs determined the participation of the women they supported in attending breast screening sessions.

		Blended framework analysis.	
17. Tuffrey-Wijne I., Abraham E., Goulding L., Giatras N., Edwards C., Gillard S. & Hollins S. (2016). United Kingdom	Hospital staff and carers of PWLDs	Aims. To understand issues around carer roles that affect carer involvement for people with intellectual disabilities in acute hospitals. Electronic hospital staff survey (n = 990), carer questionnaires (n = 88), semi-structured interviews with hospital staff (n = 68) and carers (n = 37) Mixed methods in six acute hospital trusts in England	HCPs supported involvement of CSWs in the care of PWLDs during hospitalisation. However, there were discrepancies regarding expectations on what that involvement entailed of both the HCPs and CSWs
18 Ziviani, J,, Lennox, N. J., Allison, H.. M. Lyons, and C. Del Mar (2004). Australia.	GPs (n=5) carers (n=7) and advocates(n=2).	Aim: To better understand the factors that have an impact upon the success of communication in a medical consultation.	Carers were strong advocates for the person with a learning disability but indicated they had insufficient skill and knowledge to provide the level of assistance required in the consultation. PWLDs felt frustrated for being sidelined during GP consultations.

19. Owens, J., K. Mistry, K., and Dyer, T. A. (2011). United Kingdom	10 PWLDs and their support staff.	Aims: To represent the unheard voices of people with learning disabilities and their carers concerning access to dental services. Objective: To explore the oral health experiences of people with learning disabilities and their carers using the social model of disability as a lens through which to view data Design: Qualitative methods employing a blend of ethnography and narrative. A purposive sample: PWLDs, and their carers,	CSW have poor knowledge of oral healthcare as well as low expectations of oral healthcare for PWLDs. The poor knowledge and low knowledge act as hindrances to facilitation of access

2.6 Assessment of methodological quality and limitations in primary studies

Assessment of the methodological limitations of individual studies was conducted using the Critical Appraisal Skills Programme (CASP) quality assessment tool for qualitative studies (Critical Appraisal Skills Progamme, 2018) (Appendix 2b). The CASP tool was used to summarise the quality ratings of the selected studies and to determine the extent of credibility that could be placed on the studies. All studies

were included in the review including low-rated studies, based on the recognition that they may contribute towards the review findings.

2.7 Synthesis of extracted evidence

Data from papers that met the inclusion criteria were extracted and then synthesised using thematic synthesis (Thomas & Harden, 2008). The extracts consisted of the findings of each primary study and were subsequently coded, categorised, and synthesised. Codes consisted of either single words, phrases or sentences extracted from the primary studies. In addition, where participants' words were captured, these were also coded.

Critical realism (CR) and the Social Model of Disability (SMD) were used in tandem with thematic synthesis in the analytical process throughout each stage, of coding, categorisation, analysis, and synthesis. The analytical process involved line-by-line coding, development of descriptive themes and generation of analytical themes of a thematic synthesis system (Thomas & Harden, 2008). The codes were determined by the review question. Each code was interrogated at the three levels of critical realism, namely the **empirical** (observations and experiences), the **actual** (events or actions) and the **real** (structures: factors that facilitate or act as barriers). In addition, codes were assessed from the SMD perspective to determine whether they were social or structural barriers. The first question when a code was identified was to determine how it facilitated the answering of the research question. The next question was to determine whether it was an observation or an experience, an action in the actual domain or a facilitator or a barrier, both from the perspective of CR and SMD. The answer to these questions determined whether it could be discarded or selected for further analysis. The application of CR and the SMD determined how a code was categorised as either a facilitator or a barrier. Using the example of 'staff shortage', this code was classified as an observation and consequently categorised as being structural in nature (this was both from CR and SMD perspectives) and a barrier to

healthcare facilitation. The same process was applied to initial codes as well as final analytical themes.

Identified initial codes were then categorised according to the extent of their homogeneity. While the first two stages of thematic synthesis are closely linked to the primary studies - in that the categories emerging are made up of phrases or words from the primary studies - the third stage required the reviewer to bring to the synthesis process the dimension of interpretation skills of the emerging findings (Harden & Thomas, 2008). The input of the researcher regarding their interpretations of the data recognises that a qualitative researcher is part of the research process rather than an outside observer of the data they have collected (Clarke & Braun, 2017; Saldaña, 2011).

Nine descriptive themes emerged from the process of analysing the data: a) health promotion; b) identification of symptoms and signs; c) communication; d) collaboration; e) role clarity; f) advocacy role; g) learning/self-efficacy; h) organisational; and i) skills deficit. These nine descriptive themes were further grouped into three major analytical themes: health facilitation; organizational actors; and knowledge.

2.8. Presentation of Literature Review Findings

The data for this review were drawn from 19 studies (see table 3 above) which were mainly qualitative in design; qualitative data were extracted from two mixed methods studies. The selected studies employed various data collection methods, such as semi-structured interviews, focus groups, postal survey, and video interviews. Most of the studies combined data collection methods. The review findings are presented under three major analytical themes below.

2.8.1 Theme 1: Healthcare facilitation

Facilitation is the process of providing support to individuals or groups of individuals to achieve beneficial change (Munday et al., 2009). In this context, the beneficial change is a health outcome that improves or prevents the worsening of the presenting symptoms. The broad theme of healthcare facilitation highlights areas where the CSWs were actively involved in healthcare facilitation. This theme consists of five sub-themes: health promotion; communication; identification of signs and symptoms; advocacy; and collaboration.

2.8.1.1 Sub-theme 1: Health promotion

Health promotion was evident in most of the studies and was reflected in activities such as organising appointments with the GP surgery (Burton & Walters, 2013), facilitating health checks (Willis, 2015b; Willis et al., 2010), and promotion of healthy lifestyles (Messent et al., 1999). The reviewed studies portray CSWs as staff on whom PWLDs rely almost solely for initiating activities to promote health (Burton & Walters, 2013). As the initiator of health promoting activities, the CSW could be regarded as a positive or negative agent (Willis (2015b): positive in that some CSWs encouraged health promotion; and negative in that some imposed their personal assumptions regarding the benefits of health screening procedures such as cervical screening and breast screening by indicating that such procedures were not good for PWLDs (Willis, 2015b). In addition, Owens et al. (2011), highlight how the lack of CSW knowledge of the benefits of dental health acted as a hindrance to the facilitation of access to dental healthcare services. The findings of Willis (2015b) and Owens et al. (2011) demonstrate that some CSWs are not cognisant of the health benefits associated with specific measures to promote health and prevent disease. In the absence of such awareness, CSWs' role in health promotion can potentially have a negative impact on the health outcomes of PWLDs.

The review further highlights how some activities, such as eating a healthy diet, were deemed to be important aspects of health promotion from the perspective of PWLDs (Young et al., 2007). Joint activities such as walking, were commonly participated in by both CSWs and PWLDs. CSWs occasionally found it difficult to promote the

health of PWLDs, because some of the PWLDs had difficulty giving up smoking and consuming drinks with high sugar content (Young et al., 2007).

Lack of specific expertise in helping PWLDs to break unhealthy habits was highlighted by CSWs and was done as part of their duty of care towards the promotion of the health of PWLDs. The recognition by CSWs of their lack of expertise in the specialised area of facilitating behaviour change towards healthy habits highlights both the necessity for a multidisciplinary approach in the health promotion of PWLDs as well as the need to equip the CSWs with basic skills in behaviour change. The need to focus on behaviour change from CR perspective, is a recognition that without addressing the underlying behaviour, interventions such as encouraging a healthy diet will have limited success (Dean et al., 2021). The necessity to address poor eating habits arises because among the leading causes of morbidity and mortality among PWLDs are issues related to nutrition such as diabetes, hypertension and obesity (Dean et al., 2021). CSWs as meal planners, cooks and supportive personnel have therefore a vital role in promoting healthy lifestyles and preventing diseases. Besides the lack of staff knowledge, health promotion was noted to be contingent upon other factors such as organisational issues, role clarity among staff, safety concerns and the gender mix of staff (Messent et al., 1999; Willis, 2015b).

2.8.1.2 Sub-theme 2: Communication

Communication emerged in relation to health facilitation in several studies (Antaki & Chinn, 2019; Burton & Walters, 2013; Chinn & Rudall, 2019; Jones et al., 2008; Kruger & Northway, 2019; Murphy, 2006; Tuffrey-Wijne et al., 2016; Wilkinson et al., 2013; Wullink et al., 2009). In five of the reviewed studies, communication featured prominently (Antaki & Chinn, 2019; Chinn & Rudall, 2019; Murphy, 2006; Wullink et al., 2009; Ziviani et al., 2004). The portrayal of the CSW as a communicator was varied across the studies as it was among HCPs and PWLDs. Both HCPs and PWLDs generally viewed CSWs positively (Murphy, 2006), as a critical link in providing essential information for health diagnosis (Burton & Walters, 2013), clarifying answers and questions (Wilkinson et al., 2013), and providing context to issues arising from a medical consultation (Chinn & Rudall,

2019). However, among some PWLDs, the CSW was occasionally viewed in mixed terms, ranging from them being assistive to usurping (Burton & Walters, 2013; Wullink et al., 2009). The varied perceptions of CSWs by PWLDs could be attributed to several factors, including the context in which communication took place (Chinn & Rudall, 2019) and the cognitive capacity of PWLDs providing the information (Murphy, 2006; Wullink et al., 2009). For example, some people with mild learning disabilities perceived the CSW positively in relation to their role as interpreters, clarifiers, sources of moral support and as a "second pair of ears" (Murphy, 2006; Wullink et al., 2009).

In order to demonstrate how CSWs, HCPs and PWLDs interacted during a primary healthcare consultation, Antaki and Chinn (2019) used video recordings to explore their three-way verbal interactions. The recordings demonstrated that during these interactions, the CSWs inappropriately arrogated to themselves the power to give information to the HCP, regardless of the cognitive capacity of the individual they were supporting. CSWs' actions and attitudes during these consultations demonstrated that they regarded themselves as having epistemic authority over the health information they had about PWLDs. However, some of the information given tended to be unnecessary. In addition, CSWs tended to contradict and qualify what a PWLD said and usurped conversations (Chinn & Rudall, 2019). Viewing the manner of communication displayed by CSWs in the Chinn and Rudall (2019) study from the perspective of the Mental Capacity Act (MCA) (2005) in which an individual is initially presumed to have capacity, the actions of the CSWs violated the law by assuming incapacity even when some of the people they supported did have capacity to speak for themselves.

Although the CSWs' role in communication was recognised in this review as being critical, it was however observed that CSWs have to discharge this role with due diligence owing to the greater power they have over PWLDs (Antaki & Chinn, 2019; Chinn & Rudall, 2019; Wilkinson et al., 2013). The necessity for CSWs to take due diligence in their communication arises from the findings of this review (Chinn, 2017), which demonstrate that there are factors that militate against the communication capacities of PWLDs such as power imbalances. Recognising this,

CSWs ought to be the first in being more empathetic and supportive, in comparison with HCPs when they communicate with and on behalf of PWLDs (Chinn & Rudall, 2019). From the CR and SMD perspectives, the failures in communication by CSWs act as a hindrance to healthcare facilitation for PWLDs and constitute social barriers that disable PWLDs.

2.8.1.3 Sub-theme 3: Identification of symptoms and signs

Identification of symptoms and signs is the basis for determining whether an individual is sick or well. A sign is a visual cue that a person who is unwell manifests to a clinician or an observer such as a CSW. A symptom is a subjective report from someone who is unwell. Staiano (2016) posits that pain is both a sign and a symptom even though an assessment largely depends on how the sick person presents themselves. In view of the CSWs' role as the first in line in identifier of illness, even minor changes in habits become a critical basis for determining either the presence or absence of illnesses for people who may have reduced capacity to complain.

Identification of symptoms and signs as a key role of CSWs was highlighted in several studies (Burton & Walters, 2013; Felce et al., 2008; Findlay et al., 2015; Thornton, 1999). Findlay et al. (2015) identified a variety of attitudes which CSWs brought to the skill of assessment and identification of signs and symptoms, particularly pain. Most participants admitted that they had difficulties in recognising pain among PWLDs. In addition, when PWLDs who had verbal capacity were in pain and sought help from CSWs, their complaints were in some cases either ignored or attributed to other motives such as avoiding participation in specific activities (Findlay et al., 2015). CSWs who managed to identify symptoms and signs of pain attributed this ability to trial and error, knowing the person over a long period and sharing information as a team. Equally, Jones et al. (2008) highlights how knowing a PWLD well enhanced the capacity of CSWs to identify any deviations from normal bodily functions. Knowledge of identifying signs and symptoms was helpful when it came to summoning help from HCPs either by way of making a callout at night or

when escorting a PWLD to the GP surgery (Burton & Walters, 2013; Thornton, 1999). In as much as identification of signs and symptoms is a critical skill and a role that must be demonstrated by CSWs, this review highlights the difficulty inherent in this role. Given that most participants had difficulties in identifying signs of ill-health, specifically pain, this greatly undermines the role of CSWs as first line responders in healthcare facilitation for PWLDs; the absence of this vital skill is a barrier to their accessing healthcare. The capacity to assess and identify pain promptly could be attributed both to the skills of CSWs and the nature of learning disability; this is especially so when CSWs support individuals who have profound learning disabilities.

of CR is a barrier to timely healthcare access. However, there are other structural factors associated with this such as the lack of training provision by organisations employing CSWs. The structural factors in turn put both the CSWs and the PWLDs at a disadvantage because the absence of the required skills risks impairing the CSWs' effectiveness, and in turn risking the lives of PWLDs.

2.8.1.4 Sub-theme 4: Advocacy

Advocacy is an act undertaken by one individual on behalf of another, with the aim of representing the views of the other person who may lack capacity to present their own interests (Martins et al., 2011). In the Mental Capacity Act (2005), there is a recognition of advocacy in situations where an individual cannot make their own decisions (Martins et al., 2011). However, such decisions are to be made in the best interest of the individual concerned (Jingree, 2015).

In the current review, CSW advocacy was reflected in the way they challenged wrongful decisions and actions by HCPs (Burton & Walters, 2013). Advocacy was equally notable in how CSWs articulated issues regarding healthcare needs of PWLDs (Jones et al., 2008). Burton and Walters (2013) highlight how CSWs were able to identify shortcomings in the services provided to PWLDs by HCPs, and that the advocacy role of CSWs enhanced the care of PWLDs (Burton & Walters, 2013). The advocacy role of CSWs was further noticed when doctors failed to attend home

appointments (Jones et al., 2008). Advocacy was also demonstrated by CSWs in relation to empowerment of PWLDs to participate in health promotion activities (Messent et al., 1999). Advocacy was additionally highlighted during routine consultations with GPs (Murphy, 2006) and was undertaken alongside other roles, such as prevention of ill-health (Findlay et al., 2015; Willis et al., 2010). CSW advocacy facilitates healthcare access by redressing shortcomings such as failure by GPs to attend to PWLDs as well as providing a representation for PWLDs (Burton & Walters, 2013).

2.8.1.5 Sub-theme 5: Collaboration

Collaboration is a process of interaction both within a given professional group and across disciplines with the aim of achieving specific shared mutual goals (Bookey-Bassett et al., 2017). Central to the collaboration process are aspects of communication, teamwork and mutual respect (Bridges et al., 2011). Collaboration was evident in relation to CSWs as team players with various agencies. In this role, CSWs demonstrated both positive and negative attributes (Powrie, 2003; Windley & Chapman, 2010). In the positive role, the CSW was cast as a key member of multi-disciplinary teams, whose participation enhanced such teams (Kruger & Northway, 2019; Windley & Chapman, 2010). However, negative aspects of the collaboration process were noted by all the parties involved including CSWs. The negative aspects highlighted were the domineering attitudes by other agencies in the activities undertaken in conjunction with CSWs (Windley & Chapman, 2010). In contrast, CSWs preferred "direct involvement in planning" with other agencies to receiving directives (Windley & Chapman, 2010, p. 315). In addition, CSWs found that there were occasions when there were no clear agreements as to who was responsible for jointly initiated projects with social workers and speech therapists (Windley & Chapman, 2010).

Views from collaborating agencies highlight how some CSWs were not always aware of the healthcare needs of PWLDs (Thornton, 1999). However, in contrast Tuffrey-Wijne et al. (2016) observed that CSWs were keenly aware of their role in the interdisciplinary teams as well as in relation to their specific responsibilities in the

healthcare of PWLDs. Nevertheless, CSWs were occasionally frustrated by HCPs who could not provide an enabling environment for collaboration (Tuffrey-Wijne et al., 2016).

The collaboration process highlighted demonstrates negative power dynamics between CSWs and other professionals. In the collaborative role, the CSW sought to be a facilitator of healthcare for PWLDs. However, due to the unconducive power dynamics within the multi-agency teams, the collaborative role of the CSWs was occasionally thwarted. From the perspective of the Social Model of Disability, the negative aspects of collaboration represent structural barriers to healthcare access which ultimately hinder optimum delivery of healthcare services to PWLDs.

2.8.2 Theme 2: Organisational challenges and facilitators

Unique to this broader theme are two sub-themes: organisations as factors in healthcare facilitation and role clarity. Organisational factors can be defined as specific aspects of the CSW's work which are within the remit of the employers, the government, and other agencies; such aspects are based on law, policy, management style, resource allocation and prevailing procedures at national or local levels. These aspects have been identified in relation to how they impact the role of the CSWs in the facilitation of healthcare for PWLDs.

2.8.2.1 Sub-theme 1: Organisations as factors in healthcare facilitation

The following studies cover various aspects of organisational issues, Powrie (2003); Messent et al. (1999); Murphy (2006); and Tuffrey-Wijne et al. (2016). Powrie (2003) specifically highlighted how high staff turnover impacted on the ability of women with learning disabilities to attend their GP appointments. Not only were the women failing to attend appointments, but new staff were unable to provide continuity and adequate information when they accompanied them to the GP surgery (Powrie, 2003). Messent et al. (1999) highlight that staff shortages led to the failure of PWLDs to engage in physical activities as there were not enough staff to supervise them. Staff shortages, high staff turnover and the attendant consequences of either

lack of services or failure of continuity of services to function at an optimum level undermined the role of CSWs in healthcare facilitation; consequently, these acted as barriers to the healthcare of PWLDs. The barriers highlight the culpability of institutions employing CSWs and providing support services to PWLDs. From the SMD perspective, these barriers disable PWLDs; and from the CR and SMD standpoint, they are structural. A structural barrier is foundational, and, as such other factors such as healthcare access and continuity of care are contingent upon them.

2.8.2.2 Sub-theme 2: Role clarity

Role clarity is the degree to which an employee understands and performs their job role in accordance with its demands (Bochatay et al., 2017). The demands of the job may be based on a stated job description, traditional expectations, or perspectives of collaborating agencies (Blumenthal et al., 1998).

Role clarity was explored in several studies, namely Kruger and Northway (2019); Wullink et al. (2009); Wilkinson et al. (2013); Antaki and Chinn (2019); Chinn and Rudall (2019); Murphy (2006); Findlay et al. (2015)); Willis et al. (2010); Windley and Chapman (2010); Willis (2015b); and Tuffrey-Wijne et al. (2016). Role clarity is impactful - if the role holder fails to perform the demands of their role, this translates into poor service delivery; conversely when the role holder performs according to the expectations of their role, a satisfactory service is received (Tuffrey-Wijne et al., 2016). Besides CSWs, other partners such as PWLDs, doctors, nurses, and other agencies have their various expectations of the CSW role in the facilitation of healthcare. The findings demonstrate that CSWs either carried out or failed to carry out their job roles; their role performance was determined by how CSWs interpreted their role in various situations (Tuffrey-Wijne et al., 2016). In one of the studies, the findings highlight how CSWs did not consider that support of PWLDs' health was an integral part of their role (Willis, 2015b). However, this view was not common in the other studies reviewed.

Role confusion among CSWs was identified in a study which focused on behavioural specialists who worked with PWLDs. The behavioural specialists were of the view that the needs of CSWs occasionally competed with those of PWLDs during GP consultations (Kruger & Northway, 2019). However, doctors generally viewed the role of CSWs positively (Wilkinson et al., 2013), seeing them as key partners during GP consultations and hospital admissions (Tuffrey-Wijne et al., 2016; Wilkinson et al., 2013).

Challenges regarding the clarity of the role of CSWs were equally raised by the expectations of PWLDs and nurses (Tuffrey-Wijne et al., 2016; Young et al., 2007). PWLDs expected CSWs to be an all-rounder in their supportive role (Young et al., 2007). One PWLD indicated that they expected CSW to take full responsibility for their support needs (Young et al., 2007). Nurses on the other hand, were of the view that CSWs were not performing a nursing role (Powrie, 2003; Tuffrey-Wijne et al., 2016). The nurses' concerns were that CSWs were only offering a narrow spectrum of care. Instead, nurses expected CSWs to provide not only physical support, but a broader holistic spectrum of care that also included psychological care; in this respect, nurses' expectations went beyond the remit of the role of CSWs (Powrie, 2003; Tuffrey-Wijne et al., 2016).

Reflecting on these findings from the CR perspective, the role of a CSW is impacted by structural factors, which belong to the 'actual' domain of CR. The structural factors consist of mechanisms which determine the outcomes; for example, failure by an organisation to clarify roles is a structural issue. The implications for role performance in hospitals and other clinical contexts are that there are no delineated boundaries where the role of CSWs ends and that of the nurses begins. The outcome is both role ambiguity and failure to deliver services expected of a given role. As the review findings demonstrate, nurses have their own expectations which are not in line with the CSWs' role in a similar setting. According to CR, structural issues should be addressed by policies and regulations rather than undefined expectations.

2.8.3 Theme 3: Knowledge

This broad theme of knowledge encompasses two sub-themes: skills deficit; and learning by trial and error and self-efficacy. The sub-themes share features like the CSWs' awareness of the need to fulfil the demands of their role but also of their lack of specific skills needed. The lack of specific skills for the job led CSWs to draw on their experience from other related skills (self-efficacy) to perform what was expected of them.

2.8.3.1 Sub-theme 1: Skills deficit

The phrase 'skills deficit' is used in this context to mean those critical skills which would be necessary for the efficient performance of a task in relation to healthcare facilitation for PWLDs by CSWs but were absent. The skills expected may be basic but are sufficient to undertake a task. The skills expected are not at the level of those of fully trained professionals in a specialised area such as nursing or medicine. This review identified areas where the CSWs were competent but equally, areas where they lacked adequate skills. In areas where CSWs lacked adequate skills, they resorted to adopting old skills and adapting them to new situations or learning by trial and error. The sub-theme of skills deficit was identified in research by Powrie (2003), Thornton (1999), Chinn and Rudall (2019), Findlay et al. (2015), Willis et al. (2010) and Windley and Chapman (2010). Powrie (2003) identified areas of skills deficit in breast cancer risk awareness and in the provision of continuity of appointments whenever there was a change of staff. The lack of breast cancer risk awareness by CSWs has led to a call by some researchers for GPs to provide training to CSWs in this specific area (Willis, 2015b). The inability to keep appointments with the GP was attributed to failure to provide continuity in communication between old and new CSWs supporting PWLDs due to not prioritising communication as an essential skill. The lack of communication among CSWs impacted the ability of PWLDs to keep regular appointments with the GP (Powrie, 2003). A skills deficit is evidently a barrier to healthcare facilitation for PWLDs. From a CR perspective, it is a structural issue that requires policies to address so that CSWs acquire the skills they need. From the SMD standpoint, it is equally a structural issue, in that it is a hindrance to the delivery of essential services.

2.8.3.2 Sub-theme 2: Learning by trial and error and self-efficacy

Self-efficacy and learning by trial and error were observed to be common characteristics among CSWs, as evidenced in research by Burton and Walters (2013), Kruger and Northway (2019), Findlay et al. (2015) and Windley and Chapman (2010). Burton and Walters (2013) observed that CSWs were appreciative of new innovations and embraced them. Burton and Walters (2013) further suggested that most CSWs were initially not conversant with a new scheme of *Access to Medicare funded annual health assessment* for PWLDs. However, they note that once the CSWs had a longer exposure to the new scheme, they were able to appreciate its benefits (Burton and Walters, 2013). CSWs' knowledge was also demonstrated in the same study by their ability to identify gaps in the knowledge of doctors regarding PWLDs. CSWs were also observed to be resourceful when collaborating with other agencies and providing positive behavioural support plans for PWLDs (Kruger & Northway, 2019).

These observations demonstrate that although CSWs learnt by trial and error as well as being efficacious, there is a need for systematic planned training. Lack of skills is primarily in the 'actual' domain of CR; the implication is that it is a structural issue which needs to be addressed at the organisational level. From the SMD perspective, lack of skills put PWLDs at a disadvantage by depriving them of the support they could have received had the CSWs been well trained in those specific skills.

2.9 Discussion of findings

This section discusses the key findings of the review. The findings are situated within the wider body of literature, in addition, the discussions highlight policy implications.

2.9.1 Communication and epistemic authority

Communication was the major theme underpinning various studies, The views obtained from people with mild and moderate learning disabilities suggest that they would prefer to express themselves as individuals rather than through their CSWs during GP consultations (Burton & Walters, 2013; Wullink et al., 2009). Despite this, CSWs were observed to deny them this opportunity even though the MCA (2005) does not allow the CSW to presume their incapacity (Nicholson et al., 2008). Central to the ethos of the MCA (2005) is the empowerment of PWLDs (Jingree, 2015); when this empowerment is not taken into account by those who should advocate for that right, it undermines this important principle of the MCA (2005), which is to assume a person has capacity until proven otherwise (Jingree, 2015; Nicholson et al., 2008). By taking away their right to communicate for themselves (PWLDs), CSWs create a barrier to healthcare access. Additionally, when CSWs deny PWLDs an opportunity to speak, they are acting as part of the structures that disable from the perspective of SMD. According to MCA (2005), professionals who act negligently regarding the rights of people protected by this law can be held accountable for their actions in court (Nicholson et al., 2008).

Antaki and Chinn (2019) advance a theory of epistemic authority to describe which individual is the rightful owner of information; the relevance of this theory in this review lies in the relationship between a CSW and a PWLD. According to the theory, an individual who has the most knowledge tends to exert the most epistemic authority (Heritage & Raymond, 2005). However, epistemic authority theory also recognises that the owner of an experience ought to have the primary epistemic authority over the information they give (Heritage & Raymond, 2005). In the relationship between a CSW and a PWLD, the rightful owner of the experience and consequently the information regarding their health is a PWLD. This right can only be shifted to another person after applying the principles of MCA (2005), and there should be documentation for taking such an action (Nicholson et al., 2008).

As this review has highlighted, some of the CSWs inadvertently or wilfully usurped PWLDs' right to speak for themselves during GP consultations. By disregarding PWLDs as the rightful owners of epistemic authority, the CSWs also failed in their duty of care, especially to the people with mild and moderate LDs. The MCA (2005) assumes that anyone who deals with people with diminished mental capacity must have read and understood the stipulation of the law, so that no one can claim lack of awareness when they have contravened its demands (Nicholson et al., 2008). Given that, there will be situations where CSWs should exercise epistemic authority; for example, regarding people with severe and profound learning disabilities, CSWs ought to be conscious of their greater epistemic authority and its potential to influence GP consultations (Chinn & Rudall, 2019).

As a further measure to empower PWLDs, Bakker-van Gijssel et al. (2020) argue that GPs could tailor their primary healthcare consultations with PWLDs to their cognitive capacities, especially those categorised as having mild to moderate LD. Bakker-van Gijssel et al. (2020) suggest an interview format for GPs called the 'cognitive interview technique', which could be used flexibly with some PWLDs, especially with those with mild to moderate forms. The tendency for the GP to opt to first speak to the CSW may suggest that they are unaware of the requirements of the MCA (2005).

2.9.2 Role clarity and its impact on healthcare facilitation

The issue of role clarity impacting the facilitation of healthcare was identified in several studies. Its relevance is that clarity regarding their job description is key to the CSWs' performance of their job. Consequently, role clarity or role confusion has a bearing on the outcome of a performed task (Tuffrey-Wijne et al., 2016). However, this review demonstrates there are two sides to role clarity; one side is from the perspective of the role-holder, and the other side is that of onlookers, those who interact with the 'role-holder' such as HCPs, PWLDs and even co-workers. Contrasting expectations regarding the role of a CSW were demonstrated in various settings and activities such as hospitals and GP consultations. For example, in the

hospital, nurses envisaged the role of a CSW to be like that of a nurse; this is in contrast with that of a CSW who routinely provides a supportive role when a PWLD is well (Tuffrey-Wijne et al., 2016). This finding is corroborated by Lewis et al. (2017), who found that nurses' expectations regarding the role of CSWs was unrealistic. This tension in role expectations results in poor collaboration and poor communication (Lewis et al., 2017). Furthermore, it has been acknowledged that one of the contributing factors to the poor health of PWLDs is the HCPs' negative attitude towards both CSWs and PWLDs during consultations and hospital admissions (Desroches, 2020).

The review highlighted the lack of recognition of CSWs' expertise by HCPs and the implications of this for healthcare delivery. The disproportionately higher mortality among PWLDs has been attributed to failure by HCPs to recognise the role and contributions of CSWs (Heslop et al., 2014) Despite other professions' lack of recognition of the critical contributions of CSWs in healthcare, the CSWs were evidently aware of their vital role in specific areas of the healthcare of PWLDs. This role awareness was evident in relation to identification of signs and symptoms, and health promotion and communication, even though in some cases this was through trial and error and despite inadequate skills. In addition, CSWs were able to fulfil their roles in healthcare facilitation in the absence of detailed published role expectations (Messent et al., 1999). The implication for the future is the necessity for other professions to recognise CSWs' expertise and work alongside them.

This review has highlighted that HCPs lack clarity regarding the role of CSWs by leading to either under-expectation or over-expectation. In view of this, there is a necessity for inter-professional dialogue and training between HCPs and CSWs to enhance each other's roles and provide clarity. This has the potential to improve the way PWLDs access healthcare.

2.9.3 Staff shortages and high staff turnover impact on healthcare facilitation

This review has identified how staff shortages and high staff turnover impact on continuity of service and on timely access to healthcare for PWLDs, this finding being corroborated by recent evidence (Trip et al., 2022). These two issues were organisational, implying that they were under the remit of the employers of CSWs. Staff shortages are structural issues that act as indirect barriers to health equity for PWLDs, and the solutions to which are institutional. The impact of staff shortages and high staff turnover translate into PWLDs missing planned appointments, into breaks in the continuity of care, and into a lack of time for healthy exercise (Messent et al., 1999; Powrie, 2003). Staff shortages were noted in one review as contributors to poorer health outcomes among PWLDs (Alborz et al., 2005). These findings translate into further poorer healthcare access for PWLDs, on account of fewer staff being available to facilitate timely healthcare. This assertion is corroborated by other studies (Chapman et al., 2018), which further highlight that attendance at GP appointments is very low due to staff shortages. Given the important role of CSWs in early identification of ill-health among PWLDs, staff shortages and high staff turnover are likely to worsen the health inequalities experienced by this population group. Delayed or absent access to healthcare results in the worsening of any health issues at a point when a service should have been sought.

O'Kell (2002), argues that there are several contributing factors to the twin problems of staff shortages and high staff turnover. Among them are staffing homes with a minimal number of staff, wages set at minimum wage level, long working hours leading to 'burn-out and low morale', and recruitment of low calibre staff. Organisational issues have an impact on staff shortages and high staff turnover and yet are amenable to solutions. Solutions such as increasing wages, relocation of facilities to areas affordable to CSWs, and increasing staff numbers to minimise workload have the potential to promote staff retention. These solutions fall in the 'real' domain of CR, in which organisational input from employers and policy changes form the basis of the solutions.

2.9.4 The contribution of this review

Previous systematic reviews of the role of CSWs in health care facilitation and access for PWLDs have focussed on the CSW's role in health checks (Alborz et al., 2005; Blumenthal et al., 1998; da Rosa et al., 2020). The focus on health checks is laudable as evidenced in Robertson et al. (2014) who argue that the success of health checks on PWLDs hinges on the CSWs' knowledge of the persons they support. The current review seeks to highlight the wider involvement of CSW's in the facilitation of healthcare for PWLDs and their access to primary and secondary care.

Martin and Roy (1999) recognised that the success of health checks on PWLDs depended on the realisation that CSWs are allies in the bigger team involved in health promotion. However, they noted that CSWs lacked the key skills necessary for the fulfilment of the role they were expected to undertake in health promotion (Martin and Roy, 1999). This review has identified several skills deficits such as those relating to communication, identification of early signs and symptoms as well as a failure to recognise the benefits of health checks like breast and cervical cancer screening.

The lack of CSW skills in some of the key areas of healthcare facilitation diminishes their effectiveness as primary facilitators of healthcare access. Alborz et al. (2005) specifically viewed the CSWs' role in early identification of symptoms and recognition of unmet health needs as critically important; they highlighted how without adequate training, CSWs could act as 'unwise' gatekeepers who may potentially minimise the severity of symptoms and consequently fail to take timely and appropriate action. Therefore, improving the skills of CSW has a potential bearing on both timely healthcare access and the quality and overall health of PWLDs.

Among the few previous reviews which explored CSWs in a wider role in healthcare facilitation is that by Hithersay et al. (2014); their review highlight CSWs in multiple

roles such as in health monitoring, health promotion, and health improvement. Hithersay et al.'s review (2014) further demonstrated that it is possible to have a CSW-led health intervention for PWLDs in primary health care. In contrast, most of the reviewed literature did not cast the CSWs as professionals with unique skills, but as assistive to nurses, doctors and even PWLDS.

This review highlights and locates the role of CSWs in a wider range of areas of healthcare facilitation besides health promotion, and health improvement and health checks. This review highlights CSWs as communicators, advocates, ardent learners, collaborators, and facilitators of healthcare access. CSWs undertook these roles despite various challenges such as organisational hindrances and limited skills. The CSW's role was evident both in primary and secondary healthcare systems. For example, in the secondary healthcare system, the CSW's expertise in support of PWLDs while hospitalised was deemed vital (Tuffrey-Wijne et al., 2016). This review's contribution is noted in its use of CR and SMD in the identification of structural issues which act either as enablers or hindrances in healthcare facilitation by CSWs for PWLDs. Through the lens of CR, the review has highlighted the experiences of CSWs, PWLDs and HCPs and how they were shaped by their interactions.

2.10 Conclusion

Facilitation and access to healthcare for PWLDs remain a challenge. The findings reveal that CSWs play a major role in the facilitation of healthcare access for PWLDs, from identification of early signs and symptoms of ill-health to the actual facilitation of access with an HCP. However, challenges were evident during this process. Challenges were at three levels: CSWs, organisations and HCPs. In turn, these challenges had implications for the role of CSWs in healthcare facilitation. Among the implications of these findings are the impacts on collaboration and communication between CSWs and the various partner agencies as well as on retention of staff.

The two issues of collaboration and communication featured in several studies. Among the ways they could be addressed is at organisational level. Organisation leaders, whether they be of HCPs or employers of CSWs, ought to view the impact of these issues on healthcare outcomes of PWLDs. The other challenges were skills deficit, staff shortages and high staff turnover.

The facilitative role of CSWs in the light of these findings ought to be viewed more broadly as being beyond meeting the daily care needs of PWLDs. This is because better facilitation and optimum access have an impact on not just improving the quality of the life of PWLDs but potentially reduces their morbidity and mortality. This review found that there is role confusion and ambiguity in relation to facilitating regular screening for cancers by CSWs. The need for CSWs to play a holistic role in early disease identification, prevention, promotion, and in healthcare access for PWLDs is critical. CSWs specifically need training in how to identify early signs of pain and ill-health in general in PWLDs. The review highlights that this important skill was acquired through trial and error where and when it was displayed. Recognising that CSWs are the first line in healthcare facilitation, this skill should not be left to trial and error.

The necessity to study the wider role of CSWs in healthcare facilitation for PWLDs arises on account of the paucity of primary studies dedicated to exploring this role. In the light of the findings of this review and given the multiple roles of the CSW in healthcare facilitation for PWLDs, such a study is deemed necessary. Consequently, the major gap in the primary literature was the lack of studies focusing on the barriers to and facilitators of healthcare facilitation for PWLDs from the perspective of CSWs. The experiences elicited from CSWs and cited in the reviewed primary literature were mainly from the perspective of HCPs. A study on the lived experiences of CSWs would fill this gap.

Chapter Three: Methodology and Methods

This chapter discusses the methodology used in this study and the theoretical perspectives underlying it. It also describes the methods used, including sampling and recruitment, and ethical considerations.

3.1: Methodology

This section outlines the theoretical perspectives upon which the research was conducted. It begins with an overview of the qualitative approach and then proceeds to discuss Critical Realism (CR) and the Social Model of Disability SMD).

3.1.1 Overview of the qualitative approach

This is a qualitative study conducted across England involving semi-structured interviews with Community Support Workers (CSWs) working with adults with learning disabilities. A qualitative methodology was chosen because it is considered suitable for exploring questions relating to the study of experiences (Mason, 2002), answering questions such as ‘why’ and ‘how’ (Silverman, 2009).

The focus of this research is to explore the experiences and challenges of CSWs in facilitating healthcare for adults with learning disabilities. The study seeks to answer the research question:

How do community support workers construct the challenges and experiences they encounter in facilitating the healthcare of adults with learning disabilities in healthcare?

This research question is premised on the understanding that CSWs have unique experiences both collectively and individually, and that such experiences are

constructed on how they perceive their role in healthcare facilitation for PWLDs. CSWs' experiences could also have been shaped by the challenges and facilitators both within their internal and external environments; for example, the closer working relationship with PWLDs, their knowledge about them and their interactions with HCPs. Through the CR approach, the researcher sought to identify not only the observed phenomena in the form of experiences but also the mechanisms and actions underpinning those experiences.

This qualitative study was undertaken through the lens of CR together with the Social Model of Disability (SMD) as a way of enhancing understanding of the lived experiences of CSWs. CR is closely related to qualitative methodology regarding its epistemology, in respect to its focus on the questions of 'what' and 'how'(Craig & Bigby, 2015). The SMD was used in this study to explore barriers regarding healthcare access encountered by both CSWs and PWLDs.

3.2 The theoretical approach

CR has previously been applied alongside, or embedded in, other approaches. Craig and Bigby (2015), for example, used CR in a qualitative study of PWLDs and highlighted the operational benefits of utilising CR in an environment where there is a closer relationship between a worker and a client. Similarly, CR was contextualised within this study's qualitative approach exploring the facilitative role of CSWs in the healthcare of PWLDs. As outlined in chapter 1, CR has three stratified levels or domains: empirical, actual and real (Fletcher, 2017). The real domain is at the lower level of the pyramid and consists of causal mechanisms such as governments, laws, regulations, norms and cultures (Anderson, 2020). The activities in the real domain give rise to the next level, the actual. Activities at the actual level consist of local programmes, systems, hierarchies of power, communication protocols and attitudes (Anderson, 2020). The actions in the actual domain lead to the empirical domain. The actions in the empirical domain are the events that the researcher observes and hears in the form of experiences (Anderson, 2020).

Having captured what is in the empirical level (participant interviews), the researcher proceeded to identify the actions demonstrating experiences in the actual domain. The researcher explored further by interrogating the phenomenon in the real domain to determine whether there were any mechanisms that accounted for the observed actions and experiences heard. The interrogations of phenomena took place both during data collection and data analysis. The three levels of CR are dynamic and interactive, (see Figure 5.1 for an illustration of this).

In the 'real' domain of CR, there are mechanisms which enable or restrain (Scott, 2013); in relation to this study, the knowledge of both enablers and restrainers was key in selecting CR as a theoretical approach. The choice in combining CR with SMD arises from their shared concerns as both approaches seek to remove inequalities and barriers to social change. In this respect CR and SMD are closely related.

Regarding the choice of the research question, the researcher recognised that there were specific hindrances and challenges that he was encountering in facilitating healthcare access for PWLDs, and the ability to identify some of those challenges was based on his knowledge of both the medical world and that of CSWs. In turn, this knowledge was important in the analysis of the data and the synthesis of findings.

3.3 Research Methods

3.3.1 Overview

This section describes and discusses the study design, the recruitment of participants, the data collection methods, methods of data analysis, data interpretation, and ethical issues.

3.3.2 Study Design

The researcher conducted interviews with participants (community support workers and managers) face-to-face, by telephone, and online via Microsoft Teams, across England. Initially, the study was planned to have been restricted to the Northwest of England, using face-to-face semi-structured interviews only. Due to the onset of the

Covid-19 pandemic in 2020 and the subsequent restrictions which were put in place from the beginning of March 2020 until July 2021, the necessary adoption of online data collection methods meant that the study could be broadened out to the whole of England. In addition, due to the challenges with recruitment during the early stages of Covid 19, other modes of recruitment were explored such as via Facebook, using the snowballing method. The adoption of new methods meant that the researcher had to seek new ethics permissions from Lancaster University to accommodate the circumstances.

3.3.3 The sample

The sample consisted of 12 community support workers and 10 managers. In determining an ideal number of participants for a qualitative study there are no set criteria. Marshall et al. (2013) suggest open-ended recruitment until data saturation. Data saturation is a theme-based method of determining when there are no new themes emerging within the data set; on average, this is around twelve interviews (Guest et al., 2006). A related concept is theoretical saturation, this being based on the number of participants deemed to be sufficient to meet theoretical saturation (Bryman, 2012). The term 'theoretical saturation' is normally associated with grounded theory, where data are collected until there are no new data that emerge to answer a given category (Bryman, 2012). However, the concept of theoretical saturation is now increasingly applied in other types of qualitative research (Saunders et al., 2018). Marshall et al. (2013) question the justification of having more than 40 participants in qualitative research; they argue that such a number compromises the depth of analysis devoted to the themes identified. In view of the above observations and the need to preserve depth of analysis, twenty-two participants were deemed sufficient.

3.3.4 Recruitment

Two methods were used for recruitment: purposive and snowball sampling. Purposive sampling is a non-probability technique that selects participants from the study population based on the suitability of the relevance of the characteristics being studied (Offredy & Vickers, 2013).Ten participants (managers) were recruited from one county council via their senior managers. Twelve CSWs were recruited via

snowball sampling across England, including one recruited via Facebook. Snowball sampling is a method of sampling whereby the researcher asks the primary set of respondents to invite others by word of mouth within the study population who meet the selection criteria (Bowling, 2009).

Table 4: Demographic data of participants and recruitment methods

NAME	GENDER	AGE	TITLE	METHOD OF DATA COLLECTION	METHOD OF RECRUITMENT
1 James	Male	62	Manager	Phone	Purposive
2 Bertha	Female	55	Manager	Phone	Purposive
3 Jane	Female	38	Manager	Face to face	Purposive
4 Rhoda	Female	42	Manager	Face to face	Purposive
5 Victoria	Female	55	Manager	Face to face	Purposive
6 Grace	Female	48	Manager	Face to face	Purposive
7 Dorothy	Female	36	Manager	Phone	Purposive
8 Becky	Female	43	Manager	Phone	Purposive
9 Patricia	Female	61	Manager	Phone	Purposive
10 Gertrude	Female	57	Manager	Phone	Purposive
11 Brenda	Female	59	CSW	Teams app.	Snowballing
12 Prisca	Female	61	CSW	Teams app.	Snowballing
13 David	Male	28	CSW	Teams app.	Snowballing

14 Maggie	Female	32	CSW	Teams app.	Snowballing
15 Stacy	Female	63	CSW	Teams app.	Facebook group (Purposive)
16 Mercy	Female	45	CSW	Teams app.	Snowballing
17 Gift	Male	63	CSW	Teams app.	Snowballing
18 Mary	Female	45	CSW	Phone	Snowballing
19 Annie	Female	66	CSW	Phone	Snowballing
20 Jack	Male	64	CSW	Teams app.	Snowballing
21 Richard	Male	62	CSW	Teams app.	Snowballing
22 Peggy	Female	57	CSW	Face to face	Snowballing

3.3.4.1 Review of recruitment methods used in this study

Provided below is a detailed discussion of the methods used to recruit the different categories of participants. The managers (n=10) were recruited via a senior manager of adult social services at a county council in the north-west of England. The process of recruitment took place during a meeting of the senior county manager and the ten junior managers; the researcher explained the purpose of the study, the main areas of focus, its potential benefits to policy and training. The dates for the first interviews were set for March 16, 2020. Eleven team participants were recruited, and 10 participants were interviewed (one withdrew). There were no CSWs recruited through the county council at this stage.

The first four participants were interviewed in March 2020. Owing to the onset of Covid 19, further interviews had to be rescheduled to July 2021 because the remaining participants were unavailable.

Recruitment of participants via Facebook went through the administrators of Facebook pages which had CSWs as members (see Appendix 11). Only one participant was successfully recruited and interviewed through Facebook. However,

through the (n=1) participant from Facebook, snowballing recruitment followed for the remainder of the participants (n=11).

3.4. Data collection

A semi-structured interview schedule was used to collect data. Semi-structured interviews use open-ended questions to enable respondents to easily express themselves (Flick, 2014). In addition, they allow the researcher to rephrase questions and facilitate exploration of more details based on the responses given by the respondents (Bowling, 2009) and provide a natural atmosphere of dialogue which is less interrogatory than questionnaires (Saldaña, 2011).

Two sets of interview guides were designed to accommodate the two different sets of participants: the CSWs (see Appendix 7) and the team managers (see Appendix 8). The face-to-face interviews and telephone interviews were audio-recorded. Microsoft Teams interviews were recorded and transcribed during the interviews and edited within 48 hours with the help of field notes taken during the interviews. Both face-to-face interview data and telephone interview recordings were transferred on to NVivo software, where they were transcribed and edited. Field notes were taken during and shortly after all the interviews to note non-verbal cues, silences, and emphases which a transcription may not record; these unspoken parts of the interview facilitate the researcher's understanding of the participants experiences (Papadimitriou, 2012). Field notes also facilitate the illustration of spoken words, in terms of tone of voice and other expressions of emotion (Patton, 2002). Field notes further increase the trustworthiness of the research findings by corroborating them ith the accounts of participants (Papadimitriou, 2012). Face to face interviews were used for the first four interviews with managers. A quiet room at their workplace, far from the usual working environments of the participants, was used to minimise interruptions. A recording device was used to record each interview. The advantages of using the face-to-face method were that it was possible to pick up both verbal cues and non-verbal cues. The cues allowed the researcher to assess the strength of attachment to the information given and allowed the researcher to provide clarity to questions which were not clearly understood. Owing to the onset of the pandemic, the methods of data collection needed to be adapted for subsequent interviews;

participants were offered the option of either phone interviews or online interviews using Microsoft Teams.

Telephone interviews were conducted using a mobile phone that had a recording capacity. The data collected were immediately transferred and encrypted for protection in accordance with the ethical approval earlier obtained from Lancaster University. The recordings were later transcribed using NVivo software.

The Microsoft Teams application was used because it enabled both the researcher and the participants to undertake interviews during Covid 19. In addition, the application had new features added to it during the research period. Although videos have long been used in qualitative data collection, as noted by Bryman (2012) and Silverman (2009), current technological advances have made it easier to work with video data in that recording and transcription take place simultaneously. The Teams Application had its occasional limitations, like brief loss of internet service or inaudible words. Another limitation of the Teams Application was that it transcribed words spoken both by the interviewer and interviewee in ways it understood them resulting in distortion of what was said. In view of this, the need to take field notes during the interview process to fill in the gaps during the editing of the transcription was still necessary. Due to the high resolution of pictures, the Teams App shares some of the advantages of face-to-face interviews such as the ability to pick out both verbal and non-verbal cues.

3.5 Data Analysis

Thematic analysis (TA) was selected because it is systematic, logical, and adaptable to qualitative studies (Braun & Clarke, 2006; Bryman, 2012; Castleberry & Nolen, 2018). TA was used in conjunction with CR and SMD as theoretical perspectives at every level of analysis. Braun and Clarke (2006) highlight the use of TA alongside other theories including CR. Thematic analysis is defined as a "method for identifying, analysing and reporting of patterns within data" (Braun & Clarke, 2006, p. 79). Bryman (2012) observes that despite its lack of an agreed common system of codification, TA has been applied across epistemological positions with some

adaptations. For example, TA was utilised in a qualitative study focusing on the experiences of unpaid carers of PWLDs in Australia (Newton & McGillivray, 2019a).

While cognisant of adaptations of TA, Braun et al. (2012) have provided guidance designed to avoid poor application. The Braun et al. (2012) guidance reiterates and reifies the six phases which were in the original work (Braun & Clarke, 2006). The six phases of TA espoused by Braun et al. (2012) are discussed below. Phase entails "Familiarising yourself with the data**,**" which involved rereading of the transcripts several times and listening to the audio-recordings, and, where Microsoft Teams was used, watching and listening to video replays of the original data; Phase 2 entails "Generating initial codes" and involved the identification of material from the data set that was relevant to the research question. The process of generating initial codes incorporated the perspectives of CR and SMD. Using the concepts of CR, the researcher considered collected data as belonging to the 'empirical domain.' In view of this, primary data was considered to represent a portion of the bigger picture, underpinning the 'real' and 'actual' domains. Being cognisant of this, the researcher continued interrogating the data by asking what could be underlying the experiences shared by participants. Some of the answers to the interrogation process were already in the data, others came through further analysis. For example, regarding the initial code, 'lack of knowledge of the Mental Capacity Act', the questions from the actual domain looked at why there was a lack of knowledge, what the underlying factors were and whether these might be due to lack of training. SMD was used in the asking of questions such as whether the factor was a barrier or a facilitator. In tandem with SMD, the researcher explored underlying mechanisms and their impact on healthcare access and facilitation. This interrogation process continued at all the stages of TA.

Each identified piece of data was then given a label called an initial code. The initial codes consisted of phrases that encompassed the ideas within the data set quoted from the transcripts. The process of making initial codes continued until the researcher was satisfied that there were no more items to code. The process of developing themes from the initial codes is illustrated by an extract sample in Figure 3:2 below. As this figure is a sample, it does not capture every code or the final themes, which are discussed in the findings chapter.

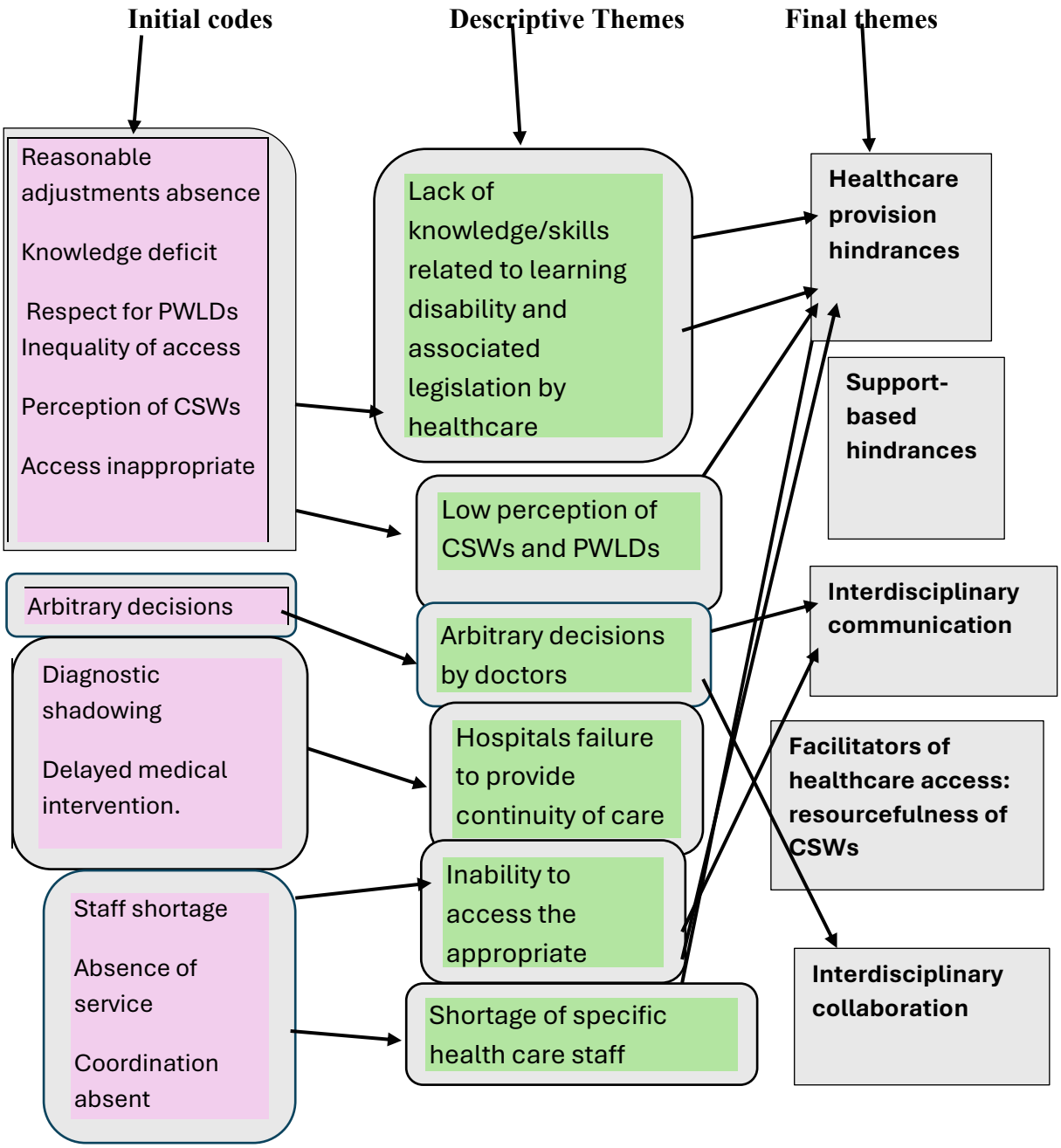


Figure 2: Sample illustration of selected final themes from initial codes

The third phase of Braun et al. (2012) is: "searching for themes", which involved assessing and searching for patterns in the initial codes found in phase two. The guiding principles were to determine which codes were related, repeated, and

overarching and then assemble the related codes under one theme. Each theme label was chosen to allow it to stand out distinctly from the other themes. In turn, each theme was selected based on its contribution to the research question. As Herzog et al. (2019) argue, the process of searching for themes is an 'active' intellectual process, whereby the researcher weighs the meanings of collated codes to ensure that the theme labels applied represent the codes under them. At this stage, sub-themes also emerge. Sub-themes are a group of related codes which share a closer pattern than the rest of the other codes in the main theme.

The fourth phase entails "reviewing potential themes." According to Braun et al. (2012), this phase has two stages designed to ensure quality of the analytical process. During the first stage, this researcher returned to the identified codes as well as the identified themes to make a review and compare. In cases where there were no closer similarities either the codes or themes were dropped altogether. In some cases, the codes were re-categorised under another theme where they were a good fit in terms of coherence and pertinence to the research question. Braun et al. (2012) suggest that the researcher further scrutinises the codes by asking a series of questions, including, for example, whether it is a theme. If it is, then the researcher assessed the utility value of the theme in relation to the data set and the research question. The researcher then undertook a delimitation process to determine what the theme could accommodate or exclude. And finally, the researcher determined the clarity of the theme in terms of how 'diverse and wide ranging' the items which constitute it.

The second stage of the fourth phase involved re-reading the whole data set. At this stage, the researcher made a dispassionate examination of the themes to determine whether they represented the data. Whereas the first stage focused on comparing themes and codes, this phase was a deeper analytic process which did not just involve rereading of the data set but went further, by posing critical questions to establish whether the themes represented the whole data set or were skewed towards what the researcher wanted to communicate. After rereading the data set and making comparisons, the researcher made a few changes by dropping certain themes.

The fifth phase of TA entails "defining and naming themes." A working definition was provided at the point where a given theme was first introduced. A definition sought to encapsulate what was involved in the theme under discussion. In some instances, the definition of a theme was a product of wide-ranging but related positions of scholarly work on a given concept. The naming of themes was followed by a further description and analysis of the theme. The analysis was then followed by data extracts which illustrated the theme and provided participant perspective. This was followed by further interpretation. As Braun et al. (2012) note, the boundary between the fifth phase of TA and the sixth is 'blurred'. Although the sixth phase, known as "producing the report" appears to be the last stage in the TA process, nevertheless, actual writing starts within the first phase of TA and goes on until the end of analysis (Herzog et al., 2019); the writing up process was iterative.

3.6 Ethical issues

The term 'ethics' means practising research in accordance with a set of principles prescribing what is considered correct based on the ethical standards given by a research-governing body such as the Economic and Social Research's Council Research Ethics Framework (Offredy & Vickers, 2013).

3.6.1 Ethics approval

Ethics approval for this research was sought from the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University (see Appendix 12) and a local authority in the North-West of England (see Appendix 10).

3.6.1.1 Participant consent

The consent of the participants was obtained after they had received the information pack containing the purpose of the study, had read it, and had indicated a willingness to participate in the research. Each participant gave their consent to participate in writing. Information packs were sent either directly, in physical form, in the case of managers or electronically for the remainder of the participants. This was done to

ensure that participants gave informed consent. As Oliver (2003) argues, participant autonomy in research is exercised when they have a right to give free consent to the research. Participants were further informed that they were free to withdraw from the research process at any stage.

3.6.2 Confidentiality and data management

Data management was governed by General Data Protection Regulation (GDPR); among its six core principles is the confidentiality of data (Goddard, 2017). In view of this, several measures were taken to meet the requirements of this regulation. For example, participants were informed that information given would be anonymised and assured that whatever information was published would not be traceable to them specifically. Participants were further assured that only their pseudonyms would be used in any research documents, and any identifiers, such as their names and the location of interviews, would be removed during transcription.

In terms of data storage, interview data were immediately anonymised by allocating unique codes representing the names of individual participants. Only the researcher had access to those codes. The data transcripts which were captured in electronic format were encrypted, stored and protected with a password on a laptop. Later, the electronic data was transferred and saved on Lancaster University server where it will be stored securely for ten years and then destroyed. Text data will be kept by Lancaster University, where it will be stored in a securely locked filing unit; access will only be for further research and evaluation of the study. A copy of the anonymised data was kept for personal use in a secure encrypted storage. Once the final submission of the thesis and a summary report have been made, any personal details accompanying the text data will be destroyed before storage. Audio data will be destroyed after the thesis has been assessed.

3.7 How rigour was achieved

The necessity for rigour in qualitative research arises on account of the recognition that the worthiness of a study lies in the transparency and actions undertaken by the researcher when conducting various stages of the research process (Long & Johnson, 2000). In view of this, various elements are considered key in determining rigour in qualitative research; these are credibility, transferability, conformability and dependability. Credibility is the extent to which research findings demonstrate the participants 'actual experiences (Lincoln & Guba, 1985). Transferability is defined as the extent to which findings can be applied and contextualised to other situations. Confirmability applies to the freedom that the findings have from the biases and preferences of the researcher. Lastly, dependability is described as the persistent relevance of the research findings to withstand the test of time. Despite the common use of the above criteria, there is however no unanimity among qualitative researchers on the full criteria to be applied to qualitative research to demonstrate rigour (Garside, 2014). Actions undertaken during the research to achieve rigour are described in

Table 5: How rigour was achieved

Assessment measure	Actions undertaken to achieve rigour
Credibility	**Reflectivity**: The researcher recognised that he was undertaking research in an area where he was known by some participants (n=4), and his experience risked biasing the research design in the development of questions, and conduct of interviews, data analysis and conclusions. Mitigation measures included being aware of the bias as well ensuring that participants known prior to the interview were treated in the same way as those who were not known. **Location of interviews**: A variety of settings including participants' private offices and homes. This was to provide comfortable natural environment for the participants. **Prolonged contact**: The researcher had prolonged contact with some of the participants to explain the aims of the study prior to the research to gain their trust. This was not possible with all participants

Confirmability	**Peer debriefing** was undertaken with peers in the same cohort during conferences, academies and informal interactions to get their feedback. In addition, there were meetings with research supervisors.
Transferability	**Rich and thick descriptions** of inclusion and exclusion criteria, settings for interviews, sample characteristics, sample collection, and data analysis methods are provided in the research document **Sampling strategies** have been clearly articulated in the relevant sections of the document,
Dependability	**Methodical documentation**: The steps undertaken in the research, such as ethics approval, data collection instruments, and the process of data analysis, have been highlighted in this research document. An audit was kept demonstrating decisions taken at various stages of the research process as well as sources of data is illustrated in chapter 3 and citations used in the reference sections.

	Appendices 1a and 1b illustrate how search terms were applied. Other decisions undertaken have been documented in the relevant chapters.

Regarding my reflections of the research process**,** I undertook this project knowing that my experiences as a CSW, former HCP and educator in the healthcare field were likely to consciously or unconsciously impact every stage of the research process. Because of this, I approached the research task as a fresh opportunity to learn, interrogate and analyse, with an open mind. In situations where participants expected me to give my own opinion to the questions posed to them, I would always state that their experiences were unique and assured them I was there to

learn from them rather than give my own opinion. My participants were drawn from various racial mixtures, and this may have affected how participants perceived me as a researcher from a Black African background with a foreign accent and vocabulary different from theirs. Yet in other aspects the researcher shared a common background of having worked with people with learning disabilities. The shared background encouraged the development of rapport, which in turn enabled them to be more open about their experiences than would have been the case if they had been interviewed by someone who did not share their experiences (Ross, 2017).

Chapter Four: Findings

4.1 Introduction

This chapter represents the findings from twenty-two semi-structured interviews conducted with community support workers (CSWs) and their managers drawn across England. The interviews capture the experiences of participants who were interviewed between March 2020 and August 2022. The group consisted of ten managers of CSWs and 12 CSWs. The interviews resulted in five overarching themes, and sub-themes emerged (see Figure 3).

The research question, aims and objectives of this study are:

Aim: To explore the experiences of community support workers in facilitating healthcare access for adults with learning disabilities.

Objectives:

1. To identify the challenges and facilitators that community support workers experience when they facilitate access to healthcare for people with learning disabilities.

2. To examine the role of community support workers in the coordination of the healthcare needs for adults with learning disabilities with other agencies.

Research question: How do community support workers construct the challenges and experiences they encounter in facilitating the healthcare access of adults with learning disabilities in healthcare?

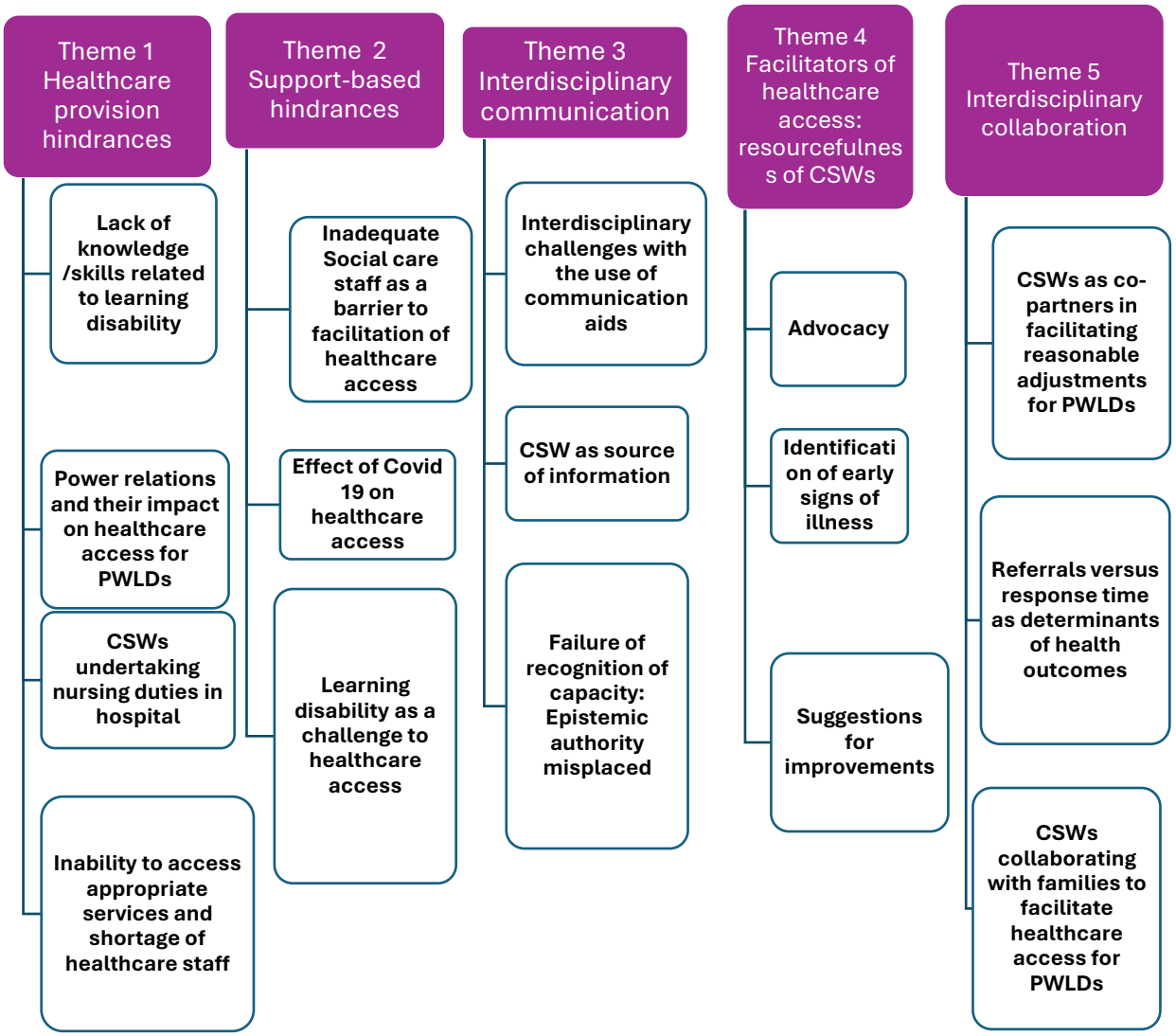


Figure 3 Themes and sub-themes.

4.2 Theme 1: Healthcare provision hindrances

This theme focuses on objective 1, which seeks to identify the challenges CSWs face as they facilitate healthcare access for PWLDs. Healthcare provision is a multidisciplinary activity and, as such, the hindrances encompass a variety of professionals other than doctors and nurses. Healthcare provision hindrances can be defined as any factors that hinder the successful access to healthcare of PWLDs, including negative attitudes, absence of reasonable adjustments and lack of skills and knowledge in dealing with PWLDs.

This theme has four sub-themes: lack of knowledge/skills related to learning disability by healthcare professionals (4.2.1); power relations and their impact on healthcare access (4.2.2); CSWs undertaking nursing duties in hospital (4.2.3); and inability to access appropriate services along with a shortage of specific healthcare staff (4.2.4)

4.2.1 Lack of knowledge/skills related to learning disabilities

The information in this section is in response to the question on challenges faced by CSWs. in meeting the goals of healthcare. Participants' accounts highlight how there was a lack of knowledge of learning disabilities and the associated legislation among some of the HCPs. This characteristic was observed mainly among doctors and nurses. Lack of knowledge and skills relating to learning disabilities constituted a barrier in that reasonable adjustments were not made by HCPs when services were accessed by PWLDs. According to the Equality Act 2010, reasonable adjustments must be made for disabled people when they access a service such as healthcare.

Reasonable adjustments are actions or changes required or expected from public institutions in the UK to their physical infrastructure, working policies and service delivery to enable disabled people access a service that is commensurate with their needs at a given point. Such reasonable adjustments include recognising the right of PWLDs to receive a service they require without discrimination.

The lack of awareness in relation to PWLDs and the associated legislation governing how HCPs should support them was observed by certain participants during healthcare facilitation. This is illustrated by the following quotation.

"And because the hospital system or the doctor's surgery system is all built on appointments and you come in, you sit here, you wait till it's your turn, and that is similar to the system that can act as a barrier to some individuals we support. They don't have the capacity to understand this process. Some things like that. So, a little bit more flexible flexibility and the way that services are provided." James (Manager)

Similar observations to the above were made in healthcare facilities such as GP surgeries, Accident and Emergency (A&E) departments, as well as during hospitalisation of PWLDs. The observation highlights that services were homogenously tailored without taking into consideration the specific needs of PWLDs. In view of this, participants considered the actions taken by HCPs, and the services offered, as discriminatory towards PWLDs as they did not accommodate their needs. While overt discrimination may not be blamed in all cases where reasonable adjustments were absent, the findings demonstrate either lack of knowledge or lack of awareness about learning disabilities as the main factors. Absence of reasonable adjustments was noted even when CSWs had made efforts to seek for their provision. This is illustrated as follows:

"You explain that she's autistic and they can't stand up to noises, but it doesn't mean a thing to them. But someone who is knowledgeable that this is an autistic person sensitive to very sharp noises they'll be careful around that person." Mercy (CSW).

This excerpt suggests that some HCPs were not only failing to provide reasonable adjustments, but they were also lacking understanding about co-morbidities associated with a learning disability, such as autism. The notable exception among HCPs who were observed to provide reasonable adjustments routinely were dentists and occupational therapists. Several participants spoke about the need to ensure that reasonable adjustments were put in place by HCPs. Among some of the reasonable adjustments expected was the creation of an environment that was autism friendly.

Durations of consultations for PWLDs are guided by government policies to accommodate the unique challenges PWLDs have. The policies require that PWLDs should be allocated extra time during GP consultations. However, some of the participants observed that the extra time was not always allocated. CSWs, as facilitators of healthcare for PWLDs, routinely asked for specific times of the day as well as extra time allocation - which they considered to be a legal entitlement - for the people they supported. However, despite making these prior arrangements with GP surgeries the necessary reasonable adjustments were not always accommodated:

"We need the first appointment of the day. They always will send you an appointment that could be eleven o'clock, twelve o'clock. So, they don't always acknowledge what we say." Mary (CSW).

This observation highlights that some HCPs appear not to be conversant with the requirements of the legislation governing reasonable adjustments. The consequences in some cases where no reasonable adjustments were provided was either having a hurriedly undertaken consultation or having none.

4.2.2 Power relations and their impact on healthcare access

The information provided in this section is in response to the question on how the role of a CSW is perceived by other agencies. Being perceived and treated as lower class by most HCPs was a common observation in the interviews. The participants who raised this issue noted that being looked down upon was a major obstacle in facilitating healthcare access, as there were occasions when CSWs were not believed or respected. This perception of inferiority was mainly evident during primary healthcare consultations when CSWs presented to HCPs what they considered to be signs and symptoms of ill-health in PWLDs. Participants understood that their experiences of knowing the people they supported could have given a level of credibility to their narratives of the illness status of PWLDs

"I think some GPs and nurses need to understand that we although we're not medically trained, we do know a lot of history with regards to the individuals we

support. And we do know the people very well that they should take some of our opinions on board and our experience of knowing the people that we support rather than just on the medical grounds, because it is all about knowing the people to understand them, they can't verbally communicate". Stacy (CSW).

In addition, Mary (CSW) had this to say: "*I do feel that if people go into hospital, we are a sort of neglected at the bottom of the pile. They want to get rid of people with learning disabilities as soon as they can".* Mary (CSW).

These excerpts highlight that on account of the low perceptions that some HCPs had of CSWs, attitudes of under-valuing their accounts were observed. The participants appear to closely identify themselves with the people they are supporting; they are of the view that as CSWs, the disrespect and intolerance shown by HCPs towards PWLDs equally applies to them. These observations on the part of the CSWs have potential negative implication for the working relationship between CSWs and HCPs. A mutually respectful attitude between CSWs and HCPs is needed, so that both parties can draw on each other's expertise for the benefit of the healthcare of PWLDs.

A perception of feeling undervalued does not create a conducive atmosphere for healthcare facilitation but rather stifles the creativity and contribution of CSWs. In turn, it deprives HCPs of the vital information they would have had if an environment of mutual respect had prevailed. Consequently, it affects healthcare access for PWLDs:

"Uh to be honest, they look down upon us. They look down upon us to do this because we we're not classified as professionals. So, the people coming on board are the ones who are professional, and our job is seen as just as to look after these people. So, in my personal experience, we are looked down upon". Richard (CSW).

Participants recognised that doctors were experts in their own field in as far as medical knowledge was concerned. However, participants equally observed that there were occasions when doctors made decisions for PWLDs without due consultation with CSWs in their capacity as support staff. Decisions made by doctors

varied from failure to manage treatable conditions to making arbitrary decisions on behalf of PWLDs. Arbitrary decisions were made in matters of life and death where involvement and due consultation with CSWs would have been a better option. In addition, there were instances where doctors chose not to have any follow-up on investigations which they had earlier instituted. It took the initiative of the CSWs to ensure follow-ups on the initial investigations. These actions by participants led to reversals of some of the doctors' decisions. Sometimes it took the convening of best interest meetings for the doctors to act according to the standard medical and ethical protocols. The tendency to make arbitrary decisions was observed by most participants. Bertha's (Manager) observations exemplify the opinion of some of the participants:

"*But the investigation again wasn't followed and again that was around with the GP practice not following the MCA* (Mental Capacity Act) *correctly and just assuming because the lady had a learning disability and sensory impairment that she wouldn't tolerate the investigations. So, there was a time delay in identifying obviously. The lady did have a tumour... Then obviously MCA process, the best interest decision making process was followed in relation to what happened whether she could access treatment or not."* Bertha (Manager).

Most participants observed both before and during the Covid 19 pandemic that arbitrary decisions were made by doctors; this was especially the case when they put on the files of PWLDs the orders: 'do not resuscitate' (DNR) in the event of an illness that required resuscitation. When asked by CSWs, the reason given by the doctors for instituting DNR orders was learning disability. Many of these orders were challenged by CSWs during best interest meetings. The participant highlighted that the MCA process had to take place, which meant convening a best interest meeting.

Participants considered that the DNR orders made by some doctors could have unfairly deprived their clients of the best treatment options had they not intervened. In view of this, DNRs were considered an obstacle to healthcare access. Equally, the reasons given by doctors to establish a DNR demonstrated that they undervalued the lives of PWLDs. Here is how Jane (Manager) put it.

"Last year we had the G.P. We have a gentleman we support. He hasn't got a voice, and all of a sudden, we had appearing on his file a DNR [Do not Resuscitate]. I contacted the Learning Disability Team. We arranged a best interest meeting at the GPs. We had a two-hour appointment... By the end of the two hours, the DNR got overturned and removed from his file and the GPs actually apologised to us on behalf of him saying that they'd learned a lot that day." Jane (Manager).

Jane's vigilance in this situation demonstrates the critical role CSWs play in the safeguarding of the healthcare and dignity of PWLDs. Further, the quotations cited highlight how there are some doctors who take it upon themselves to either knowingly or carelessly make life-changing decisions arbitrarily on behalf of PWLDs without due consultation with CSWs, PWLDs or their families. In the above quotation, the compassion, assertiveness and initiative of the participant are evident. The participant here acted as a confident advocate on behalf of a PWLD who could not speak for themselves. The observations underline the need for cooperation between HCPs and CSWs for the purpose of successful working relationships.

The fact that CSWs collaborate with people from various organisations and disciplines creates new power dynamics. The power dynamics arise as each professional recognises and exerts their own role identity. Participants expected that the relationship that ought to have existed in an interdisciplinary team was that of partners working towards a shared goal. However, aspects of hierarchical relationships were more evident than those of colleagues with mutual respect.

The experiences shared by participants demonstrate that power relations impacted healthcare access for PWLDs. James (a manager) reported a situation where they felt the HCPs had unfairly exerted their power regarding the healthcare of a PWLD. Below, he highlights his role as both a facilitator and an advocate for a PWLD, and the power dynamics between CSWs, the learning disability team and HCPs:

"I mean, prior to the appointment..., what led to the best interest meeting was the fact that the learning disability team on our behalf started a safeguarding because we felt that our opinion wasn't being taken into account because they kept trying to discharge this lady from hospital without any real investigations or any care. So, at

that point… we moved through to the formal process and moved the clinicians away from the ward environment, if you like, to the meeting environment. Then they started to listen to us. In the ward environment, it was almost like, 'we know best. So, this is what we want to do'." James (Manager).

This quotation demonstrates that when power is unilaterally exercised and is left unchecked, there are consequences which may be irreversible. The scenario portrayed in the narrative highlights the necessity for collaboration and advocacy on the part of CSWs to counter power imbalances which they experience in environments where their role in the lives of PWLDs is undermined. In the scenario illustrated above, the first level of collaboration should have been between CSWs and HCPs, as implied in the participant's account. Further, there is a recognition of HCPs failing to appreciate equal partnership with CSWs in healthcare provision. However, the effect of a unilateral exertion of power by HCPs would have had a greater impact on the healthcare access for a PWLD had there not been an intervention initiated by CSWs and their manager.

It is also evident that different settings impacted the collaborative process. In the ward setting, which the doctors felt was their domain, they appeared to have epistemic authority over the CSW. Here there is a demonstration of CSW recognising his role, that of duty of care to his client. This was done by highlighting the unfair decision arrived at by the other party - the clinicians. Cognisant of their role, the CSWs enlisted the help of the Learning Disability Team. CSWs in this incidence recognised that collaborating in the setting where power dynamics were unequal was an ineffective strategy, as that setting facilitated unequal relationship and authority. The involvement of the Learning Disability Team by CSWs was based on their knowledge and provisions of the law.

The above excerpt further reveals that CSWs viewed the clinicians as exerting authority arbitrarily, lacking mutual respect and failing to trust them. The actions on the part of the clinicians went against the norms of collaboration, which require the collaborating parties to demonstrate respect for the other partners in decision-making, rather than creating a hierarchy. Cognisant of their duty of care towards the PWLDs,

the CSW escalated the matter further while avoiding a direct conflict with the clinicians.

What began as an issue of discharging a PWLD without proper investigation ended up as a safeguarding matter. In re-defining the issue and changing the setting for the collaboration process, this meant the various players needed to collaborate in neutral territory. By agreeing to collaborate further, all the parties demonstrated that they recognised each other's expertise and the need to resolve the matter. At the same time, the CSWs, through the Learning Disability Team, had changed the focus of discussion from failure to make routine investigations to one that was more serious. The matter shifted to that of negligence (a safeguarding issue) rather than a routine clinical decision. In this incident, it is evident how positive role awareness on the part of the CSWs countered the power which was incorrectly wielded.

There were however situations when collaboration failed due to power imbalance and the unwillingness of the CSWs to seek other avenues for resolving a problem. The following quotations exemplify such situations.

"… them, like social workers and other agencies normally they would just want to listen to the customer himself or the service user. Sometimes they do not listen to us. It's very frustrating. Like there is one customer, we have been telling them that this customer needs more support, he is not fit to be here where he is." Brenda (CSW)

"Other time we were meant to have … when somebody was going on under anaesthetic for the dentist, we were meant to have a chiropodist there because he couldn't or wouldn't tolerate his teeth being done. That didn't happen because they didn't liaise between the two of them" Bertha (Manager).

In the excerpt from Brenda, the collaborative process was started due to the realisation that the support needs of a PWLD had changed. The request to change the status quo was based on the experience that the CSWs had with a PWLD. However, it is apparent that the perception that the CSWs had was different from that of the other agency (social worker) who was entrusted with the responsibility to make final decisions over support needs of PWLDs. In reviewing Brenda's concerns, the

participant's words are suggestive of someone who was aware of the limitations of their decision-making power. The consequent effect of such a situation was living in a state of frustration on their part. Although Brenda provides a veiled criticism of the other agencies, she did not appear to feel she had sufficient grounds to raise a safeguarding matter. The two excerpts demonstrate collaboration failure as well as the powerlessness of some CSWs. The excerpt from Bertha above, has similar elements to that of Brenda, except in the case of Bertha, the collaboration process failed when two different professionals, that is, the dentist and the chiropodist, failed to liaise (the collaboration was designed to distract a PWLD who feared dentists but liked chiropodists). The failure of collaboration between the two professionals resulted in a situation where the PWLD was unable to access the required health intervention as planned. This further demonstrates that poor collaboration has an impact on healthcare access. In this scenario, we find the CSW in a powerless position after having worked hard to get planned surgery for their client and seeking to ensure that other parties worked together.

This sub-theme provides examples of situations in which CSWs were partners in collaborating teams. The CSWs demonstrated that they were fully cognisant of their roles in the collaboration process despite the power differentials.

4.2.3 CSWs undertaking nursing duties in hospital

The information in this section is in response to a question posed to both CSW and their team leaders (supervisors) regarding the challenges they encountered in facilitating healthcare. Participants observed that during the occasions when their clients were admitted to hospitals, the responsibility for caring for PWLDs was largely left to them instead of nurses. Several CSWs were also not sure of their legal standing when attending to a PWLDs while they were in hospital. The participants realised that it was one thing to support a PWLDs in the absence of illness, in the confines of their home environments, and yet another when those same individuals were ill and were in a wholly different environment. The skill sets for the two environments were considered different. In the light of this, some of the participants

were of the view that there was a noticeable level of dereliction of duty on the part of the hospital staff, which was evident in the way nursing staff in particular left nursing care tasks to CSWs.

The participants felt that not only were they uninsured for the nursing tasks they were carrying out, but that they equally felt they did not have the skill sets for those responsibilities. The assigning of CSWs to hospital had implications on funding and staffing levels as CSWs were drawn away from their usual workplaces during the hospitalisation of any PWLDs.

This is how Dorothy highlighted the issue:

"So therefore, we maintain that people do still have some level of support in hospital. So, what we do find sometimes is that an expectation from the hospital team that obviously that the support worker is always going to be there. But obviously that's not always funded for." Dorothy (Manager)

Dorothy highlights that hospital staff took it for granted that CSWs will continue to look after PWLDs during their hospitalisation; however, Dorothy is asserting that this expectation is not shared by CSWs.

In addition, Becky, who was also a manager, made the following observation concerning the uncertainty of the legal position of a CSW when supporting their clients during hospitalisation:

"They don't have to have any kind of responsibility, that, you know, they are not looking after them, but we are not really insured. What if that person is not admitted in time?" Becky (Manager)

The views from these two participants were expressed in recognition of the fact that CSWs were undertaking duties for which they felt untrained for in hospital; this created uncertainty as to whether they should have been undertaking these duties at all. The participants were concerned about the funding for supporting their clients while they were hospitalised and secondly, they were concerned about whether they were giving their clients the best care possible, realising that they did not have the skill set for the hospital tasks they were carrying out. The other concern related to

their legal and insurance standing; this was evident in an excerpt by participant, Dorothy:

"*And we're not insured to provide that care in the hospital. And there is a bit of a grey area. I am worried with how people are treated when they go into hospital."* Dorothy (Manager)

These citation underly the fact that there are no agreed written protocols defining the boundaries of CSWs' duties during the time they support their client in hospital.

4.2.4 Inability to access appropriate service and specific healthcare staff.

The participants highlighted two interdependent issues, namely, lack of availability of appropriate healthcare services as well as a shortage of HCPs such as occupational therapists and dermatologists. This area focuses on the question of the challenges faced by both CSWs and their team leaders (supervisors). The inability to access appropriate services meant that some PWLDs went without a service at a specific point of seeking access to healthcare. Participants indicated that where a service was available it took a long time to access it. The delay was attributed to shortage of specific healthcare staff. Noteworthy was the critical shortage of occupational therapists, who are responsible for making decisions regarding modifications of houses, vehicles, and provision of new equipment whenever there were significant changes to the health of a PWLD. As a result of these staff shortages, services sought by PWLDs were either not provided or were characterised by long waiting periods:

"The occupational health, the same. It takes a long time." Prisca (CSW).

Another participant had this to say:

"*I think the first thing I say would be about them, is that they are very scarce. I'm not sure maybe they have a very big shortage of occupational therapists."* Richard (CSW).

Richard's client referred to in the above quotation could not use a specific form of transport because the occupational therapist was not available to recommend an

appropriate modification to the vehicle. Consequently, they could not access other services requiring the use of a modified vehicle, resulting in limited access to other services and activities outside their home. In addition, Richard highlighted another occasion when they could not obtain a dermatologist's appointment for more than six months for their client.

Participants also cited situations where failure in inter-professional collaboration or shortage of staff resulted in CSWs being asked to solve health problems which they had initially referred to an appropriate HCP. This occurred when an urgently needed intervention was required from an occupational therapist. Consequently, this resulted in further delay and inconveniences for PWLDs, and in some cases to the detriment of their health.

4.3 Theme 2: Support-based hindrances

This theme addresses objective 2 of the research. the focus of the theme is on challenges that CSWs encountered as they facilitated healthcare access for PWLDs. Support-based hindrances could be defined as primary obstacles to healthcare facilitation which are outside the remit of CSWs. Instead, they are to an extent the responsibility of employers of CSWs. The nature of these hindrances was such that they were the primary challenges CSWs encountered in the process of healthcare facilitation. Many of these hindrances, such as inadequate resources, were organizational in nature, while others were unprecedented such as the impact of Covid 19. Other hindrances were related to the unique challenges associated with some co-morbidities of PWLDs.

This theme has three sub-themes: 4.3.1 inadequate social care staff as a barrier to facilitation of healthcare access; 4.3.2 the effect of Covid 19 on healthcare access; and 4.3.3 learning disability as a challenge to healthcare access.

4.3.1 Inadequate social care staff as a barrier to facilitation of healthcare access

Shortage of staff was mentioned by most participants as a major obstacle to healthcare access. This information was provided in response to a observations related to the facilitation of healthcare. The first two excerpts exemplify the views given.

"*On that one, shortage of staff, ... there's shortage of staff sometimes you can't do what you want to do. no matter how much the organization tries to recruit. But actually, the staff shortages is the big one because it affects your work in such that sometimes you hardly had time. You hardly have time to write case notes because it's very important to write case notes by the end of the day.*" Mercy (CSW).

"Due to staff shortage, we had to do multi-tasking as a result paperwork was neglected or suffered. Due to staff shortage people would leave employment too frequently. It was difficult to care, to provide continuity and being unable to use one's own initiative." Gift (CSW)

These excerpts highlight the significance of staff shortages and their consequences. Additionally, participants state that the challenges of retention and recruitment appear to be in an unbreakable circle. The implication of having the two issues entangled together is that both ought to be resolved simultaneously. One serious consequence of staff shortage led to lack of continuity of care resulting in stifling the initiative of staff. The attendant consequences of staff shortages such as inability to document work and provide continuity have serious consequences in an area such as social care, including the inability to have accurate records necessary for informed decisions by both the CSWs and HCPs during healthcare facilitation.

Although both participants cited above identify caring as a central role of their work, this key role was being undermined by staff shortages. In addition, lack of continuity of care due to staff shortages impacted the mental wellbeing of PWLDs as a result of frequent staff changes:

"*So, clients want consistency when there is change of staff or when there are people they don't know, they challenge."* Mercy (CSW).

4.3.2 Effect of Covid-19 on healthcare access

The information provided was in this subsection was in response to the question relating to any other observations that participants had which impacted facilitation of healthcare. One such observation was the arrival of Covid in 2020. The arrival of the Covid-19 pandemic brought multiple restrictions on healthcare access and facilitation, as is evident in participants' accounts. Chiefly, among these effects was the inability to access healthcare services when required. Although several adaptions as well as adoptions of some methods which were rarely used prior to the pandemic were instituted, the level of access was still limited:

"*The pandemic has affected our work very much because we even stopped doing the things we were supposed to be doing like most of the activities we are just now starting again, for one year we haven't been doing activities"* Brenda (CSW).

Due to Covid restrictions, it was not possible to always be with the PWLDs when they were hospitalised. PWLDs form attachments with their CSWs; however, during Covid restrictions these attachments were severely curtailed. Lack of the presence of CSWs during hospitalisation meant that the PWLDs had to cope on their own in unfamiliar surroundings. In terms of healthcare facilitation and access, the absence of CSWs left a vacuum in the provision of vital information to facilitate the care of PWLDs during hospitalisation.

4.3.3 Learning disability as a challenge to healthcare access

The findings highlight various challenges impacting healthcare access as being inherently related to the nature of some types of learning disabilities. Some of these challenges were so severe as to seriously affect the healthcare facilitation process. The information provided in this section is in response to the question on the challenges and it addresses objective 1 of the study. The following excerpts highlight major challenges where participants worked with a variety of PWLDs who had comorbidities such as mental illness and learning disabilities; severe autism and

learning disabilities and severe behaviour that challenges others. Anne (CSW) observed that the challenges came in the form of the inability of PWLDs to wait their turn to be seen by the HCPs. During the waiting period, some PWLDs would exhibit behaviour that challenges others such as wanting to leave the primary health care facility before being seen by the HCP. Several participants indicated that on some occasions when doctors were unable to fully assess a PWLD, it was not due to the failure of the doctor to provide reasonable adjustments, rather it was due to failure of PWLDs to wait during GP consultations. Behaviour that challenges others became a further barrier to healthcare access:

"When you are trying to do things in their best interests they don't understand. They start challenging, it triggers reactions" Mercy (CSW).

What Mary says supports the above point:

"Usually, it's very difficult. Because when the first thing is, they sometimes don't want to mix with people that they're not familiar with, So, you find that when you get there, they are very hesitant even to sit down there are very hesitant to be examined." Mary (CSW).

These excerpts highlight the complex nature of learning disabilities and the level of effort required to make reasonable adjustments for PWLDs on both sides, by CSWs and HCPs. James, a manager, discussed some of the measures taken by doctors when they were willing to make extra effort in the creation of reasonable adjustments for PWLDs and consequently provide healthcare to a person who otherwise would not have had healthcare had such an effort not been made:

"It is very difficult for them to attend a formal clinic centred clinical setting such as a doctor's surgery. Whereas in the past, when doctors were more willing to come out and meet that individual for person-centred service, it made support easier. Also, I think the fact that sometimes services are very structured. So, for example, we may support somebody who has very complex needs around behaviour or routines." James (Manager).

This suggests that good practices in relation to the placement of reasonable adjustments may have been abandoned leading to the situations observed by participants. By inference, the participant is stating that in the absence of good practices, PWLDs and behaviour that challenges had difficulties accessing healthcare.

These accounts recognise that certain types of learning disability can pose an obstacle to healthcare access. However, with careful collaboration between HCPs and CSWs, these obstacles could be mitigated.

4.4 Theme 3: Interdisciplinary communication

This theme addresses objective 2 of the research; the coordination of healthcare needs of PWLDs by CSWs. Interdisciplinary communication is communication that takes place across varied healthcare disciplines. However, communication in this context is premised on the intelligibility of the message of the sender, the cognitive capacity of the receiver to decipher the message of the sender, as well as a mutual agreement on what constitutes a message or expected action. Communication between CSWs and HCPs as well as between PWLDs and HCPs was recognised by most participants as a major factor impacting healthcare facilitation and consequently access for PWLDs. However, communication challenges did not exist in isolation but were premised on and related to other factors such as power relations, as highlighted in section 4.2.2 above.

The overarching theme of interdisciplinary communication consisted of three sub-themes: interdisciplinary challenges with the use of communication aids (4.4.1); CSWs as a source of information (4.4.2); and failure to recognise capacity and independence in PWLDs: Epistemic authority misplaced (4.4.3).

As earlier highlighted in theme 1, CSWs work with multiple teams to facilitate healthcare for PWLDs. This implies that communication is at the core of multidisciplinary interactions. This in turn brought with it nuanced scenarios of communication challenges across the professions.

4.4.1 Interdisciplinary challenges with communication aids

Although interdisciplinary communication challenges took various forms, noteworthy was a failure by some HCPs to use standard agreed communication aids provided by CSWs like hospital passports, also known as communication passports. Hospital passports are vital communication documents compiled by CSWs and their managers that contain important information about PWLDs (name, allergies, risk assessments and level of independence and reasonable adjustments expected), and they are supposed to accompany them during hospitalisation.

In recognition of how critical hospital passports are, participants highlighted that some HCPs ignored them, did not read them at all, or failed to locate them among documents accompanying a PWLD. As an attendant consequence of failing to use hospital passports, HCPs were usually left with needless information vacuums of their own creation regarding PWLDs. This situation led to frequent requests to CSWs to provide more information. One of the serious consequences was when HCPs failed to ascertain the intellectual capacity of a PWLD, resulting in that person being unable to drink fluids.

"So, when we go to hospital with people, we find that we always take a red, amber, green hospital information [Communication aid to indicate intellectual capacity]. And in there it tells you everything about that person and what their likes and dislikes are. Now the hospital staff is supposed to read that, and there have been times we've actually gone in to visit and found a drink left at the end of the bed, that person can't reach because they haven't got capacity to …. And so, they've had no drink." Patricia (Manager).

This illustrates that failure to read the hospital passport leads to serious consequences which impact on the wellbeing of a PWLD, and potentially their health outcomes. The failure of a PWLD to either drink or eat while hospitalised demonstrates a lack of understanding of the Mental Capacity Act (2005) by HCPs and its stipulations on dealing with a person without capacity to make their own decisions. Participants

further reported that in incidences where hospital passports had been used, they were used inconsistently:

"Yeah, we send hospital passports with every individual who's admitted to hospital, whether we attend with them or not currently, but not always able to attend because of the current Covid restrictions. However, I would say that hospital passports are used totally ineffectively. They are lost between departments. They are either unread or undervalued. Frequently we will be asked the same questions over the phone that we've provided in hospital passports." James (Manager).

In view of these observations, CSWs took it upon themselves to remind HCPs and to talk with them as a way of encouraging them to read and use the hospital passports appropriately. Mercy (CSW) reports on a positive incident where this initiative was appreciated by HCPs.

"They do use them; some nurses you need to remind them that it is in his or her hospital passport. Check her, the patient's hospital passport and you will realise that it is not supposed to be done. There was especially one sister in charge who said, I will ask all the nurses and the care workers to read to make sure they are familiar with it."

As CSWs recognised the value of the hospital passports, they were keen to take a leading role in ensuring that PWLDs always had their hospital passports during their hospitalisation and that they were properly used by HCPs. Conversely, the poor use of communication aids by HCPs translates into their lack of appreciating them, which has potential consequences for the health access and outcomes of PWLDs. In incidences where the CSWs worked with a learning disability nurse who acted as a liaison nurse between CSWs and the hospital staff, the use of hospital passports was reportedly higher:

"If somebody is going into hospital and they're uncomfortable with hospitals, we spent a lot of time and [sic] trying to involve them. And we worked with a learning disability nurse and hospital team alongside with ourselves to produce a good outcome". Victoria (Manager)

The above account demonstrates that reasonable adjustments are better implemented where there has been advance planning on the part of the hospital and CSWs. Another dimension to Victoria's account is that a nurse specialising in learning disabilities is likely to be held in higher estimation by HCPs than a CSW; consequently, the liaison nurse's authority carried more weight, and she was better regarded as a fellow HCP. It is worth pointing out that there were some hospital staff who were ready to use communication aids prepared by CSWs once they were sensitized to their use.

4.4.2: CSW as a source of information

The information provided in this section is in response to the question on how the CSW understood the concept of facilitating healthcare. According to the Mental Capacity Act (2005), PWLDs are assumed to be responsible for communicating on their own behalf regarding their healthcare needs if they have been deemed to have the capacity. However, given the varied spectrum and different intellectual capacities of PWLDs, CSWs find themselves as sources of information on their behalf:

"Actually, we do provide support, when they need say information, because sometimes they can't, sometimes there are those clients who can't say communicate properly." Brenda (CSW).

Brenda responded to a question exploring how PWLDs are supported when seeking medical intervention. However, even in situations where PWLDs have a level of intellectual capacity to articulate their own healthcare needs to an HCP, the role of a CSW in collecting and providing information is still vital:

"But because of the nature of the accident, I had to go with him to Accident and Emergency so I could go and explain properly to the paramedics or doctors. So, that's how we come in most of the time as support workers… we need to know the medication and other issues we report. That is why we are present even for those ones who can manage by themselves because they wouldn't know what type of medication they are taking." Brenda (CSW).

CSWs have detailed knowledge of the people they support and such knowledge is vital in making critical clinical decisions relating to an individual with a learning disability. In the above narrative, the CSW situates themselves as an important repository of information both in terms of receiving and giving it. Information collected by CSWs during a visit to Accident and Emergency or a GP surgery on behalf of PWLDs is used for future reference, provides for continuity of care, and better healthcare facilitation in future consultations.

Despite being recognised as sources of information, participants cited incidences where their expert opinions on PWLDs was not always taken on board or valued by HCPs:

"And we do know the people very well that they should take some of our opinions on board and our experience of knowing the people that we support rather than just on the medical grounds, because it is all about knowing the people to understand them, they can't verbally communicate." Mary (CSW)

There is a suggested expectation on the part of Mary that her expert knowledge ought to carry credibility on issues that pertain to PWLDs.

Some participants observed that within their work teams, CSWs relied upon the memories and experiences of colleagues to make various decisions specifically on matters related to the health of PWLDs. The memories and experiences that CSWs collectively shared were used to fill in the gaps in knowledge about a person at a given point where there was no documentary record of specific pieces of information. This is how Dorothy (manager) stated it:

"*And I'd say as a service, we don't have a lot written on paper communication, each individual staff communicate what they know. And we rely on the individuals that know them best on how to communicate."*

This excerpt suggests that not everything that goes on within the lives of PWLDs is recorded. Instead, unwritten anecdotes from staff and families of individuals with learning disabilities form part of their unwritten history. This history provides continuity of care and vital traditions within the CSWs teams. It is also a source of

information when dealing with other agencies. This excerpt also suggests that it is sometimes the collective memories of a team that keep the wheels of communication running both in intra-team communication as well as within interdisciplinary communication. The absence of written records could be a significant issue especially when those staff members who have key knowledge about individuals leave an organisation and do not pass on the vital knowledge to new staff. The issue of lack of or incomplete documentation was also raised in section 4.3.1. in relation to staff shortages.

4.4.3: Failure to recognise capacity and independence in PWLDs: Epistemic authority misplaced.

The information provided in this section is in response to the question on challenges to healthcare provision for adults with learning disabilities. Among MCA (2005) stipulations is a recognition that incapacity of an individual should not be presumed without assessing their capacity to make decisions. The MCA further states that a person supporting or providing a service to a disabled person should facilitate such an individual's right to decide without any coercion. In view of this, many participants, having been sensitised through training to the principles of MCA, were able to take note of specific incidences when HCPs assumed lack of capacity of a PWLD without prior assessment of their capacity. Participants observed that PWLDs were talked over by GPs or other HCPs during healthcare consultations. The next quotation echoes the experience of most participants:

"And my experiences are, sometimes people talk to me and not the people that I support. They make the assumption that they can't communicate with them." Bertha (Manager).

Bertha's assertion demonstrates her awareness of the MCA principles. Given this awareness, Bertha took note when an HCP failed to act in line with those principles. When HCPs assume that a PWLDs lacks capacity having had no prior knowledge or assessment of them, it suggests a disregard for a PWLD as a primary source of knowledge about their illness. Seeking information from another source deprives the

PWLDs of their epistemic authority especially where a functional intellectual capacity has been deemed to be present.

Although participants generally agreed on the tendency by HCPs to overlook PWLDs, there were however exceptional situations where HCPs were appreciated for talking directly to PWLDs:

They tend to talk to the staff rather than the person. Apart from the doctor, the consultant, they made a point of talking directly to her and asking her questions. He was directing everything at her. That's quite rare. They usually get talked over by people. In my experience." Prisca (CSW).

In as much as a CSW is considered a vital source of information, as evidenced in section 4.3.2, the CSW should only fulfil the role of supplementing information given by the primary seeker of a service, in this case a PWLD. That supplementation ought to take place when there are gaps in the information provided; or the health seeker has been assessed to lack capacity to provide information on their own.

4.5. Theme 4: Facilitators of healthcare access: resourcefulness of CSWs

This overarching theme highlights factors which participants considered to be relevant and positive regarding the facilitation of healthcare access for PWLDs and addresses objective 1 of the research. The factors identified in this theme as facilitators are those in which CSWs demonstrated a level of resourcefulness that enabled safer or better healthcare access. In addition, these factors demonstrated a level of innovation in the face of major challenges. The information in this section is in response to questions on what participants considered facilitators of healthcare as well as what role participants played with other agencies in healthcare provision.

Resourcefulness as a work trait and as manifested in the participants' excerpts may be defined as the ability to adapt, respond and maintain independence in varied activities despite challenging and negative situations. Participants highlighted several

incidences of resourcefulness. Resourcefulness was evident in three main areas: advocacy (4.5.1); identification of early signs of ill-health (4.5.2); and suggestions for improvement (4.5.3).

4.5.1: Advocacy

While exploring how participants perceived themselves and their role with regard to PWLDs, it became clear that most participants viewed themselves as advocates. This was besides other roles some of the participants identified themselves with, such as being friends, parents, and even support workers. In the advocacy role, participants viewed themselves as speaking for people whom they considered had either no platform or limited capacity to speak for themselves. Although the law makes a provision for official advocates for PWLDs, known as Independent Mental Capacity Advocates (IMCA), the participants were of the view that they were the primary advocates for the people they supported. This view was either openly or covertly evident in the citations. In as much as participants understood the role of IMCAs and in many cases involved their services, the participants were the primary initiators of the advocacy process:

"... they felt it wasn't necessary to refer the individual for investigations, and also, they put a DNR [Do not resuscitate] *in place for the individual citing learning disability, epilepsy, and frailty. I contested that with the support of the learning disability team, with the support of the advocacy services ... I knew that we were entitled to access the rapid response team, and it was an eligible referral, the rapid response team that was required that obviously fulfilled that equipment, eventually committed with me chasing up and challenging some of the decisions that the GP had actually made in relation to that lady not being a suitable referral."* Dorothy (Manager).

Dorothy demonstrated their resourcefulness by not accepting two decisions made by doctors, namely, refusal by a doctor to go ahead with investigations for a PWLD, and secondly, the instituting of a DNR order on the same person. Instead of accepting the status quo, Dorothy challenged both decisions and took further action by enlisting the

support of other agencies such as the learning disability team and IMCA. These actions demonstrated an ability to assess unfairness, take an independent stance, and collaborate with others as well the as the ability to assess a challenge and determine a course of action. These actions also demonstrate capacity to undertake advocacy and determination to facilitate healthcare for their client in the face of challenges.

Mary (CSW) cites an incident where they witnessed a wrong practice and briefly describes the action they took.

"... they knew in the past what sedation he needed. And they still didn't give the sedation he needed. They needed to hold him down, which was restraint, which was against the law. We reported it."

This account demonstrates the participant's knowledge of the law and their duty of care towards the person they supported. The advocacy of the participant is demonstrated in reporting a prohibited practice. The excerpt also reveals that the party to whom Mary reported to were expected to know the standard protocol of treating the individual. The party that was in the wrong failed to treat the PWLD according to both known protocols for that individual and the stipulation of the law.

Participants' advocacy skills were also demonstrated by initiating best interest meetings when participants were of the view that without legal safeguards a PWLD would have difficulties accessing healthcare. For example, a decision that required more than the expertise of one professional for a matter to be resolved. Such decisions would include IMCAs, GPs, occupational therapists and any other relevant professional, depending on the nature of the problem.

4.5.2: Identification of early signs of ill-health

Resourcefulness was evident in the way participants demonstrated their capacity to identify early signs of ill-health among PWLDs. Identification of early signs and symptoms is a primary step and skill in facilitating healthcare access. However, this important skill was challenged at various levels of facilitating healthcare for PWLDs. The information in this section is in response to the question regarding the facilitators

and challenges faced by participants in the facilitation of healthcare for adults with learning disabilities. The major challenge to healthcare access became acute at the height of the Covid-19 pandemic. During this period, there were very few occasions when the GPs could provide direct face-to-face consultations at their surgeries, and neither could HCPs visit the sick in their homes. As cited under section 4.3.2, staff shortages put a burden on the process of healthcare facilitation and access; consequently, this had an impact on early identification of signs of ill-health for PWLDs. Additionally, most CSWs did not have any medical training background in identification of signs and symptoms of illness. CSWs were provided with a few diagnostic tools such as thermometers, blood pressure machines and oximeters. Despite these challenges, the participants demonstrated their resourcefulness in the identification of signs and symptoms more by experience than medical skill.

"Yeah, we've sent pictures if somebody is complaining of discomfort say, on the hands or possibly as a kind of redness or potential fungal infection or obviously facilitated that by myself kind of emailing photos or communicating with the telephone consultation with the GP." Dorothy (Manager)

In the above account, Dorothy was using a type of technology which was rarely used prior to the onset of Covid-19 pandemic for the purpose of identification of signs and symptoms. The actions of the participant overcame the barriers posed by the lack of face-to-face appointments with GPs during the pandemic. Similarly, Maggie's (CSW) account below illustrates the same type of resourcefulness.

"But now that changed with Covid we are doing as much as we can on phone now. Sometimes we do, you know if the doctor wants to see something. He says, 'that one at the swelling, you may have to use video' so that they can see." Maggie (CSW).

The Covid-19 pandemic brought with it new challenges such as how to access healthcare when it was unsafe to get a direct face-to-face consultation. However, instead of being treated as an insurmountable obstacle, the pandemic prompted in the participants and their teams' attitudes of innovation, resilience, and self-efficacy. All these attitudes are components of resourcefulness as encapsulated in the definition above. However, despite the CSWs' resourcefulness they still faced challenges in

their ability to identify early signs of ill-health. This is demonstrated in Dorothy's account:

"So, and how they express pain and things like that. There isn't a standard for one to follow." Dorothy (Manager).

Dorothy highlights a common problem that CSWs face as untrained facilitators of healthcare for PWLDs regarding the identification of signs of ill-health. The participant recognises the absence of standardised format for eliciting symptoms like pain. Instead, participants demonstrated their resourcefulness by drawing on their knowledge and experience of supporting PWLDs. The lack of a standardised format has implications for early identification of ill-health and consequently prompt access to life-saving expert interventions by HCPs for PWLDs.

Brenda's (CSW) account below illustrates another challenge faced by CSWs even in a situation where the PWLD could speak and is expected to verbalise their symptoms.

"They can communicate but they are not very good. And how can we identify that this person may be ill if they don't want to tell us? Sometimes they just withdraw, they are not participating in other things that their friends are doing. They sometimes maybe stop eating properly. And then we keep asking, are you alright? Yeah, with that, they eventually, they open up. Yeah, 'I don't feel well'." Brenda (CSW).

The common feature identifiable within the cited accounts is the initiative taken by the participants whenever they suspected ill-health. Consequently, follow-up actions were made after initial suspicions of ill-health. The follow-ups and further inquiries demonstrate that CSWs genuinely had an interest in the health of the people they supported. In addition, by their actions, CSWs demonstrated that their knowledge of PWLDs put them in a better position to suspect signs of ill-health albeit with minimum skills. The participants recognised the limited capacity of some PWLDs to articulate their own healthcare needs; this was equally true with those who could speak for themselves. The resourcefulness of CSWs was evident in their capacity to detect subtle changes in the behaviour of PWLDs. This characteristic appears to have been learnt by CSWs over a course of time of association with PWLDs.

4.5.3 Suggestions for improvements

During the research, most participants made suggestions which in their view could improve healthcare facilitation and access for PWLDs. Suggestions were made for organisations employing CSWs, as well as collaborating organisations such as the government and HCPs, on how they could improve services. The information in this section is in response to the question on whether the participants had any suggestions.

Participants highlighted their concerns regarding the lack of shared perceptions with some of the stakeholders (HCPs) concerning legal requirements as well as knowledge relating to learning disabilities.

Yeah, I think the root of it all this comes back to I think always comes back to the MCA. Really, to be honest and obviously make sure that legal framework is followed to make sure that there's equality in relation to access to the services that people we support have. .... still kind of obviously that some element of lack of understanding in relation to people with learning disabilities. Dorothy (Manager).

Dorothy here highlights the aspect of lack of awareness and failure of HCPs to apply the law relating to learning disabilities; the participant also hints on what they perceived to be acts of discrimination against PWLDs by some HCPs. In view of this, the suggestion is to have a mechanism whereby HCPs know and follow the stipulations of the law.

Stacy (CSW) made a related suggestion:

"*Yeah, I think nurses and doctors do need more learning disability training definitely around the whole area of general learning disabilities and autism."* Stacy (CSW).

This participant echoes some of the suggestions made by Dorothy above; in addition, Stacy suggests specific areas where HCPs could be trained in. It is noteworthy that Stacy singled out autism as one such specific area in which HCPs need training; autism is very pervasive among PWLDs. Besides, most participants were of the view that HCPs had little knowledge of autism, and this translated into a lack of reasonable

adjustments for PWLDs and those with autism specifically. While recognising the problems of lack of awareness concerning learning disabilities in general and autism in particular, some participants with a longer period of working with PWLDs had noted some improvements in the course of time in relation to HCPs' knowledge:

"Yeah, I'd say generally healthcare professionals are getting better. They're getting a lot better in the way they approach things. As I said, I think that the generally within the healthcare profession is now the understanding of learning disabilities is improving. You know that the time taken by a hands-on staff has improved. It doesn't appear to be as such a deficit in their knowledge." James (Manager).

James' comments were in the minority and were in contrast with those from most participants; however, participants who had worked for a period of 15 years or longer shared James' view.

Another set of suggestions made by participants were related to collaboration. Some participants were of the view that there was a lot of fragmentation in the way various disciplines collaborated.

"And we did struggle of who to contact to get the right equipment from. We were passed around a lot. Yes. Oh, yes. We went to the district nurses. No, no, it's not us. It's the GP. No, it's not us. It's these. So, we did struggle to that extent, but each person we spoke to were very helpful to us. But we thought they'd be better if there was one contact number we could deal with straightaway." Brenda (CSW).

Here was a situation where equipment was needed for PWLDs, and yet it is apparent none of the agencies appeared to know where the equipment could be sourced from. The lack of information as well as a lack of central coordination for issues pertaining to PWLDs could have been a factor that potentially impacted timely access to urgently needed services and healthcare access.

Equally, suggestions were made regarding the need for more staff among HCPs and CSWs. In fact, a great majority of participants were of the view that poor staffing and high staff turnover both within their organisations and those of collaborating partners were factors that negatively impacted their ability to facilitate healthcare access:

"The mental health crisis team. Sometimes it's overwhelmed, but I think it's because of shortages because if there were many. I would say we need more of them so that they are readily available." Stacy (CSW).

Stacy further recognised the effect of staff shortage in a collaborating agency such as the mental health crisis team and its attendant effect on the care of PWLDs. The mental health crisis team was often called upon when CSWs had failed to manage severe behaviour that challenges others. The intervention of a mental health crisis team prevented an acute episode of mental health crisis from escalating further. The shortage of mental health crisis team staff had a further effect on work routines of CSWs; it affected their capacity to cope mentally and physically while attending to other clients when there was a major mental health crisis among PWLDs.

Participants also made suggestions in relation to their own training needs as well as the training needs for HCPs. Regarding their own training needs, participants suggested that they would like to have more training in how to manage and understand autistic people and PWLDs with severe mental illness. In addition, participants suggested that the training of general nurses should include a brief period of working with PWLDs. One participant reminisced about the early days of their career as CSWs when student nurses were assigned to work in homes for PWLDs for the purpose of gaining relevant experience. However, the participant bemoaned the fact that the practice had since stopped.

Several participants suggested that they would like to be better remunerated for their work. However, despite participants considering their job to be low paid, many of them found their work to be personally rewarding emotionally. The participants felt emotionally rewarded as they saw progress in new skills acquisition in some of their clients.

4.6 Theme 5: Interdisciplinary collaboration

Facilitation of access of healthcare for PWLDs is through multi-disciplinary teams. The nature of the services offered by each team are usually diverse. Some of the services provided have a direct impact on healthcare access and outcomes; for example, services provided by the GP, the psychiatrists, learning disability teams, physiotherapists, pharmacists, nutritionists, language and speech therapists and dentists. On the other hand, services provided by social workers, occupational therapists, and Independent Mental Capacity Advocates (IMCA) have an indirect impact on the healthcare of PWLDs. However, regardless of whether a service is directly impactful or not, they all have a bearing on the working relationships across the various disciplines. Consequently, the quality of the collaboration across the disciplines has the potential to make healthcare facilitation and access either easier or more difficult for PWLDs. The information provided in this theme is in response to the question on how the role of a CSW is perceived by other agencies. The responses also arise from the question on how the participants viewed other agencies in the provision of healthcare services for PWLDs.

Interdisciplinary collaboration may be defined as various people or disciplines working together by bringing their expertise to a task, while accommodating and learning from each other's skills and knowledge to achieve a common goal without one discipline domineering or acting subserviently. This definition implies that collaboration is a team effort rather than a top-down relationship among collaborating teams, and that there needs to be a shared perception of a common goal, problem or need. In this context, a shared goal is the successful access to healthcare for PWLDs. This theme addresses objective 2 of the research which is concerned with how CSWs coordinated the healthcare needs of PWLDs with other agencies.

The theme: 'interdisciplinary collaboration' has three sub-themes: 4.6.1 CSWs as co-partners in facilitating reasonable adjustments for PWLDs; 4.6.2 referrals and response time as determinants of health outcomes for PWLDs; and 4.6.3 collaboration between CSWs and families to facilitate healthcare access for PWLDs.

4.6.1 CSWs as co-partners in facilitating reasonable adjustments for PWLDs

Provision of reasonable adjustments is one of the core activities in the provision of equitable healthcare access for PWLDs. However, it takes collaborative effort to have reasonable adjustments in place. In as much as it is always desirable on the part of CSWs to ensure that HCPs put in place reasonable adjustments for PWLDs, this expectation cannot always be guaranteed without collaboration with other stakeholders in other disciplines. This sub-theme highlights how CSWs together with other agencies collaborated to provide reasonable adjustments for PWLDs. The information provided here is in response to the questions on how participants understood their role in facilitating healthcare, as well as how participants perceived how other agencies met the goals of providing health for PWLDs. The scenarios cited by participants are of incidents where the presence of reasonable adjustments made a significant difference to the health outcome of a PWLDS.

Prisca (CSW) cites a case of a PWLD who needed an admission to hospital for a planned surgery. However, this client was known for not tolerating injections. In view of this, collaboration was needed from a variety of disciplines to facilitate reasonable adjustments and meet the goal of healthcare access.

"Everybody that was involved in every stage. I mean, even down to the facts, because she shows behaviour that challenges others, and she wouldn't tolerate things like needles. ..... So again, that would be, there was always contact with the GP. The GP put in place measures." Prisca (CSW).

The need for the placement of reasonable adjustment arose out of the realisation that the fears of the PWLD were likely to act as a barrier to healthcare access. By accommodating those fears instead of dismissing them, the team worked together to facilitate healthcare access.

Without this collaboration process, and possibly without the CSWs in their capacity as partners in the facilitation of healthcare, the unwanted outcome would have been

a client turning up in hospital but being unwilling to cooperate because of their intolerance of injections. The result would have been a failure to access the necessary healthcare. Yet such a failure to access a service was prevented by timely collaboration initiated by CSWs.

Oral health is an important aspect of the general health of PWLDs; however, there were situations when it was difficult to provide dental healthcare due to inherent fears a person may have had. Without the placement of reasonable adjustments by both the dentist and the CSWs, the inherent fears of a PWLD would act as obstacles to healthcare access. The next quotation demonstrates how the placement of reasonable adjustments led to the achievement of dental healthcare access.

"It's not a recent case I've been involved in, but one dentist spent an awful lot of time doing desensitization work with an individual where they initially started by meeting them in the car park in their own car and getting to know them. And then they could come in and they could just stay in reception. So, you know, this kind of work, the more proactive approach, the more working in collaboration with healthcare professionals when it works, is working very well." James (Manager).

This excerpt demonstrates that where an HCP recognises that a learning disability could be an obstacle to healthcare access, the HCP could and should take mitigation measures together with CSWs to facilitate this access. This quotation demonstrates that when an HCP knows the needs of their patient, they are likely to provide reasonable adjustments appropriate to those identified needs.

4.6.2 Referrals and response time as determinants of healthcare outcomes for PWLDs

Participants' accounts suggest that referrals were not responded to in time, potentially affecting healthcare access and health outcomes. The experiences of the participants in this sub-theme provide scenarios where services were delayed or never delivered. The referrals reflect a system of collaboration impacted by several factors. Among the known factors which distorted the referral system was the arrival of the Covid 19 pandemic as well as a critical shortage of certain types of HCPs.

PWLDs were observed to have been the worst affected by cancelled or delayed appointments during the Covid 19 pandemic. This is reflected in one of the excerpts selected. In as much as the CSWs were in the role of facilitating healthcare access, they found themselves unable to do much, and neither were the GPs nor other related agencies. Most referrals were initiated by a GP, a hospital consultant, a Learning Disability Team, and a few by the social workers. However, it was incumbent upon the CSW to follow-up on these referrals.

The common observation cited by most participants was the length of time it took for referrals to be responded to by specific professionals. Specific professional groups were cited by most respondents as tending to delay in responding.

"The occupational health, the same. It takes a long time, but quite often you do get an arranged referral through. But once it's through they are very honourable and they will put everything in place, that needs to be there" Prisca (CSW).

The above quotation reveals a pattern of delays with occupational therapists. Some participants who had had several dealings with occupational therapists felt frustrated by the delayed responses. The excerpt from Prisca above recognises the competency of occupational therapists while admitting their slower response. However, delayed responses were noted to have had a negative impact by worsening the medical conditions for which a referral was initially made. This is attested to by other participants who had made referrals to specialists like dermatologists. Participants further observed the impact of Covid 19 on response time to referrals; the response time was noted to be much longer.

4.6.3 CSWs collaborating with families to facilitate healthcare access for PWLDs

Apart from collaborating with professionals from other disciplines, CSWs also collaborated with the families of people they supported. Participants reported a variety of ways in which families were involved in the collaboration process for the purpose of healthcare access for PWLDs. The family involvement ranged from full

formalised arrangements of consultations to minimum involvement by the families. Other families of PWLDs were observed to have had no contact with their relatives once their relative started living in staffed accommodation. In the area of person-centred support, a person's family is recognised as an important partner in healthcare planning. A person-centred approach is defined as a holistic approach to care that incorporates the individual and their identified family in the process of assessing, planning, and implementing of care, in conformity with that individual's preferences and aspirations based on informed decisions. Identified families in this context may include friends, a spouse, siblings, parents, other relatives, and any identified significant others. The cited excerpts highlight collaboration with the family at either bilateral level (family and CSWs) or multilateral level (family and multi-disciplinary team). The purposes for collaboration were varied, ranging from deciding a new course of treatment options to discussing routine matters such as preferences.

"We would be following, obviously the Mental Capacity Act, assessing whether somebody's capacity in relation to kind of obviously in regard to accessing treatment, whether they need to be best interest process was followed. And especially when we're looking at kind of obviously further treatment to further investigations with the MCA process, obviously with a multidisciplinary and obviously including and the individuals' families or advocacy services" Dorothy (Manager)

In the above excerpt, Dorothy highlights some situations where collaboration with the family takes place. The family is involved in decision-making as partners whose input is likely to reflect the preferences of their family member. The decisions made on behalf of a PWLD in such situations should be as if they had the capacity to make those choices themselves. It is in cognisance of this that the family is involved as they are in a better position to know their relation than the CSWs or other professionals. This is demonstrated in the next quotation.

"So, from the social care providers' point of view, what they were asking is information on her quality of life, information on what type of support we could provide. And also, they were using us to fill in more information around who this lady was. She was unable to communicate her needs; we worked in conjunction with her

family to try and paint a picture of the lady so that the health care professionals had a rounded picture when looking at her and making the decisions." James (Manager).

In as much as the PWLDs lived in staffed accommodation, participants were of the view that involving the family in the collaboration process would lend credibility to their case. In addition, involving the family was a way of accommodating the individual's preferences. The family in this incidence was treated as a trusted partner in collaboration. The information provided by the family was taken at face value, in the belief that the family would work in the best interests of their family member. Information received from the family was necessary in making informed decisions which would have a consequence on further healthcare access for a PWLD. For example, the family may be aware of allergies better than CSWs.

However, there were some CSWs who were of the view that once a PWLDs was living in supported housing, the individual's family ought not to have a role in decision making. This is exemplified below:

"It is our job now; we don't go back to the families. Sometimes they don't even know. Them the clients when you tell them, they ring back to say, 'Today I went for this and that'. Otherwise, we don't tell the families, no. Now that they are in our care, it is us to do everything." Brenda (CSW).

Brenda is of the view that all decisions pertaining to a PWLD under their care are within their remit. Brenda emphasises the idea of doing everything without the input of the family. This view was in the minority, and it goes against the concept of the person-centred approach.

This sub-theme suggests that an individual's family has a key role in positive collaboration with other stakeholders such as CSWs and healthcare providers and that such collaboration leads to better healthcare access for PWLDs.

The next chapter discusses these findings in relation to the wider literature and policy.

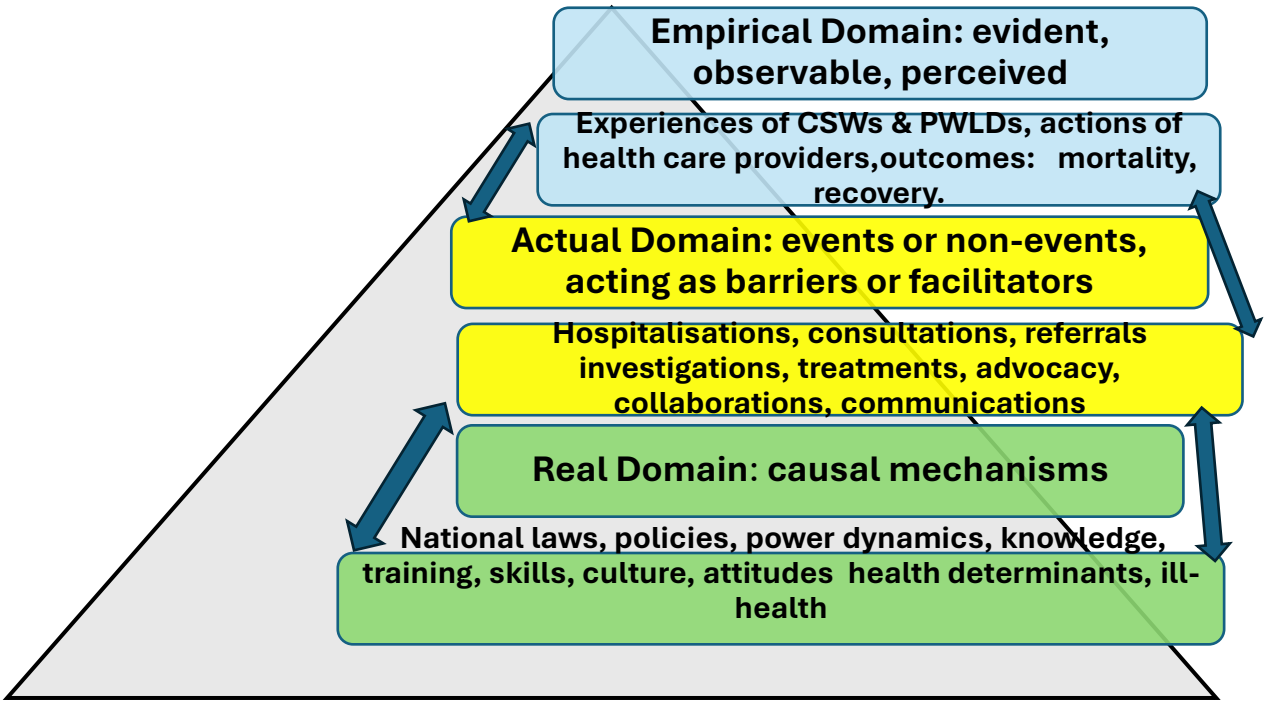
Chapter Five: Discussion and Conclusion

5.1 Introduction

This chapter covers the discussion of findings as well as the conclusions. The discussion focuses on the application of the findings and their implications. The conclusion draws together various aspects of the whole study.

5.2 Key Findings

Figure 4 below is a pyramid illustrating how the empirical, actual and real domains of CR interact together with barriers in the process of accessing healthcare as perceived from SMD. The figure also highlights facilitators in accessing healthcare from the perspective of CR. To illustrate this, events in the empirical domain are observable, perceived, or evident in the form of the experiences and actions of CSWs and healthcare providers that have an impact on the healthcare of PWLDs. Events in the actual domain, such as hospitalisations, referrals, treatments and communications, affect the experiences and actions of CSWs, PWLDs and HCPs (in the empirical domain). In turn, the causal mechanisms in the real domain - national laws, policies, power dynamics, skills and attitudes - impact on the events in the actual domain. For example, barriers in the actual domain may result in the formulation of new policies or laws, hence the arrows that point in both directions.



Interaction of the three levels of Critical Realism with the social, cultural and political factors of the Social Model of Disability.

Figure 4.

5.2.1 Key Finding 1: Readiness to ensure reasonable adjustments were provided for PWLDs

The participants (CSWs and Managers) of this study highlighted how reasonable adjustments were in most instances not made for PWLDs by HCPs; this failure contravenes the stipulations of the Equality Act (2010). The absence of reasonable adjustments appears to have been on account of various underlying factors, including a lack of awareness and knowledge about relevant legislation by HCPs. This could be attributed to a lack of training on the stipulations of the law, which requires the implementation of reasonable adjustments for disabled people. Previous research has revealed the absence of reasonable adjustment provision in healthcare settings for

PWLDs (Atkinson, 2019; Newton & McGillivray, 2019b). The current study reveals that little has changed since then.

In a study undertaken by Tuffrey-Wijne et al. (2014) to explore the barriers and facilitators of reasonably adjusted health services for PWLDs in hospital, CSWs were not recognised by HCPs as active partners in the implementation of reasonable adjustments. Consequently, the reasonable adjustments provided solely by HCPs were disorganised, inadequate and not tailored to the needs of PWLDs (Tuffrey-Wijne et al., 2014). In contrast, a systematic review by Haines and Brown (2018) highlights that successful health outcomes for PWLDs could be better achieved through working in partnership with CSWs. The current study builds on these studies by demonstrating that CSWs took proactive action to ensure that reasonable adjustments were implemented, including sensitising nurses and collaborating with them on the necessity of providing reasonable adjustments, all of which supported PWLDs to access services. In as much as the primary implementation of reasonable adjustments is incumbent on hospital staff, the findings of this research demonstrate that partnership with CSWs has the potential to be more effective than when one party single-handedly implements them. In addition, the role of CSWs has been acknowledged in the National Institute for Health and Clinica Excellence(NICE) guidelines (Murphy, 2017). Whilst the NICE recommendation was based on limited research evidence, as highlighted by its author (Murphy, 2017), the current study findings further strengthen the theoretical basis upon which NICE made its recommendation.

CR has previously been used to explore the social structural mechanisms underlying healthcare access (Fletcher, 2017). Among the structural issues in this context are power dynamics between HCPs, PWLDs and CSWs. In terms of impacting healthcare access, power dynamics between patients and HCPs has received minimal attention in the literature (Halvorsen et al., 2020). Accordingly, Halvorsen et al. (2020) posit that one of the underlying factors in the power disparity between HCPs and their patients is the inherent traditional paternalistic attitudes which exist in healthcare professionals. Given this positioning by HCPs, the possibility of a shift in power dynamics is low; consequently, the negative impacts of this imbalanced

relationship - such as poor collaboration and arbitrary decisions by HCPs, as evidenced in this study - are likely to continue. From a CR perspective, the possible solution is through a shared recognition by all parties (HCPs and CSWs) of the factors that hinder solutions and those that foster them. The recognition of the social structural components that underpin a problem has the potential to lead to a solution (Anderson, 2020).

The recognition that CSWs are qualified partners in ensuring reasonable adjustments for PWLDs is premised on the findings of previous studies (Durrant, 2020; Heslop et al., 2019; Tuffrey-Wijne et al., 2016) which have highlighted that this cadre of staff have key knowledge of the needs of PWLDs. Despite this recognition, the role of CSWs working with HCPs in the provision of reasonable adjustments is still marginal. In a few cases where the role of CSWs was recognised by HCPs, the expected role conflicted with how it was to be fulfilled (Tuffrey-Wijne et al., 2016).

In contrast to the above general finding there were other exceptional HCPs who were noted for their readiness to provide reasonable adjustments. This finding corroborates previous research (Lennox et al., 2003) which highlight that dentists were among some of the few groups of HCPs who routinely provided reasonable adjustments for PWLDs. The practice implication for this finding is that if one group of HCPs is able to routinely provide reasonable adjustments, this could be attributed to factors such as their training as well as the protocols they follow in practice (Turner et al., 2012). In turn, as a policy implication, other HCPs could learn from dentists how they manage to routinely provide reasonable adjustments.

The participants demonstrated understanding of both the knowledge of the law relating to disability and PWLDs specifically. The CSWs' depth of personal knowledge of the people they support is an asset when working in partnership with other professions; this in turn has the potential to lead to better shared perspectives on the provision of reasonable adjustments for PWLDs (Tuffrey-Wijne et al., 2016). The absence of reasonable adjustments in some healthcare settings confirms one of the major tenets underpinning the SMD: that disability is premised on the barriers that society places in the path of disabled people (Dawn, 2021). The current finding

on the absence of reasonable adjustments confirms the findings of Northway et al. (2017), who indicated that the absence of reasonable adjustments in healthcare settings risks the health of PWLDs. Northway et al. (2017) argue that failure to make reasonable adjustments in cases of known underlying conditions such as allergies and swallowing difficulties may lead to serious health consequences. This study's contribution is the assertiveness and proactive attitudes demonstrated by participants in the facilitation of reasonable adjustments,

5.2.2 Key Finding 2: Learning Disability as an obstacle to healthcare access

Having a learning disability is in itself a barrier to healthcare access for PWLDs as has been implied in a range of studies (Durrant, 2020; Mansell, 2010; Michael & Richardson, 2008; Reppermund et al., 2020). Learning disabilities act as a barrier at various levels of healthcare access in the lives of PWLDs. However, this is not a homogenous scenario among all PWLDs. This study has revealed that it is more evident, for example, in PWLDs with behaviour that challenges or in autistic people with a learning disability.

A learning disability has equally been observed to be a barrier to healthcare access on account of the failure by some HCPs to recognise that some diseases, such as hypothyroidism, skin conditions and weight gain in Down syndrome people (Hermans & Evenhuis, 2014), were directly linked with specific learning disabilities (Willcutt et al., 2019). Due to a failure by some HCPs to link some of these comorbidities with specific groups of learning disabilities, symptoms and signs arising from comorbidities have routinely been missed (Ruddick, 2005).This failure to make these critical links in diagnosis has led to unnecessary ill-health, with conditions that are amenable to treatment or control. One previous study (Ruddick, 2005) attributed the inability to make links between specific diseases and a learning disability to the lack of doctors having received relevant training.

While recognising that a learning disability can act as a barrier to accessing healthcare services, the findings highlighted that there was negative interaction between PWLDs

and some HCPs in situations where services were poorly designed and delivered without considering their needs. This observation suggests that learning disabilities are compounded by other factors such as poorly designed healthcare services which do not address the needs of PWLDs. This confirms the findings of a previous study by Dern and Sappok (2016a) which demonstrate that people with specific forms of learning disabilities and autistic people with learning disabilities are sensitive to how services are organised. The degree to which a service has been designed to be sensitive to the needs of PWLDs determines its accessibility (Dern & Sappok, 2016a). In the current study, PWLDs demonstrated their negative reactions to services that did not accommodate their needs in various ways, such as by refusal to enter a healthcare facility, refusal to be examined or refusal to have blood taken. This resulted in services not being accessed. Consequently, the PWLD went away unexamined or untreated. Although this study confirms the findings of previous studies which demonstrate that a learning disability impacts healthcare access, the current study further demonstrates that on occasions where CSWs were included in the medical management of PWLDs, their input made a difference in enabling healthcare facilitation. This was achieved by taking specific initiatives such as liaising with HCPs before planned surgery for a PWLD. Generally, for most PWLDs, access to healthcare was facilitated with some difficulty due to erroneous perceptions held by some HCPs that PWLDs have behaviour that challenges others. By involving CSWs in the healthcare of PWLDs, what may have initially posed a barrier to healthcare access was removed. The involvement of CSWs as part of a wider multi-disciplinary team in addressing barriers and other behaviour that challenges others in PWLDs has long been suggested as an effective strategy, but not always actioned (Hogg, 2001; Kruger & Northway, 2019; Kwok & Cheung, 2007). The Kruger and Northway (2019) study provides evidence which suggests that without a multi-disciplinary approach to mitigate behaviour that challenges others, very little can be achieved in terms of healthcare access.

Mansell (2010) observed that PWLDs were often left unsupported while in hospital because they were misunderstood and stigmatised by HCPs on account of having a learning disability. This observation is supported by the accounts of the participants

in the current study, who also observed incidences where PWLDs were left to themselves. However, some participants in the current study took it upon themselves to sensitise HCPs to the need to use hospital communication passports.

Most PWLDs rarely pose any threat; the few that may have behaviour that challenges others can be supported by staff who are adequately trained to support them (Gentry et al., 2001). Carnaby et al. (2010) posit that using person-centred support, PWLDs presenting with behaviour that challenges could successfully interact with other people safely. The lack of understanding of PWLDs by HCPs is due to their general lack of knowledge of learning disabilities and specific knowledge of a learning disability coupled with autism. In addition, as this study has found, the lack of understanding of the need for specific reasonable adjustments tailored to the unique needs of each individual with a learning disability was evidently a barrier to healthcare access. The findings highlight how HCPs' knowledge of factors that trigger behaviour that challenges others among PWLDs goes a long way in eliminating such behaviour in a healthcare setting. One way HCPs could learn about the unique factors that trigger behaviour that challenges is using hospital passports (Northway et al., 2017).

Another dimension to the problems faced by PWLDs in accessing healthcare, is HCPs' failure to demonstrate friendly attitudes towards PWLDs and CSWs. Although previous research has suggested that HCPs' attitudes towards PWLDs have positively changed (Pelleboer-Gunnink et al., 2017), the evidence from this research demonstrates that this was not always the case with the majority of participants. Positive attitudes by HCPs towards PWLDs play a facilitative role in healthcare (Pelleboer-Gunnink et al., 2017). One negative attitude displayed by some HCPs is the portrayal and treatment of PWLDs as mentally unstable and easily provoked (Dawn, 2021). This attitude may be based on a lack of training and awareness.

The fair basis upon which PWLDs are to be treated is based on equality principles of the United Nations Convention on the Rights of Persons with Disabilities (UNAssembly, 2006). This expectation is also based on UK laws such as the Equality act (2010).

In recognition of the need for HCPs to provide equitable healthcare to PWLDs, one approach is to include CSWs in the delivery of healthcare interventions for PWLDs where possible. Another approach is for HCPs such as nurses, healthcare assistants and doctors to undergo further training in how to work with PWLDs (Burns, 2017; Lindsey, 2002; Redley et al., 2012; Unwin et al., 2017).

5.2.3 Key finding 3: CSWs' willingness to be assertive

This study highlights how CSWs' assertiveness went beyond the boundaries of routine work, as demonstrated in areas such as advocacy, which led to the improvement of healthcare access for PWLDs. The participants' assertiveness refutes the notion held by some HCPs and society in general that CSWs are 'low-status helpers' without capacity to stand up to doctors or other professionals (Shakespeare, 2000a); within this study, CSWs demonstrated assertiveness by initiating actions which were primarily based on their own assessment of situations. For example, advocacy actions were initiated on behalf of a PWLDs whose investigations were not followed up by HCPs.

Although there have been previous studies highlighting the assertiveness of carers in relation to healthcare facilitation (Willis, 2015a), this appears to be the first to highlight the depth and variety of areas in which CSWs demonstrate assertiveness. The study by Willis (2015a), suggests that the CSWs were not certain about their role in relation to healthcare, despite being assertive in other areas pertaining to PWLDs. In contrast, this study demonstrates that the CSWs recognised that it was within their remit to facilitate healthcare This key finding is discussed further in the following section.

5.2.3.1 Advocacy as a safeguarding tool in the hands of CSWs

Advocacy as an expressed attribute demonstrated the assertiveness of CSWs; this in turn indicates that CSWs closely identified with the healthcare needs of PWLDs. By taking on an advocacy role on behalf of PWLDS, the CSWs ensured that the

healthcare needs of their clients were not neglected. Previous studies have indicated that PWLDs would like to undertake their own advocacy (Callus et al., 2022; Di Lorito et al., 2018; Ryan et al., 2017; Sullivan & Heng, 2018). However, for some PWLDs, such as those with severe disabilities, the second best option for advocacy is through a person who knows them better; a CSW or a family carer with regard to healthcare (Di Lorito et al., 2018). Although participants understood the role of official Independent Mental Capacity Advocates (IMCA), participants took on advocacy roles alone or in conjunction with an IMCA. According to the Mental Capacity Act (MCA) (2005), IMCA's advocacy remit covers adult protection, serious medical treatment and long-term accommodation for people with various mental and sensory disabilities (Martins et al., 2011). The areas in which participants undertook advocacy on their own did not infringe on the exclusive remit of IMCA. Nevertheless, the implication for this unofficial role of CSWs may require them to have better skills in advocacy, especially in those areas where the role of IMCA is not advisable, such as seeking clarification from a professional, when the person represented lacks the capacity and confidence to talk to professionals, or in situations where there is an urgent need for advocacy. The Mental Capacity Act (2005) provides scope for people other than IMCAs to exercise advocacy on behalf of PWLDs (Brown, 2009). The acquisition of advocacy skills by CSWs has been encouraged by the UK government (Windley & Chapman, 2010). By default, CSWs are expected to take on the advocacy role at short notice so as to stand up for the rights of PWLDs (Windley & Chapman, 2010). Sullivan et al. (2006) argue that advocacy undertaken by CSWs on behalf of PWLDs ought to be viewed by HCPs as facilitative and supportive rather than disruptive or intrusive. The findings of this study demonstrate the necessity of advocacy skills to enable PWLDs to receive timely and equitable access to healthcare.

The concept of advocacy is closely related to that of access: both seek to redress potentially unfair situations which prevail at a given moment. It is in view of this, Nind and Seale (2009) highlight how the act of advocacy is a major component in facilitating healthcare access. With advocacy, a deliberate decision is made to voice

one's opinion in order to obtain a better outcome for another person (Nind & Seale, 2009).

The current study reveals that participants took on advocacy roles where the healthcare needs of PWLDs were at risk of either not being met or had not been met at all. CSWs observed situations where PWLDs had delayed treatments, unfair decisions had been made, and medical investigations were never followed up. Such issues were of concern to CSWs, and they took up the advocacy role on issues like these that they perceived as being discriminatory or negligent. Previous studies have highlighted that CSWs' efforts to address discriminatory actions were often not accommodated by HCPs ((Michael & Richardson, 2008; Redley et al., 2012). This study reveals that more than ten years later, CSWs still face challenges in needing to advocate for fairer access and treatment of PWLDs and the need to be resilient and escalate issues where direct advocacy has failed.

5.2.3.2 Innovation

The innovation and resourcefulness of the participants in this study add another dimension in understanding the role of CSWs as dependable partners in healthcare facilitation. During the Covid19 pandemic, face to face interaction with HCPs was considered risky. CSWs therefore devised innovative ways in conjunction with HCPs to communicate signs and symptoms of ill-health of PWLDs effectively. This innovation was achieved through multiple communication channels consisting of emails, the use of video cameras, telephones, and mobile phones (collectively referred as telemedicine) during the pandemic. However as Smith et al. (2020) observe, there were situations during the pandemic where direct physical examination was necessary and telemedicine was limited and not appropriate.

Telemedicine had been used prior to the Covid19 pandemic for consultations between GPs and CSWs and PWLDs (Krysta et al., 2021). However, its use increased during the pandemic as a way of meeting the healthcare needs of PWLDs (Smith et al., 2020). This increased use was demonstrated by the participants. Although Krysta et al. (2021) argue that the CSWs' capacity to use telemedicine was limited in scope

and technical ability, this study reveals that most of the participants were conversant with the use of telemedicine equipment such as computers, mobile phones, and landlines. Given the challenges that limit certain groups of PWLDs from accessing healthcare, telemedicine ought to be used side by side with current modes of access.

5.2.4 Key finding 4: Role awareness

This study demonstrates how CSWs often find themselves at the centre of delicate relationships between PWLDs and HCPs; this finding is corroborated by previous research (Luke et al., 2008). The balancing of role relationships requires CSWs to redefine their role according to the group they interact with. This is based on the recognition that each group has a particular perception of the role of CSWs (Pockney, 2017). Pockney (2017) found that PWLDs considered CSWs as friends; however, CSWs maintained professional boundaries despite being perceived as friends by PWLDs. In view of PWLDs' perception of CSWs, there is need for professional awareness on the part of CSWs to prevent the blurring of relationships and negative outcomes. This observation arises because the role CSWs demonstrate has implications on the health outcomes of PWLDs; for example, if there are too emotionally attached they may not be objective observers of any health changes (Williams et al., 2014). Previous research has further highlighted that there is a relationship between the awareness that CSWs have of their role s and the healthcare outcomes of the PWLDs (Dunn et al., 2010; Tuffrey-Wijne et al., 2016).

In response to the question posed in this study regarding how CSWs perceive their role in relation to PWLDs, four roles emerged, namely, friends, parents, advocates, and support workers. Most of the CSWs viewed themselves in the four roles, but a few did not want to view themselves as friends or parents. A study by Windley and Chapman (2010) had similar findings regarding CSW roles. In addition, Windley and Chapman (2010) found that CSWs identified themselves as 'facilitators,' and 'role models.' The implication in relation to CSWs' healthcare facilitation role, is that the degree to which they are aware of their role determines how well they discharge their responsibilities.

CSWs' perception of themselves in the current study in relation to HCPs was that they considered themselves to be experts in matters pertaining to PWLDs in general and not necessarily confined to healthcare. In view of this, CSWs perceived themselves as making a positive contribution towards the healthcare of PWLDs.

The question of role awareness was explored in this study to determine if role perception by CSWs acted as a hindrance or a facilitator in healthcare facilitation. Previous studies on role perception between CSWs and PWLDs have demonstrated that each party had a different perception of the role of the other (Dunn et al., 2010; Kruger & Northway, 2019). Dunn et al. (2010) highlight how CSWs' responsibility towards the people they support was based on how they perceived themselves as facilitators of care. Willis (2015b) states that CSWs perceived themselves as gatekeepers in matters relating to health facilitation for PWLDs. The current study highlights how CSWs still act as facilitators in healthcare access even though they act as gatekeepers in the decision-making process of determining if there is presence or absence of ill-health among PWLDs. However, in contrast with Willis (2015a), who highlighted CSWs as having role ambiguity in relation to the healthcare of PWLDs, the current study demonstrates that CSWs had role clarity regarding healthcare for PWLDs. Further, the two roles of facilitator and gatekeeper are not mutually exclusive when discharged in the best interests of PWLDs.

This study confirms that role awareness is related to role clarity, and is evident when CSWs participate in multidisciplinary teams (Williams et al., 2014).Williams et al. (2014) observe that the absence of role clarity results in lack of ownership of the decisions arrived at in multidisciplinary teams; consequently, this resulted in decisions not being implemented or not fully respected when implemented by CSWs.

From the perspective of the SMD, the role of CSWs could be viewed as an extension of a culture that encouraged dependency (Shakespeare, 2000a). This perspective, however, cannot be wholly justified with PWLDs given their variations in levels of needs. Given the scenario of PWLDs with profound learning disabilities whose level of dependency for carrying out the activities of daily living is very high, the role of

CSWs as providers of support is still essential especially with regard to healthcare facilitation.

Some scholars on disability have realised that the concept of dependency cannot wholly be dismissed and have consequently introduced a concept of co-dependency and empowerment (Keyes et al., 2015; Shakespeare, 2000b). Co-dependency in this context is between the providers of care (the CSWs and healthcare professionals) and the person being supported. Co-dependency recognises that the act of caring or support of a disabled person is not just meant to produce dependency in the person receiving care, but rather seeks to empower them to gain more independence (Keyes et al., 2015). The participants of this research saw themselves in the role of empowering their clients. Viewing the SMD from the empowerment perspective does not violate the epistemological underpinnings of the model. Among the underpinning principles of SMD applicable in this situation are independence and freedom from oppression.

5.2.5 Key finding 5: Collaboration with other agencies

Collaboration forms part of the work of CSWs and arises both by necessity and default. In this study, it occurred by default because the nature of healthcare access facilitation requires collaboration at several levels; it occurred as a necessity because CSWs could not achieve healthcare access for PWLDs without other agencies (Williams et al., 2014). According to Haines and Brown (2018), the collaboration process starts from a position of disadvantage for CSWs due to negative perceptions on the part of other professionals. CSWs were viewed as non-professionals by other collaborating partners, who considered them to have little or nothing to bring during interdisciplinary meetings such as best interest meetings (Graves, 2007; Tuffrey-Wijne et al., 2016). This perception is corroborated by the current study findings. Haines and Brown (2018) argue that a collaborative process that views CSWs as outsiders does not lend itself to being successful. A successful collaboration partnership ought to treat all members of the team as equal partners regardless of their

professional status and the knowledge they bring to the collaboration process (Bochatay et al., 2017; Bridges et al., 2011).

The second objective of this research is to explore the role of CSWs in the coordination of healthcare needs for PWLDs with other agencies. The findings confirm previous studies (Graves, 2007; Haines & Brown, 2018), in that participants in this study had difficulties getting their views heard. However, this study builds on previous studies by demonstrating that despite facing difficulties with collaboration, the participants did not accept the status quo when faced with collaborative challenges. Instead they resorted to other mechanisms for resolving issues, such as instigating best interest meetings and initiating the involvement of IMCAs. Bochatay et al. (2017) observes that HCPs in general lack an understanding of the roles of other professionals outside the healthcare system. This lack of understanding militates against a successful collaborative process across the professions (Bochatay et al., 2017).

By not allowing power differentials or negative perceptions of their role to hinder their collaborative efforts, CSWs in this study demonstrated that consensus through a collaborative process was the better option in facilitating healthcare access for PWLDs. Despite the negative collaborative environment in which most participants operated, the findings demonstrate that they were resilient and assertive as well as being knowledgeable about the legal process to follow. These characteristics demonstrate role awareness. The implication for practice on the part of HCPs is the need for them to cultivate an attitude of accommodating and respecting the views of other professionals such as CSWs.

5.2.6 Key finding 6: Communication.

Communication plays a major role in relationships. However, as this study has highlighted, communication becomes challenging when the CSW must transmit the bodily discomforts, feelings and needs of a non-verbal person or one who has limited capacity to articulate their own health needs to an HCP. CSWs often find themselves in this challenging position. Failure by some HCPs to engage with PWLDs either

directly, or indirectly through the CSWs during GP consultations and hospitalisation, was among the common challenges reported by participants.

In addition, there was failure by some HCPs to use hospital passports, as well as to engage with CSWs regarding the need to provide appropriate reasonable adjustments for PWLDs when accessing both primary and secondary care. This has been observed in previous studies, Chinn & Rudall, (2019); Wilkinson et al., (2013); Antaki & Chinn, (2019); Northway et al., (2017) but the current study builds on these previous observations by demonstrating how proactive some participants were in responding to the communication challenges highlighted in the findings. To address such challenges, CSWs utilised the services of liaison nurses to act as a link between them and the healthcare staff especially regarding the use of hospital passports. The practice of using liaison nurses or care co-ordinators to help communication between PWLDs and the hospital was not new, as observed in NHS England (2019). However, the initiative by participants in this study to utilise the services of the liaison nurses was borne out of the recognition that left to themselves, HCPs would do very little to improve communication with PWLDs.

The importance of hospital passports and the information contained in them has been observed to make a difference in the health outcomes of PWLDs (WHO, 2017). However, Northway et al. (2017) note that one of the factors contributing to the low utility value of hospital passports was that some of them contained limited information, and critical information such as allergies was missing. The responsibility for preparing hospital passports falls upon CSWs (Northway et al., 2017). However, in contrast with previous findings, participants of the current study adequately prepared hospital passports, although they were in most cases unread by HCPs, and the information contained in them was not utilised. Nevertheless, participants took it upon themselves to sensitise the nurses to the benefits of using hospital passports to maximise their use. Considering that most of the information in hospital passports is potentially key in the healthcare facilitation process as well as in arriving at critical medical decisions, their neglect puts the PWLDs at risk, in addition to potentially denying them the opportunity to receive healthcare tailored to

their individual situations. Hospital passports are key tools in the transmission of vital information for decision-making and patient safety (WHO, 2017).

Barnes and Mercer (2006) argue that when disabled persons are expected to fit into services that are not tailored for them, providers create unnecessary barriers to access. Barnes and Mercer point out that to provide equity of access to services; providers ought to start with the needs of disabled persons first. The experiences of the participants of this research indicate that the communications of PWLDs were in most cases never considered. Previous research (Bridges et al., 2011; Burton & Walters, 2013; Clarke & Fung, 2022) has suggested the need for more training for doctors and nurses to increase their understanding of the needs of PWLDs. The current study recommends the need for additional and specific training for HCPs as well as CSWs in the understanding of PWLDs, with an emphasis on those on the autistic spectrum with a learning disability. Participants realised that their own knowledge of autism was not as comprehensive as it ought to have been this is in recognition of both the range and the breadth of traits of people on the autistic spectrum.

Regarding the training needs of HCPs, participants were of the view that their knowledge of autism was comparatively far lower than that of CSWs. Previous research has highlighted that most doctors' knowledge of autism was almost the same as that of non-professionals (Kirchner et al., 2010). Corden et al. (2022) found that doctors' knowledge of autism was 'moderate' and that most doctors had had no training in autism.

From a CR perspective, training is in the 'actual domain'; as such, it is a factor which acts as a catalyst for change. Consequently, the effectiveness of training is premised on factors in the 'real domain' such as government policies and the willingness of learners to learn and produce outcomes which make a difference. HCPs as key players in healthcare access and provision are expected to have up-to-date skills in relation to PWLDs; however, previous research has shown that despite GPs undergoing training in learning disabilities, the application of that knowledge in daily practice was very low (Gill et al., 2002). Judging by the findings of this study, little has changed in terms of skills acquisition and knowledge related to learning disabilities.

This is despite UK government measures such as financially incentivising GPs to have longer consultation times with PWLDs (Atkinson et al., 2013). In addition, since 2009, there has been a legal requirement for mandatory training for those who deal with autistic people. The high profile death in 2016 of Oliver McGowan, an autistic person with a learning disability in the UK, highlighted the impact of the lack of training of HCPs (Smith, 2023), This event and others like it led to the enactment of the Health and Care Act, 2022, which requires mandatory training for all HCPs in aspects of autism and learning disabilities (Russell, 2022; Smith, 2023). The emphasis on mandatory skills acquisition underlines the scale of the problem from the healthcare perspective.

The need for specific training in autism arises from the recognition that 25% of all PWLDs are within the wider autistic spectrum (Dern & Sappok, 2016b). Furthermore, the Autism Act (2009) stipulates that all staff dealing with people on the autistic spectrum be provided with appropriate training in autism (Aylott, 2011). Clark et al. (2016) observed that key frontline staff, such as secretaries, receptionists in GP surgeries and hospitals, are potential obstacles to PWLDs accessing healthcare due to their poor knowledge and skills in dealing with autistic people. An understanding of autism has the potential to enable doctors to recognise and treat some of the comorbidities associated with a learning disability during routine GP consultations. From an epistemological perspective, an understanding of autism and learning disabilities has the potential to contribute to a reduction in the prevailing higher morbidity and mortality rates among PWLDs.

Regarding the deficit in CSWs' knowledge of autism, as identified in this study, previous studies identifying training needs for this group of workers did not identify autism training as a special area. In a qualitative study with CSWs by Windley and Chapman (2010), several training needs were identified but not training in the autism spectrum. This paucity of training in autism needs to be addressed. The further implication for this finding is that the current foundational training as well as ongoing training for all cadres of staff who deal with autistic people with learning disabilities need re-evaluating. Providing training in autism and learning disabilities to trainee doctors can increase their confidence in handling PWLDs (Warfield et al., 2015).

Viewing the inadequate training of both healthcare staff and CSWs from the perspective of both CR and SMD, several aspects can be identified as causal mechanisms, chiefly the failure to integrate autism training in the education of both nurses and doctors; this is attested by a review by Corden et al. (2022) However, the inadequate training in the UK is not on account of a lack of policy or legislation, as there has been government policy since 2010 on autism training. There is equally a monetary incentive to GPs for seeing PWLDs (Atkinson et al., 2013). However, as Tuffrey-Wijne et al. (2014) observed, training without a change in attitudes on the part of GPs and other HCPs will achieve very little. Previous research highlight that previous efforts to train GPs, but that the schemes have not resulted in higher numbers of staff taking up relevant courses in autism or learning disabilities (Hogg, 2001; Tuffrey-Wijne et al., 2014). These observations require attention to be given to what else can be done. Potentially, a change in attitudes towards both training and PWLDs by HCPs seems necessary. Negative attitudes by HCPs towards PWLDs have been singled out as the major obstacle to healthcare access (Pelleboer-Gunnink et al., 2017).

5.3 Strengths of the study and its contribution to knowledge

Being a CSW gave the author a better understanding of some of the experiences of study participants. The inside knowledge of the researcher enabled him to make an in-depth exploration of the phenomenon being studied. Prior to this study, there were very few studies that had been undertaken by CSWs who were in current employment in their research field. In contrast, there were many studies conducted by doctors and nurses within their professional areas, and which extending their scope to research into CSWs and PWLDs. The fact that the researcher understood some of the underlying phenomena experientially, lent strength to the various stages of the research process such as the research design, data collection and analysis. This experiential knowledge of the researcher can therefore be considered one of the strengths of this research. The researcher had also previously worked both as an HCP and educator; these additional experiences allowed the researcher to view data from varied angles during both the data collection and analysis phases.

The separation of participants into two categories with two slightly different interview schedules (CSWs and managers) facilitated convergence of views. These views complemented each other, resulting in a balanced perspective of the phenomenon. This approach facilitated the exploration of research areas which would have been neglected had only one group been interviewed.

Participants were recruited from across England from various organisations such as local authorities and privately run facilities. Although this diversity of participants does not imply that the findings can be generalised, it does indicate the richness of the sources of data. The use of a diversity of data collection methods, although this was not part of the initial design, overcame the limitations of the use of a single method. For example, participants who may have been uncomfortable with face-to-face interviews were able to express themselves without inhibition on the phone or online in Microsoft Teams meetings.

The combination of CR and SMD as theoretical lenses for this study stands out as a methodological strength of the study, in that both explored societal structural issues but from varied perspectives. Further, the combination of CR and SMD facilitated exploration of the underlying mechanisms and barriers associated with the study phenomena during interviews, data analysis and discussion of findings.

5.4 Limitations of the study

The wider time scale in which the recruitment and data collection took place due to the pandemic (March 2020 to May 2022) was beyond the researcher's control. However, this meant that some findings were affected, either positively or negatively, by what was happening during and after the pandemic.

Recognising that the participants supported of PWLDs, some experiences may have been limited to only certain groups; for example, those who have profound learning disabilities or mild learning experiences. This meant that those who only supported people with a mild learning disability may not be able to relate to the experiences narrated by those who supported people with a profound learning disability.

The first 10 participants (managers) were recruited through gatekeepers who were senior managers of one organisation; potentially, this group may have been selected to provide the institutional perspective of events. However, the researcher had no way of knowing this. There are benefits of recruiting through gatekeepers such as getting the participants that fit the criteria as well as providing an opportunity to build rapport with would-be participants and their organisations (Dempsey et al., 2016). However, there are some disadvantages to using gatekeepers such as potential bias in their selection of would-be-participants (Guillemin et al., 2017)

5.5 Policy and practice implications

In view of the findings, several policy and practice implications can be drawn. The implications could be applicable in the training of healthcare providers, CSWs and in the formulation of policies governing interprofessional collaboration. Although the concept of healthcare access was central to this study, the goal is to ensure a reduction in the current disproportionate morbidity and mortality rates of PWLDs. This study has demonstrated the key role in the mitigation of some of the health inequalities PWLDs still face. In view of this, it is expected that through policy changes as well as collaboration between providers of services to PWLDs and HCPs, there will be a recognition of the role of CSWs in partnerships. This recognition should be documented rather than just assumed.

In view of the limited skills that CSWs have in identifying early signs of ill health, CSWs training should be within their work environment (on site). Supervisors of CSWs should play a greater role in mentoring their subordinates in identifying early signs ill-health. Visual aids (in form of diagrams and pictures) of early signs of diseases such as sepsis, stroke and heart attack should be made available in the work environments.

Although training has been a prominent factor both in the analysis and discussion, regarding what is needed to improve access to healthcare by PWLDS, a change in attitude on the part of HCPs is also important. Below is a tabulation of policy implications:

Table 6: Tabulation of suggested policies

Policy area	Suggested policy
Training for health care providers	Knowledge about legislation such as the MCA (2005) and the Equality Act (2010). Skills in how to implement reasonable adjustments and in the use of hospital passports
Training for community support workers	Acquisition of skills in advocacy, assertiveness, and collaboration and autism as well as in the identification of early signs of pain and serious conditions like sepsis, strokes, and meningitis.
Collaboration and communication between managers of adult social services and managers of	A system of routine collaboration and communication between managers of adult social services and managers of healthcare services to

healthcare services	ensure removal of barriers to healthcare access.

5.6: Conclusion

This thesis has highlighted the key role of CSWs in the facilitation of healthcare in several areas such as collaboration, communication, and assertiveness in advocacy and telemedicine. Through the combined approaches of CR and SMD, some of the underlying barriers and facilitators impacting healthcare facilitation were identified.

The key concepts in the study were the role of CSWs in healthcare facilitation, equity of healthcare access for PWLDs, and the challenges and facilitators encountered in that process. Other concepts central to the study were support versus care, or how the two concepts could co-exist under the Social Model of Disability when applied to PWLDs.

The study revealed barriers to healthcare access which included the absence of reasonable adjustments due to lack of training of HCPs regarding learning disabilities and their failure to use hospital passports. It also uncovered facilitators of healthcare such as the skills of assertiveness and collaboration on the part of CSWs. Such assertiveness was evident in advocacy and the use of telemedicine. There was also cooperation displayed by some of the HCPs, and this acted as a facilitator to healthcare facilitation. The first objective is as follows: to identify the challenges and facilitators that community support workers experience when they facilitate access to healthcare for people with learning disabilities. This objective was premised on the SMD in its recognition of societal barriers as disabling (Marks, 1997). The first objective was also premised on CR in respect to facilitators and barriers of healthcare access. The researcher's utilization of CR went beyond the recognition of barriers and facilitators; CR was used to explore the underlying causal mechanisms such as

the lack of training, lack of skills, and identification of legislation and policies governing healthcare provision for PWLDs. In the case of PWLDs, these barriers were not merely physical, but also included prejudiced attitudes, cultural perceptions of disability as well as failure to accommodate the various potential comorbidities in someone with a learning disability.

As CSWs encountered barriers to healthcare, they demonstrated their skills by mitigating against those challenges. The mitigation measures took various forms including dialogue, collaboration, and the use of IMCA. These were pivotal in facilitating healthcare access. By highlighting the mitigation measures that CSWs took in the light of the barriers they faced in healthcare access, the study used CR to explore underlying causal factors (Mitchell, 2015).

Objective two explored the role of CSWs in the coordination of healthcare needs of PWLDs. The findings demonstrated that CSWs were at the forefront of the coordination process through interdisciplinary collaboration. CSWs demonstrated role awareness, and as such they were not deterred by power differentials within multidisciplinary teams. The research further articulated the various roles CSWs took on in coordinating healthcare access with other agencies. Although CSWs did not always succeed in their coordination process, failures led them to explore innovative ways of resolving issues. In situations where CSWs could not collaborate at a bilateral level with healthcare providers, CSWs initiated the involvement of external teams such as the Learning Disability Teams.

CR recognises the reality of the body as having impairments; the body in turn imposes restrictions on an individual who has those impairments (Shakespeare, 2014b; Thomas, 2004). This acknowledgement is demonstrated in one of the findings which suggests that simply having certain types of learning disability can be a barrier to healthcare access. The barriers occurring because of body impairments are largely independent of societal barriers. The argument being advanced is that barriers to healthcare access for PWLDs are not always necessarily limited to those that are imposed by societal factors as viewed from the SMD perspective but can be

independent of society's actions. However, there is always an interplay between inherent barriers (bodily) and external barriers (societal).

Based on the findings, this study has been able to meet its aim and objectives as well as answer the research question on how CSWs constructed their experiences. The experiences of CSWs were constructed around their assumed roles as well as their assigned roles. In view of this, CSWs perceived themselves as facilitators, agents in mitigation, collaborators, advocates, resourceful people routinely providing support to PWLDs. The findings of this research add both to the theoretical underpinnings of the ever-evolving Social Model of Disability as well as to Critical Realism as a theoretical approach to learning disabilities. In addition, these findings can potentially contribute to healthcare policy and public health knowledge.

5.7: Recommendations for further research

In view of the study findings, several recommendations are made for further research. The first is the need for exploration of factors demotivating or motivating healthcare staff to undergo further training in learning disabilities and autism. Secondly, research is needed into how CSWs can be equipped with skills on the promotion of good health in PWLDs. Thirdly, exploration into how CSWs can be equipped with an understanding of the benefits of keeping accurate records and the skills to do this, needs to be undertaken.

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APPENDICES

Appendices 1-13

1a Sample search strategy

1b updated search strategy October 2023

2a Data extraction form

2b CASP qualitative assessment form

3 Expression of interest form

4 Flyer for recruitment of participants

5 Participant information sheets

6 Consent form

Appendix 1a: Sample search strategy

Search Terms	Search Options	Actions	
S14	S5 AND S9 AND S13	**Search modes** - Find all my search terms	**Results** (124)
S13	S10 OR S11 OR S12	**Search modes** - Find all my search terms	**Results** (37,397)
S12	AB "mental retardation" OR "intellectual Disabilit*"OR "intellectual impairment" OR "learning disorder*" OR "learning disabilit*"	**Search modes** - Find all my search terms	**Results** (37,271)
S11	TI "mental retardation" OR "intellectual Disabilit*"OR "intellectual impairment" OR "learning disorder*" OR "learning disabilit*"	**Search modes** - Find all my search terms	**Results** (14,473)
S10	(MH "Learning Disorders") OR (MH "Intellectual Disability")	**Search modes** - Find all my search terms	**Results** (27,354)

S9	S6 OR S7 OR S8	**Search modes** - Find all my search terms	**Results** (113,003)
S8	AB "healthcare" OR "primary care" OR "community care"	**Search modes** - Find all my search terms	**Results** (83,290)
S7	TI "healthcare" OR "primary care" OR "community care"	**Search modes** - Find all my search terms	**Results** (80,082)
S6	(MH "Healthcare")	**Search modes** - Find all my search terms	**Results** (66,128)
S5	S1 OR S2 OR S3 OR S4	**Search modes** - Find all my search terms	**Results** (132,858)
S4	AB "social care" OR "personal assistan*" OR "healthcare personnel" OR "support worker*" OR "care worker" OR caregiver* OR carer*	**Search modes** - Find all my search terms	**Results** (92,764)
S3	TI "social care" OR "personal assistan*" OR "healthcare personnel" OR "support worker*" OR "care worker" OR caregiver* OR carer*	**Search modes** - Find all my search terms	**Results** (88,458)
S2	(MH "Health Personnel")	**Search modes** - Find all my search terms	**Results** (41,361)

S1 (MH "Caregivers") **Search modes** - Find all my search terms **Results** (37,405)

Appendix 1b: updated search October 2023

	Search ID#	Search Terms	Search Options	Actions
	S15	S6 AND S10 AND 14	**Limiters** - Full Text; Peer Reviewed; Published Date: 19850101-20230931 **Search modes** - Find all my search terms	**View Results** (140) **View Details** **Edit**
S14		S11 OR S12 OR S13	**Search modes** - Find all my search terms	**View Results** (42,866) **View Details** **Edit**
S13		AB "mental retardation" OR "intellectual Disabilit*"OR "intellectual impairment" OR "learning disorder*" OR "learning disabilit*"	**Search modes** - Find all my search terms	**View Results** (42,761) **View Details** **Edit**
S12		TI "mental retardation" OR "intellectual	**Search modes** - Find all my search terms	**View Results** (41,421)

	Disabilit*"OR "intellectual impairment" OR "learning disorder*" OR "learning disabilit*"		**View Details** **Edit**
S11	(MH "Learning Disorders") OR (MH "Intellectual Disability")	**Search modes** - Find all my search terms	**View Results** (30,713) **View Details** **Edit**
S10	S7 OR S8 OR S9	**Search modes** - Find all my search terms	**View Results** (127,785) **View Details** **Edit**
S9	AB "healthcare" OR "primary care" OR "community care"	**Search modes** - Find all my search terms	**View Results** (97,583) **View Details** **Edit**
S8	TI "healthcare" OR "primary care" OR "community care"	**Search modes** - Find all my search terms	**View Results** (93,337) **View Details** **Edit**
S7	(MH "Healthcare")	**Search modes** - Find all my search terms	**View Results** (73,087)

			View Details **Edit**
S6	S2 OR S3 OR S4 OR S5	**Search modes** - Find all my search terms	**View Results** (160,193) **View Details** **Edit**
S5	AB "social care" OR "personal assistan*" OR "healthcare personnel" OR "support worker*" OR "care worker" OR caregiver* OR carer*	**Search modes** - Find all my search terms	**View Results** (109,989) **View Details** **Edit**
S4	TI "social care" OR "personal assistan*" OR "healthcare personnel" OR "support worker*" OR "care worker" OR caregiver* OR carer*	**Search modes** - Find all my search terms	**View Results** (105,006) **View Details** **Edit**
S3	(MH "Health Personnel")	**Search modes** - Find all my search terms	**View Results** (52,300) **View Details** **Edit**

S2	(MH "Caregivers")	**Search modes** - Find all my search terms	**View Results** (43,434) **View Details** **Edit**
S1	(MH "Caregivers")	**Search modes** - Find all my search terms	**View Results** (43,434) **View Details** **Edit**

Appendix 2a: Data Extraction form

(adapted from Joanna Briggs Institute) (2017).

Study characteristics

Author and year

Title of study

The journal

Objective of the study

Study participant

Country of the study

Study design

Sample size

Sampling technique

Data collection method

Data collection period

Data analysis method

Ethically approved from

Quality score of the article

Relevant findings

Author

Reviewer's comments

Appendix 2b: CASP Qualitative Assessment

Critical Appraisal Skills Programme (CASP)

The CASP tool for qualitative studies 2018 edition consists of three broad sections.

The sections are: a) consisting of six questions focusing on the validity of a study; b) consisting of three questions focusing on the results of the study and c) focusing the utility value of the results (CRITICAL APPRAISAL SKILLS PROGRAMME, 2018).

There are three options to consider for each question. The options are *yes, can't tell and no.* The Yes option means that the particular item is suitable for the study, the No option' means that the item is not suitable for the study and the 'Can't tell' option means that the reviewer is not clear to determine a 'Yes' or 'No' option. The questions are as follows:

1. Was there a statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participant been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently vigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Appendix 3: Expression of interest form

Lancaster University Research

Project: Community Support Workers and Healthcare

.

I am interested in taking part in this evaluation because I am currently involved in Community support work in the Northwest of England

Please return this form either by post or by email to the Lancaster University researcher at the UK address below, who will be in contact with you to discuss the project, answer any questions you may have about the research and whether you would like to take part.

Please complete the following but only provide contact details that you are happy to share:

I have read and understood the 'Participation Information Sheet'

Name:_____ Contact: Mobile phone:

Email: Home phone: Work phone: Postal address:

Researchers contact details: c.sitali@lancaster.ac.uk

Appendix 4: Flyer for recruitment

Lancaster University

Lancaster University Research Project

Community Support Workers and Primary health care

We need your help!

Would you take part in this research?

Do you support an adult with learning disability?

Would you take part in a project that aims to identify the experiences, challenges, and benefits you face in supporting adults with a learning disability to access Healthcare?

If so, we would like to hear from you!

What would be involved?

- Sharing your experiences, challenges and benefits in facilitating healthcare for adults with learning experiences with the researcher
- Taking part in a focus group discussion to discuss your experiences with other Community Support Workers within your service area

Where and when will the study take place?

The study will take place during winter and spring of 2019 within or near your workplace

If you would like to participate in the study and for more details please complete and return the attached expression of interest form by email: c.sitali@lancaster.ac.uk or contact the researcher by phone: 07449022072(mobile).

Appendix 5 : Participant Information Sheets

Participant Information Sheets

EXPERIENCES OF COMMUNITY SUPPORT WORKERS IN FACILITATING ACCESS TO HEALTHCARE SERVICES FOR ADULTS WITH LEARNING DISABILITIES

My name is Clement Sitali, and I am conducting this research as PhD student in Public Health programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to identify any challenges and facilitators that you encounter when you facilitate access to healthcare services for adults with learning disabilities you are supporting. We are also seeking to understand your role in the coordination of healthcare for the service users as you work with other agencies such as the GP, Learning Disability Team and others.

Why have I been approached?

You have been approached because the study requires information from people who have worked with adults with learning disabilities and have facilitated their healthcare.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. However, your participation may help future decision making and future research.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to participate in a one-to-one interview or group discussion known as a focus group. You will be asked a series of open-ended questions. Both the one-to-one interviews and focus group discussions will be audio-recorded. The interview session will not take more than an hour.

Will my data be Identifiable? No, your data will not be identifiable. Your name will not be associated with what you will say. The information you provide is confidential. You will remain anonymous and any quotations from you will not be attributed to your real name, instead a pseudonym will be assigned to what you have said.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- Hard copies of text transcripts will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, hard copies of transcripts will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.

- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and I will talk to a supervisor at the first instance.

What will happen to the results?

The results will be summarised and reported in a dissertation and may be submitted for publication in an academic or professional journal. A summary of findings will be presented to the management of your organisation.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher: c.sitali@lancaster.ac.uk and my supervisors:

1. Professor Chris Hatton at chris.hatton@lancaster.ac.uk Telephone no. 01524 592823
2. Dr Siobhan Reilly at s.reilly@lancaster.ac.uk Telephone no. 01524 594367

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Clinical Director

Division of Health and Medicine

Lancaster University Lancaster

LA1 4YG

If you wish to speak to someone outside of the Department of Public Health Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746

Associate Dean for Research Email: r.pickup@lancaster.ac.uk Faculty of Health and Medicine

(Division of Biomedical and Life Science

LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance from:

Your **workplace counselling services**: Telephone: **01524 387857**

NHS: Telephone **01257 231660**, Address: 80-82 Devonshire Road, Chorley, PR7 2DR

Samaritans: Telephone: **01524 61666**, Address: 21 Sun Street, Lancaster, Lancashire, LA1 1EW. National number: **116 123.**

Appendix 6 Consent form

Consent form

Study Title: EXPERIENCES OF COMMUNITY SUPPORT WORKERS IN FACILITATING ACCESS TO HEALTHCARE SERVICES FOR ADULTS WITH LEARNING DISABILITIES.

We are asking if you would like to take part in a research project which in we would like you to share your experiences and challenges in facilitating Healthcare for adults with learning disabilities. The goal is to identify any barriers and challenges that you perceive you encounter when you facilitate access healthcare for the service users. We are also seeking to understand your role in the coordination of healthcare for the service users as you work with other agencies such as the GP, Learning Disability Team and others. Before you consent to participating in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Clement Sitali. **Please initial each statement**

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study. ☐

2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐

4. I understand that audio recordings will be kept until the research project has been examined. ☐

5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐

7. I understand that the information from my interview will be pooled with other responses, anonymised and may be published. ☐

8. I consent to information and quotations from my interview being used in reports conferences and training events. ☐

9.I understand that the researcher will discuss data with their supervisor as needed. ☐

10.I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor. ☐

11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

12 I consent to take part in the above study. ☐

Name of Participant_Signature____ Date _

Name of Researcher__Signature____Date

Appendix 7: Community Support Workers interview schedule

INTERVIEW GUIDE for Community Support Workers

Community Support Workers' understanding of what is meant by "facilitating Healthcare"

How do you understand the phrase: "facilitating healthcare" to adults with learning disabilities (service users*)? What activities would you consider constitute healthcare?

Opportunities the interviewee has had to facilitate healthcare for adults with learning disabilities

If you have had an opportunity to facilitate healthcare within the last three months, what was your experience?

How the goals of healthcare are met by the interviewee

Given your understanding of healthcare, how do you meet this goal for the service users?

How the interviewee perceives the goals of healthcare are met by other agencies, for example the GP, Specialist Doctors, Nurses and the Community Learning Disability Teams, etc towards adults with learning disabilities.

In your experience, how do the other agencies meet the healthcare goals of the service users?

How the Community Support Workers role in healthcare is perceived by other agencies

Is your input in terms of opinion sought regarding healthcare by other agencies such as the GP, Nurses, Community Learning Disability Team? During routine

interactions with these agencies how do you know your opinion is valued? Do you consider that other agencies view your role as essential to the facilitation of healthcare?

Facilitators and challenges faced in meeting the goals of healthcare fora adults with learning disabilities.

Are you able to share with me any challenges or any facilitators you and other team members have had in meeting the healthcare needs of the service users?

Any specific experiences recalled in facilitating healthcare for adults with learning disabilities.

Are there any specific experiences which stand out in your memory regarding occasions when you had to facilitate HEALTHCARE for the service users? Any specific experiences from within the past few days, weeks or months?

Are there any obstacles you are facing or have faced in meeting the HEALTHCARE needs of the service users?

What in their view are factors contributing to those hindrances if any.

If you have had any obstacles in meeting the healthcare needs of the service users, what in your opinion are the contributing factors?

Any other suggestions or observations the interviewees may have regarding healthcare access for adults with learning disabilities.

Are there any further observations or suggestions you would like to make regarding access to healthcare for the service users?

*The term **"service user"** is preferable and in common use than the term **"learning disability"** among Community Support Workers and their Team managers.

Appendix 8: Interview schedule for team leaders

INTERVIEW GUIDE for interviews with Team Leaders (Managers)

Team leaders' understanding of what is meant by "facilitating Healthcare".

How do you understand the phrase: "facilitating healthcare" to adults with learning disabilities (service users*)? What activities would you consider constitute healthcare?

Opportunities the interviewee has had to facilitate healthcare for adults with learning disabilities.

If you have had an opportunity to facilitate healthcare within the last three months, what was your experience?

How the goals of healthcare are met by the interviewee.

Given your understanding of healthcare, how do you meet this goal for the service users and the team you lead?

How the interviewee perceives the goals of healthcare are met by other agencies, for example the GP, Specialist Doctors, Nurses and the Community Learning Disability Teams, etc. towards adults with learning disabilities.

In your experience, how do the other agencies meet the healthcare goals of the service users? As a team leader, how do the other agencies collaborate with you in facilitating healthcare?

How the Community Support Workers/team leader's role in healthcare is perceived by other agencies.

Is your input in terms of opinion sought regarding healthcare by other agencies such as the GP, Nurses, Community Learning Disability Team? During routine interactions with these agencies how do you know your opinion is valued? How do other agencies view your role in the facilitation of healthcare?

Facilitators and challenges faced in meeting the goals of healthcare for adults with learning disabilities.

Are you able to share with me any challenges or any facilitators you and other team members have had in meeting the healthcare needs of the service users?

Any specific experiences recalled in facilitating healthcare for adults with learning disabilities.

Are there any specific experiences which stand out in your memory regarding occasions when you had to facilitate healthcare for the service users?

Any perceived hindrances they have faced in meeting the goals of healthcare for adults with learning disabilities.

Are there any obstacles you are facing or have faced in meeting the healthcare needs of the service users?

Any perceived facilitators of healthcare worthy sharing

In your opinion are there any factors you recall as a team manager/ team which have had a positive impact in the facilitation of the health of the service users you have had as a team?

What in their view are factors contributing to hindrances in facilitating healthcare if any.

If you have had any obstacles in meeting the healthcare needs of the service users, what in your opinion are the contributing factors? What expectations do you have of the team you lead regarding healthcare? If there are any barriers, what are they?

Any other suggestions or observations the interviewees may have regarding healthcare access for adults with learning disabilities.

Are there any further observations or suggestions you would like to make regarding access to healthcare for service users? Any suggestions you have regarding the role of the Community Support Workers in facilitating healthcare?

Appendix 9: Email application to conduct interviews

November 2018

Dear Ms xxx,

Directorate's Social Work and Social Care Workforce Group

(via xxxx)

Re: Application to conduct research

As a follow-up to my initial contact with you in 2017 through Mrs Kellie-Anne Buczynski regarding the possibility of carrying out research in Lancashire County Council. I am hereby making a formal request for permission to carry out research with some of the staff involved in supporting adults with learning disabilities. The research involves Community Support Workers together with their team leaders. The staff to be interviewed are those who are currently working with adults with learning disabilities living residential homes. The research focus is on the experiences of Community Support Workers regarding the barriers and facilitators they face in facilitating Healthcare for adults with learning disabilities.

I am intending to interview 22-28 Community Support Workers and their supervisors drawn from Adult Social Services. The make of the group will be as follows: 10-12 Community Support Workers will participate in face-to-face interviews; 6-8 Community Support Workers will participate in focus group discussions, and 6-8 immediate supervisors will participate in interviews.

Attached to this email is the outline of the research proposal and information sheet for the research project. Also attached is a completed ethics application form you had earlier sent me when I made the initial inquiry. Included also is a copy of an email from the Faculty of Health and Medicine Research Ethics Committee of Lancaster University indicating approval of my proposal and research ethics application.

For any further enquiries, you may get in touch with me at c.sitali@lancaster.ac.uk or you may get in touch with one of my research supervisors: Professor Chris Hatton and Dr Siobhan Reilly, their respective emails are: chris.hatton@lancaster.ac.uk and s.reilly@lancaster.ac.uk

I am looking forward to hearing from you.

Yours Sincerely,

Clement L. Sitali

Appendix 10: Email reply granting permission to conduct interviews

FW: Research application for Clement Sitali5

clementsitali@yahoo.co.uk/Inbox

xxx, xxx <xxx.xxx@xxx.gov.uk>

To: clement Sitali

Cc: xxx

Thu, 20 Jun 2019 at 08:08

Good Morning Clement

I am writing to confirm, that xxx, Head of Service has approved your research request based on the amended application and reassurance in your email below.

Your contact for this project is xxx – I have copied her into this email, so you have her email address.

Thank you.

xxx

xxx
Skills, Learning and Development
xxx County Council

xxx.xxx@xxx.gov.uk

Appendix 11: Information sent to Facebook Support Group for Social support workers.

Dear Xxx, I am a member of this group I am currently working as a support worker as well as a researcher with Lancaster University. I would like to put the following message and request to the group: I am looking for participants for my research on the challenges and experiences of support workers in facilitating healthcare for adults with learning disabilities. If you are interested contact me on my email: c.sitali@lancaster.ac.uk A small payment of 10 pounds will be given in appreciation of your time. All information given for the research will be kept in confidence in accordance with the latest laws governing information.

Thank you.

Clement Sitali.

Appendix 12 Sample of primary codes from literature review

HEALTH FACILITATION

-Evidence of good communication by CSWs.

-Evidence of poor communication by CSWs and other health care providers

-CSW are active advocates for PWLD

-Support workers participate in health promotion activities

-CSWs are a link between doctors and PWLD.

-CSWs initiate health related actions to promote the health of PWLD

-CSWs act as a gatekeeper of critical decisions impacting

ORGANISATIONALCHALLENGES AND FACILITATORS

-Role clarity issues of support workers in relation to health promotion, identification of signs and symptoms

-Staffing shortage among support workers

-High staff turnover among support workers

-Poor collaboration styles impact health outcome.

-Varied role perceptions and expectations by other professionals and PWLD.

-Poor knowledge by other professions regarding learning disabilities.

-Disparity between hospital written policies supportive of the role of CSWs and their actual implementation.

-a lack of clarity about mutual roles between nurses and CSWs

KNOWLEDGE

-CSW demonstrate varied knowledge of signs and symptoms, especially assessment of pain.

-Tools for assessment of pain are not widely utilised

-Skills deficit regarding communication, Mental Capacity Act, support of women who need to access breast and cervical screening

-Poor knowledge of menopause and how to support women going through it

-CSWs learn through experience, teams and from

health promotion

--Support worker acts as an exemplar to health care professionals

-Support acts as an exemplar to PWLD

-Support workers collaborate with other agencies

-Majority of CSW felt supported by HCP

-Minority (one third) of CSWs did not feel supported by HCPs.

-Support workers as communicators are key to an effective GP consultation.

-Lack of awareness of need for dental health hinders facilitation

other professionals

Support workers are assertive and able to identify poor practices by other professions.