

**Including people with learning disabilities in conversations about climate change**

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## Abstract

**Background:** People with learning disabilities may be disproportionately affected by the consequences of climate change, yet their perspectives are almost entirely absent from climate research and discourse.

**Aim:** This study explored the perspectives of people with learning disabilities on climate change, including their understanding of it and whether and how they wished to be involved in conversations and actions to address it.

**Methods:** Fourteen adults with learning disabilities were recruited from a community day centre in East England and took part in individual semi-structured interviews. Nine participants subsequently attended an informal feedback group in which the findings were shared and discussed. Data from the interviews were analysed using Braun and Clarke's (2006) reflexive thematic analysis, generating two overarching themes and six subordinate themes.

**Results:** The first theme, Understanding Climate Change, identified a spectrum of understanding ranging from little to no familiarity with the concept, through weather-based associations, to a more complex and comprehensive awareness of its human causes and global consequences. The second theme, Inaccessible Climate Change, explored the structural, communicative, and attitudinal barriers that have prevented people with learning disabilities from accessing climate information and participating in climate discourse, and examined participants' own reflections on why they have been excluded from these conversations.

**Conclusion:** The findings challenge deficit-based assumptions about the capacity of people with learning disabilities to engage with climate change and

support a social model interpretation in which the barriers to engagement are located in systems and structures rather than in individuals. The study argues that the inclusion of people with learning disabilities in climate conversations is not only practically possible but ethically necessary, and that their voices and perspectives have both the right and the capacity to contribute to one of the most significant challenges of our time.



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# **1. Introduction**

## **1.1 Chapter Overview**

This introduction chapter has been organised into three parts.

Part one sets out to provide an overview of the specific characteristics pertaining to people with learning disabilities, including a brief description of the language and definitions used and with an overview of people with learning disabilities in the United Kingdom (UK). It then goes on to discuss the research on the inclusion of people with learning disabilities in conversations that might be considered as ‘difficult’ for them.

The second part outlines the systematic literature review, which explored people with learning disabilities’ experiences of support from the National Health Service (NHS), with the method used to synthesise research being meta-ethnography.

The final part introduces the topic of climate change, the significant impacts it has on health and wellbeing, the potential disproportionate impact on people with learning disabilities, and the lack of research on this topic. The chapter ends with a description of the aims of the research and its relevance within the wider context of climate research.

## **1.2 Part One: People with Learning Disabilities and Inclusion in Difficult Conversations**

### ***1.2.1 Language and Learning Disability***

The language used to describe people and experiences shapes how meaning is constructed by the reader. It is therefore necessary to give careful consideration to the terminology and definitions used in this thesis. In 2001, the UK Department of Health published the ‘White Paper’ titled *Valuing People*, which defined learning disability as: “*a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood.*” This definition corresponds closely with the International Classification of Diseases 11 (ICD-11) definition of ‘Disorders of Intellectual Development’ for which a diagnosis requires the following: limitations of intellectual functioning, significant limitations to adaptive functioning and onset during the developmental period, and categorises developmental intellectual disability across six levels of severity of impairment (World Health Organization, 2019, 6A00). The UK Department of Health and Social Care (DHSC) specifically differentiates between learning disability and learning difficulty, which is a reduced ability for a specific form of learning and includes conditions such as dyslexia (reading), dyspraxia (affecting physical co-ordination) and attention deficit hyperactivity disorder (ADHD). Moreover, though often co-occurring, autism is a developmental disorder that does not classify as a learning disability by the DHSC. Learning difficulties and learning disabilities are not



mutually exclusive, as a person with a learning disability may also have one or more learning difficulties, but they are distinct concepts or diagnostic categories.

In their article, Emerson and Heslop (2010) explain that the UK is one of the only countries to use the term learning disability in this way. For example in the United States the term learning disability can be used to describe different learning difficulties. It is therefore important to note that evidence from the USA on services or interventions for people with learning disabilities, may refer to what would be classed as learning difficulties in the UK. Additionally, the term ‘intellectual disability’ is the preferred terminology in many countries and can be considered interchangeable with the UK term learning disability. In NHS and social care settings in the UK the term learning disability is commonly used, whereas intellectual disability is more commonly used in academic writing.

As this project was based in the UK, the terms used throughout this thesis are ‘learning disability’ and ‘people with learning disabilities’ for consistency and clarity across the systematic literature review and the overall research. Furthermore, this was the term used by the participants of this research and by the community day centre they attended, and therefore it felt important to use the same language.

Whilst it is acknowledged that classifying disorders serves a purpose, particularly in organising and thinking about people on a large scale, it is informed by the medical model of disability which categorises disabilities as individual pathology. The medical model locates the problem within the individual, framing disability as a deficit or impairment that requires treatment or correction, and has historically been used to justify the exclusion of disabled people from mainstream society on the basis

that they deviate from a perceived norm (Oliver & Barnes, 2012). Thus, in accordance with the ethos of this project, which is largely based on community psychology principles, the inclusion of the social model of disability provides a more balanced and compassionate stance as it considers the societal barriers disabled people face as a significant part of the "othering", inaccessibility and discrimination faced by people with disabilities (Chappell et al., 2001). The social model, by contrast, locates disability not within the individual but within the structures, attitudes, and environments of society that fail to accommodate human difference, arguing that it is these barriers rather than impairments themselves that disable people (Oliver, 1990; Shakespeare, 2013).

### ***1.2.2 People with Learning Disabilities in the United Kingdom***

Although finding an accurate number is challenging, it is estimated that people with a learning disability make up about 2.16% of the population in the UK. Thus, there are approximately 1.5 million people with a learning disability in the UK and approximately 1.3 million of these people are in England (Public Health England, 2025; Office for National Statistics, 2024). This data is calculated using different learning disability prevalence rates from Public Health England (2025) and population data. The absence of precise prevalence estimates is partly due to the lack of a single national register for learning disability and suggests that whilst the numbers might provide a good estimate, certain groups may be missed. Individuals with learning disabilities are recorded separately across health, education, and social care systems, and the extent to which these registers are integrated at a national level varies

considerably (Lee et al., 2024). The number of people with a learning disability recorded in health and welfare systems is much lower. Those known to learning disability services are likely to be people with a more significant learning disability.

The marginalisation of people with learning disabilities from mainstream society has deep historical roots. Nirje first articulated the concept of normalisation in 1969, in direct response to the poor conditions, limited autonomy, and widespread exclusion experienced by people with learning disabilities in large institutional settings that had dominated much of the twentieth century. He argued that people with learning disabilities should have access to the same patterns and conditions of everyday life as are available to the rest of society (Perrin, 1999). This principle was later developed into the concept of Social Role Valorization by Wolfensberger (2011), which placed particular emphasis on the importance of valued social roles as a means of counteracting the stigma and devaluation historically experienced by people with learning disabilities. Whilst normalisation has been critiqued for its implicit assumption that non-disabled ways of living represent the desirable norm (Culham & Nind, 2003), it nonetheless marked an important move away from the institutional model of care and laid the groundwork for the community-based support structures that exist today. As discussed earlier in this chapter, the social model of disability (Oliver, 1990, p.2) extended this thinking further, shifting the focus from the individual to the societal structures and barriers that produce exclusion. Oliver argued that framing disability as a personal tragedy leads inevitably to disabled people being treated as passive victims of circumstance, and that challenging this framing is a prerequisite for genuine inclusion and social change (Oliver & Barnes, 2012, pp. 17–

18). The extent to which inclusion and participation in community life has been achieved remains contested, and the health inequalities described below suggest that structural and societal barriers continue to significantly shape the lives of people with learning disabilities in the UK.

People with learning disabilities face marked health inequalities arising from increased health risks linked to biological factors and from wider structural and social influences, including communication and cognitive difficulties, health-related behaviours, and socioeconomic disadvantage (Lee et al., 2024). Children with learning disabilities account for 14% of all British children with a diagnosable psychiatric disorder, with the prevalence of psychiatric disorder at 36% in children with learning disabilities, compared to 8% in children without learning disabilities. Additionally, people with learning disabilities face significant barriers to accessing healthcare which can put them at risk for health complications (Allgar et al., 2008). People with learning disabilities are also at increased risk of exposure to social determinants of health, such as poverty, poor housing and unemployment. For example, it has been estimated that among British children and adolescents with learning disabilities, increased exposure to low socio-economic position/ poverty may account for 20-50% of the increased risk for poorer physical health and mental health (Emerson & Hatton, 2007).

### ***1.2.3 Inclusion, Voice and Participation***

Due to the potential implications of conducting research with vulnerable populations there has historically been a strong emphasis on ‘protection’. However, in

some instances this has resulted in certain populations being excluded from research under the guise of preventing potential harm. Some examples of these populations are pregnant women, children and people with learning disabilities. As a result, the evidence for the care of these groups often has significant gaps (McClimens & Allmark, 2011). To address this barrier, the Department of Health added the following statement in the Research Governance Framework:

*Research and those pursuing it should respect the diversity of human culture and conditions and take full account of ethnicity, gender, disability, age and sexual orientation in its design, undertaking, and reporting. Researchers should take account of the multi-cultural nature of society. It is particularly important that the body of research evidence available to policy makers reflects the diversity of the population* (Department of Health, 2005).

These guidelines were withdrawn in 2017 and replaced with the UK Policy Framework for Health and Social Care Research (NHS Health Research Authority, 2025). Interestingly, the updated guidelines do not specifically highlight the importance of including vulnerable and often overlooked populations in research, but more generally advises the important role research plays in health and social care. It states that research should improve the evidence base, reduce uncertainties and lead to improvements in care, and that where possible and appropriate, service users and the public should be involved in the design, management, conduct and dissemination of research. It further states that the research conducted, in an ethical, safe and scientifically sound way, is for the benefit of the patients, service users and the public.

Furthermore, in the government response *Liberating the NHS: Nothing about me, without me*, the UK government clarified that where possible, information should be made available in a variety of formats so that all groups can access it, including people with learning disabilities (Department of Health, 2012). There has been a push to include people with learning disabilities in research both as participants and as co-producers and researchers. This is also present in NHS settings and service delivery, for example as experts by experience on interview panels, and as co-facilitators of the mandatory Oliver McGowan training, in which parts of it are delivered by people with learning disabilities.

A prominent 'White Paper' (Department of Health, 2001) put particular emphasis on the principles of inclusion, rights, independence and choice, which underpins the UK learning disability services. This paper argued for the importance of not just partnerships between services but also with people with learning disabilities and their support systems, to enable their participation in strategic planning.

Similarly, the past few decades have seen a shift in the attitude of research where a new discourse of participation and inclusion has been established, one which has shed light on the necessity of new approaches. In the spirit of the social model of disability, and moving away from a reductionist view of participants' ability to engage with "traditional" research methods, Booth & Booth (1996) suggested that the main principle underpinning the involvement of people with learning disabilities in research is the recognition that barriers to participation reflect limitations in research methods, rather than deficits within individuals. Some suggested adaptations to research to include people with learning disabilities were accessible information and ensuring

ongoing consent, adapting interview questions to focus the questions and responses whilst reading the silences, and explicitly asking for contextual clues (Gilbert, 2004). Another suggested adaptation, particularly to include people with more “severe” forms of learning disability, is to ensure that processes of consent prioritise and respect a person's autonomy and ensures that participants have not been wronged and have been included to the best of their abilities (McClimens & Allmark, 2011).

Milner and Frawley (2019) suggested that hearing the ‘unknowing voice’ might expand the ability to theorise for people with learning disabilities and make room for them in research. They highlight that people with learning disabilities’ role in research has often been delegitimised due to assumptions that they lack theory building capacity, and that their tendency to use their own lives as reference points for new information makes it difficult for them to generalise beyond their own experiences. However, as Milner and Frawley go on to explain, this perspective overlooks the importance of personal experience as a base for knowledge and activism. It further exposes the challenge faced by researchers when asked to go beyond typical privileged stories. Langdon et al. (2025) further argue that excluding people with learning disabilities from research is both ethically unjustifiable and counterproductive, and that when given the opportunity, people with learning disabilities have shown themselves capable not only of participating in research but of leading it.

To empower a community, it is necessary to work *with* the community, encouraging mutual challenge and reflection whilst engaging in culturally competent, power- and race-sensitive inquiry (Chávez et al., 2008).

### ***1.2.4 Community Psychology and Community Oriented Research***

Attempting to promote individual emotional and physical health, and social inclusion within an unfair and inflexible system is unrealistic. This fails to consider the extent to which the “problem” is also external to the person and is impacted by the incongruent societal expectations and the support that is available to marginalised communities. In a move from individualised and deficit-based models which have dominated clinical practice and research in Western and high-income countries, modalities like community psychology focus instead on the relationship between the individual and their social context to address root causes of distress, such as marginalisation. The core principles of community psychology are empowerment, social justice, participation, and context and systems. Community psychology offers an alternative approach to working with people marginalised by social systems that promotes critical awareness and social change. It emphasises value-driven participatory work and alliance-building and is not confined to any single methodological tradition. In this way, it stands as an alternative to the individualistic psychology that dominates teaching and practice in high-income countries (Burton et al., 2007).

In a society where an individual’s value is often based on their fiscal contribution and subsequently their relative proximity to power, those on the basal end of this spectrum, such as people with learning disabilities, may suffer more from societal injustices, neglect and exclusion. Community psychology legitimises talking *with* communities rather than about them and has been linked to understanding empowerment in the context of the Capabilities Approach, which views capabilities as



the freedom to engage in socially valued roles and activities (Shinn, 2015). As described by Riemer and colleagues, exclusion and oppression of the subordinate group occurs when the dominant group is not held accountable for their effect on subordinate groups (Riemer et al., 2020, p. 145). Therefore, accountability and change can only be achieved and upheld when the voices of the marginalised are heard.

Research within community psychology tends to be applied and action-oriented, as it is not conducted purely for the sake of generating new knowledge, but to create knowledge and change social conditions (Riemer et al., 2020, p. 7). From a methodological perspective, community-based participatory research closely reflects the core values of community psychology. Its emphasis on early and sustained involvement of community stakeholders, alongside the use of qualitative, observational, and creative methods, makes it particularly appropriate for disability research in a range of contexts. At the same time, it seeks to generate meaningful change for participants, emphasising the agency of all those involved (Baum et al., 2006; Hergenrather & Rhodes, 2008).

Participatory research involves people with learning disabilities in the research process with the support of non-learning-disabled researchers and is grounded in a qualitative focus on lived experience. This approach may be informed by both normalisation and the social model of disability, although responsibility and accountability generally remain with the researcher and funding body. In contrast, emancipatory research is explicitly rooted in the social model of disability and seeks to bring about social change by placing control of the research process in the hands of people with disabilities themselves; it may employ either qualitative or quantitative

methods, with researcher accountability focused primarily on the disabled participants. Participatory research is often viewed as a transitional approach, occupying a middle ground between traditional research practices and fully emancipatory models (Gilbert, 2004). Whilst this research does not claim to be wholly embedded in participatory action research, the methodology and philosophical lens of the work is informed by community psychology and is oriented on the participation and inclusion of people with learning disabilities.

### ***1.2.5 Including People with Learning Disabilities in “Difficult Conversations”***

In addition to a lack of inclusion in research, people with learning disabilities have often been excluded from conversations on topics that have been considered “difficult” for them to understand or cope with, such as health, death, risk or uncertainty. The term "difficult conversations" is used here deliberately and with a specific meaning. The difficulty is not located in the capacity of people with learning disabilities to engage with complex or uncomfortable topics, but in the discomfort, assumptions, and protective instincts of those without learning disabilities who have historically controlled access to these conversations. In this sense, the difficulty is relational and social rather than cognitive and reflects a broader pattern of epistemic exclusion rather than an inherent characteristic of the person being excluded. Whilst historically being more vulnerable to certain health conditions, people with learning disabilities are now living longer and are increasingly susceptible to age-related health issues. When it comes to physical health, particularly breaking bad news about health

and terminal illness to people in the general population, there has been a lot of discussion and consideration around how to involve the affected persons in these conversations to ensure they are as helpful as possible. However, people with learning disabilities have often been excluded from conversations about their own health, including terminal illnesses and care (Tuffrey-Wijne & Rose, 2017). This raises ethical concerns and dilemmas for those caring for people with learning disabilities about whether to disclose bad news or not (Lord et al., 2017). Truth-telling patterns in staff and professionals when it comes to people with learning disabilities are irregular and primarily lean towards nondisclosure, with a predominant lack of information and involvement in conversations and discussions about health (Bernal & Tuffrey-Wijne, 2008; Brownrigg, 2018). This is despite the appearance of wider preference towards truth disclosure in the general population, and for this disclosure to be person-centred and individualised to patients (De Valck et al., 2001).

There are several reasons for this exclusion, such as a presumed lack of understanding of complex or abstract concepts, such as death and illness, or from a misplaced desire to protect. This has often meant that many people with learning disabilities are not informed of deaths of people close to them and may be excluded from associated rituals (McRitchie et al., 2014).

In the case of truth disclosure with people with learning disabilities, consideration is often directed towards supporting carers and staff, including creating guidelines of how to approach and maintain difficult topics. For instance, a model for breaking bad news to people with learning disabilities, created by Tuffrey-Wijne (2013), highlights four main components: building a foundation of knowledge;

understanding; people involved; and support. Moreover, it has been highlighted that an awareness of related behavioural responses can help professionals and families support people with learning disabilities during bereavement or end-of-life experiences (Dusart, 2008). In their literature review, Brownrigg (2018), found that where there were issues around disclosure, these were often concerned with maintaining the rights and dignity of the person with learning disability, a concern with upholding duty of care and an underestimation of the resilience of the people with learning disabilities. Furthermore, the justifications for nondisclosure were concerned with protecting people with learning disabilities from distress and misgivings about their ability to understand the withheld information. Brownrigg also found that these varied depending on the level of intellectual ability, and that people with learning disabilities' perceptions of an abstract and complex concept like death is often greater than expected. However severe intellectual impairment may be associated with incomplete understandings of death, and emotional responses can influence perception regardless of disability level.

As with the general population, people with learning disabilities and their preferences for what they wish to know and how much information they want, varies greatly and needs to be considered at an individual level (Blackman & Todd, 2005, as cited in Brownrigg, 2018). In many cases the involvement in “difficult” content has been found to be beneficial to people with learning disabilities, such as being informed about a loved one passing or taking part in bereavement rituals, with some participants reporting feelings of pride and achievement due to being included in these rituals (McRitchie et al., 2014). Equally, as some may have different preferences in

what they want to participate in, McEvoy et al. (2012) and Tuffrey-Wijne et al. (2013) emphasize that the level of involvement should be responsive to an individual's preferences. It is therefore concerning that less than half of those in McEvoy et al.'s (2012) study felt that they had received adequate bereavement support; similarly, in Tuffrey-Wijne et al.'s (2006) study on people with learning disabilities' needs for cancer related information, where all participants reported wanting information, they found this had not been provided.

Amidst all the research about truth-telling and disclosure with people with learning disabilities it is striking, but not unsurprising that the research predominantly focuses on the perceptions and fears of those involved in the care of and supporting this population rather than hearing their voices directly. People with learning disabilities are often overlooked amid the broader discussion about them, and much of that conversation tends toward generalisations about them as a large and homogenous group, rather than acknowledging the significant differences in individual needs and experiences.

## **1.3 Part Two: Systematic Literature Review: What Are the Perspectives of People with Learning Disabilities on Their Experiences of Receiving Physical and Mental Health Care Support from the NHS?**

### ***1.3.1 Overview***

This chapter reviews the literature related to people with learning disabilities' experiences of physical and mental healthcare. Due to the paucity of research that directly explores the perspectives of people with learning disabilities in relation to climate change, a decision was made to conduct the systematic literature review in an adjacent but related area. Examining how people with learning disabilities experience inclusion and exclusion within NHS healthcare settings may offer an indirect lens through which to begin exploring how this population engages with organisations and systems that make decisions directly affecting their lives, and to tentatively draw parallels with how they might engage with climate change conversations more broadly. The researcher therefore conducted a qualitative systematic literature review using a meta-ethnographic approach, and this chapter provides an overview of the search strategy and included studies, the synthesised findings, the limitations of the review, and its conclusions in relation to the broader aims of the thesis.

### ***1.3.2 Introduction***

As highlighted in part one of the introduction, people with learning disabilities often have additional health and social needs. Many have additional developmental needs, a predisposition for genetic disorders, or are more susceptible to health conditions that require routine monitoring and check-ups. Additionally, compared to the general population people with learning disabilities have a 12–23-year shorter life expectancy (Tyrer et al., 2022). Many of these inequalities are unnecessary and avoidable, and some of them are related to difficulties accessing good quality healthcare (Equality and Human Rights Commission, 2017).

Thus, people with learning disabilities in the UK often engage with the NHS more frequently than those without, a service that at its best saves and improves lives, and at its worst can cause significant harm through systemic and individual neglect, malpractice or discrimination. Unfortunately, there are many instances where people with learning disabilities have not been listened to when self-advocating for their care, one such example from recent NHS history being the appalling failures that led to the preventable death of Oliver McGowan. Despite policies and initiatives put in place to reduce the health disparity in England, Tyrer et al (2022) did not find evidence to suggest that health disparity decreased for people with learning disabilities between 2001-2019, recommending further and more collective policy response. Furthermore, in their inquiry into premature deaths among people with learning disabilities in the UK, Heslop and colleagues (2014) reported that 37% of deaths in this population were considered avoidable through timely and effective healthcare, compared with 13% in the general population of England and Wales. They identified systemic contributory

factors to premature deaths such as problems in advanced care planning, living in inappropriate accommodation, adjustment of care as needs changed, and carers not feeling listened to. Highlighting that when the voices of people with learning disabilities and their carers are absent from key discussions, it can result in serious harm.

As a primary point of contact for people with learning disabilities, the NHS is a system in which “difficult conversations” already occur regularly. Broadly speaking, understanding barriers to accessing services and the experiences of people with learning disabilities, and examining them can provide a critical backdrop for understanding inclusion in other complex conversations. The NHS is a system where exclusion and inclusion are especially visible across the population. Health inequity is a considerable and worsening issue in the UK (Marmot et al., 2020), with significantly higher mortality rates documented in women from global majority ethnic groups compared to white women (Knight et al., 2023). Additionally, people with learning disabilities are at particular risk of diagnostic overshadowing, where their symptoms are mistakenly attributed to a behavioural problem or seen as being part of their learning disability (Blair, 2016). For example, challenging behaviours (such as aggression, destruction and self-injury) are experienced by 10%-15% of people with learning disabilities and have in some instances been found to result from pain associated with untreated medical disorders (Emerson & Baines, 2011).

Under the Equality Act (2010), healthcare providers are legally required to make reasonable adjustments to ensure that patients with disabilities, including those with learning disabilities, can access healthcare. In response, many NHS trusts now



employ learning disability nurses who provide support to patients and offer guidance to services on implementing appropriate adjustments (Lee et al., 2024), though experiences of care are inconsistent.

In their systematic review exploring the barriers to people with learning disabilities accessing cancer screenings, Chan and colleagues (2022) found several prominent barriers across the qualitative and quantitative data; fear of medical procedure, previous negative interactions with healthcare professionals, feelings singled out or embarrassed, lack of knowledge of the procedure, mobility issues, high severity of learning disability, lack of capacity to consent and lack of ability to communicate verbally.

Suggestions made to reduce health inequality experienced by people with learning disabilities include reducing exposure to social determinants of (poorer) health, making reasonable adjustments in all areas of health promotion and healthcare considering the specific needs of people with learning disabilities, improving health literacy of people with learning disabilities and their support networks, and improving the knowledge and awareness of professionals with regards to high risk conditions associated with certain syndromes (Emerson & Baines, 2011).

This review is undertaken to explore the experiences of people with learning disabilities within NHS contexts. Given the central role of healthcare services in many individuals' lives, examining qualitative accounts of NHS support may offer valuable insight into the relational and systemic factors that shape experiences. Existing qualitative studies are often small, fragmented and context specific, thus a systematic review across NHS settings may shed light on overarching and recurring patterns. In

addition to this, most research on experiences related to learning disabilities include a variety of shareholders perspectives, such as carers, staff and policy holders alongside people with learning disabilities. Although this can provide holistic views, it also muddles the voices of people with learning disabilities, whose perspectives should be the cornerstone that quality improvement is based on.

The current systematic review therefore aims to explore the direct experiences of people with learning disabilities within healthcare settings, examining whether and how their voices are included in decisions that affect them. It further aims to identify patterns, gaps, and areas of uncertainty within the existing literature. In doing so, it is intended to inform both the focus and methodological orientation of the primary research that follows, and to provide a rationale for adopting a qualitative and inclusive approach with this population.

### ***1.3.3 Methods***

#### **1.3.3.1 Design and Methodological Framework**

Meta-ethnography is a rigorous method for synthesising qualitative research in order to advance understanding beyond individual study findings. Initially developed in the field of education by Noblit and Hare (1988) it is now widely used in applied health research. The approach is essentially a “qualitative interpretation of qualitative interpretations”, which requires researchers to engage with the complexity inherent in this form of synthesis (Luong et al., 2023). Noblit and Hare (1988, p.12) described meta-ethnography as a different approach to other meta-analyses on account of the

focus being on constructing interpretations and argued that qualitative synthesis should be as interpretive in nature as ethnographic work.

Meta-ethnography typically follows a seven-stage process, as outlined by Noblit and Hare (1988), which includes initiating the review, determining the relevance of studies to the research focus, reading and familiarising with the studies, exploring relationships between studies, translating studies into one another, synthesising these translations, and presenting the resulting synthesis. This framework was used to guide the present meta-ethnographic review and has been described in further detail later in this chapter.

Meta-ethnography was selected as the approach for synthesis due to its alignment with the aims of this review and its capacity to incorporate studies employing a range of qualitative designs. Unlike some qualitative synthesis approaches, such as grounded theory, meta-ethnography permits the inclusion of studies with diverse research designs rather than restricting synthesis to methodologically similar studies (Soilemezi & Linceviciute, 2018). In contrast to more descriptive approaches, such as scoping reviews, meta-ethnography emphasises interpretive synthesis, enabling the development of new conceptual understandings across studies. This was considered particularly valuable given the relatively underexplored nature of this research area, the potential for the relevant research to focus on a variety of healthcare contexts, and the need to move beyond summarising findings to generate deeper insight.

### 1.3.3.2 Search Strategy

A systematic electronic search for relevant studies was carried out on 23rd February 2026. To capture as broad a range of evidence as possible, searches were conducted across multiple platforms. Using the EBSCOhost research platform, an advanced search was performed simultaneously across four databases: APA PsycArticles, APA PsycInfo, CINAHL Ultimate, and MEDLINE Ultimate. Additional searches were conducted via PubMed and Scopus, and a manual search of Google Scholar was also undertaken. Across all platforms, search terms were applied to all available fields and combined using Boolean operators as follows:

- (Learning Disabilities OR Intellectual Disability OR learning disab\* OR intellectual disab\* OR mental retard\*)
- *AND* ("Access to healthcare" OR "barriers to healthcare" OR "healthcare experiences" OR "health care experiences" OR "patient experiences" OR "patient perspectives" OR "lived experiences")
- *AND* ("National Health Service" OR "NHS" OR "United Kingdom" OR "UK" OR "England" OR "Wales" OR "Scotland" OR "Northern Ireland"\*).

The search terms and scope of the current review were informed by a preliminary scoping search conducted in October 2025, using the EBSCOhost platform across APA PsycArticles, APA PsycInfo, CINAHL Ultimate, and MEDLINE Ultimate. This scoping search applied equivalent search terms but restricted the healthcare setting to mental health services specifically. This returned only six papers, which was

insufficient to support a meaningful synthesis or to achieve the breadth of evidence required for a robust meta-ethnographic review. On this basis, the decision was made to broaden the search to encompass experiences of NHS healthcare more generally, rather than limiting to a specific service type or speciality. This decision was also considered conceptually appropriate, as the broader NHS experience of people with learning disabilities forms an important contextual backdrop to understanding patterns of inclusion and exclusion, and findings from across healthcare settings may offer transferable insights relevant to the primary research question.

The search terms were constructed to capture the population of people with learning disabilities and intellectual disabilities as defined by diagnostic criteria, using both current and historical terminology to maximise sensitivity. The decision was made not to include diagnostic terms specific to autism spectrum conditions or other developmental or related disorders, such as Down Syndrome. In relation to autism, this decision reflected the recognition that autism does not necessarily co-occur with a learning disability, and including autism-specific literature risked introducing a population that did not meet the inclusion criteria for the review. The exclusion of other developmental or related disorders from the search terms is acknowledged as a limitation of the review, as individuals with these conditions may in many cases meet the diagnostic criteria for a learning disability and their experiences of healthcare may be directly relevant. This was not a theoretically motivated exclusion but rather reflects the scoping decisions made at the outset of the review, and future research may benefit from explicitly including such populations within broader reviews of this kind. Records were limited to publications written in English, however not by year of

publication. To ensure a transparent search strategy and allow future replication of this review, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) were followed (see Figure 1).

Following the completion of database searches, all retrieved records were imported into Covidence systematic review software (Veritas Health Innovation, 2026), which served as the platform for managing all subsequent stages of the review process. Covidence automatically identified and removed duplicate records prior to screening. Title and abstract screening was then conducted against the inclusion and exclusion criteria, followed by full-text review of potentially eligible studies. Data extraction was also carried out within Covidence, providing a structured and auditable record of the review process.

### 1.3.3.3 Eligibility Criteria

The review question and eligibility criteria were developed using the PICO framework (Population, Phenomenon of Interest, Context), which is commonly used to structure and guide qualitative evidence synthesis (Lockwood & Oh, 2017). The framework ensured that the inclusion and exclusion criteria were systematically derived from the review question, and that the search terms were consistently aligned with the scope of the review. The resulting framework is summarised in Table 1.

**Table 1**

*PICO Framework for the Systematic Literature Review*

| Component | Definition | Search Terms |
|-----------|------------|--------------|
|-----------|------------|--------------|

|                                   |                                                                                                     |                                                                                                                                                             |
|-----------------------------------|-----------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>P (Population)</b>             | People with learning disabilities, including those with intellectual and developmental disabilities | Learning disabilities; intellectual disability; learning disab*; intellectual disab*; mental retard*                                                        |
| <b>I (Phenomenon of Interest)</b> | Experiences and perspectives of physical and mental healthcare support received from the NHS        | Access to healthcare; barriers to healthcare; healthcare experiences; health care experiences; patient experiences; patient perspectives; lived experiences |
| <b>Co (Context)</b>               | NHS healthcare settings within the United Kingdom                                                   | National Health Service; NHS; United Kingdom; UK; England; Wales; Scotland; Northern Ireland                                                                |

The PICO framework directly informed both the construction of the search string and the development of the inclusion and exclusion criteria detailed below. Each criterion maps onto one or more components of the framework, ensuring that only studies directly relevant to the review question were considered for inclusion.

#### **1.3.3.4 Inclusion Criteria:**

1. Qualitative research, or mixed methods studies containing sufficient qualitative data directly reflecting the perspectives of people with learning disabilities.
2. Studies in which people with learning disabilities are interviewed directly, rather than their carers or support staff.
3. The topic of discussion relates to participants' experiences and opinions of physical and/or mental healthcare support from the NHS.

4. Studies conducted within the United Kingdom, to capture experiences specific to NHS care.
5. Publications written in the English language.
6. No restriction on year of publication.

#### **1.3.3.5 Exclusion Criteria:**

1. Studies not subject to peer review, including unpublished dissertations and grey literature, unless produced by a recognised public health or policy body.
2. Studies conducted outside of the United Kingdom or in non-NHS healthcare settings.
3. Studies in which the perspectives of people with learning disabilities are not captured directly, including studies in which data were collected solely from carers, support staff, or healthcare professionals.
4. Studies using solely quantitative designs, where no qualitative data reflecting the subjective experiences of people with learning disabilities are reported.
5. Publications in languages other than English.

#### **1.3.3.6 Article Selection**

The database searches yielded a total of 1,415 records across the three platforms, which is recorded in the PRISMA diagram in Figure 1. This comprised 787 records from PubMed, 512 from EBSCO Host, and 113 from Scopus. A further three records were identified through the manual Google Scholar search, bringing the total number of identified records to 1,418. Following importation into Covidence, 112 duplicate records were removed, of which 111 were identified automatically by

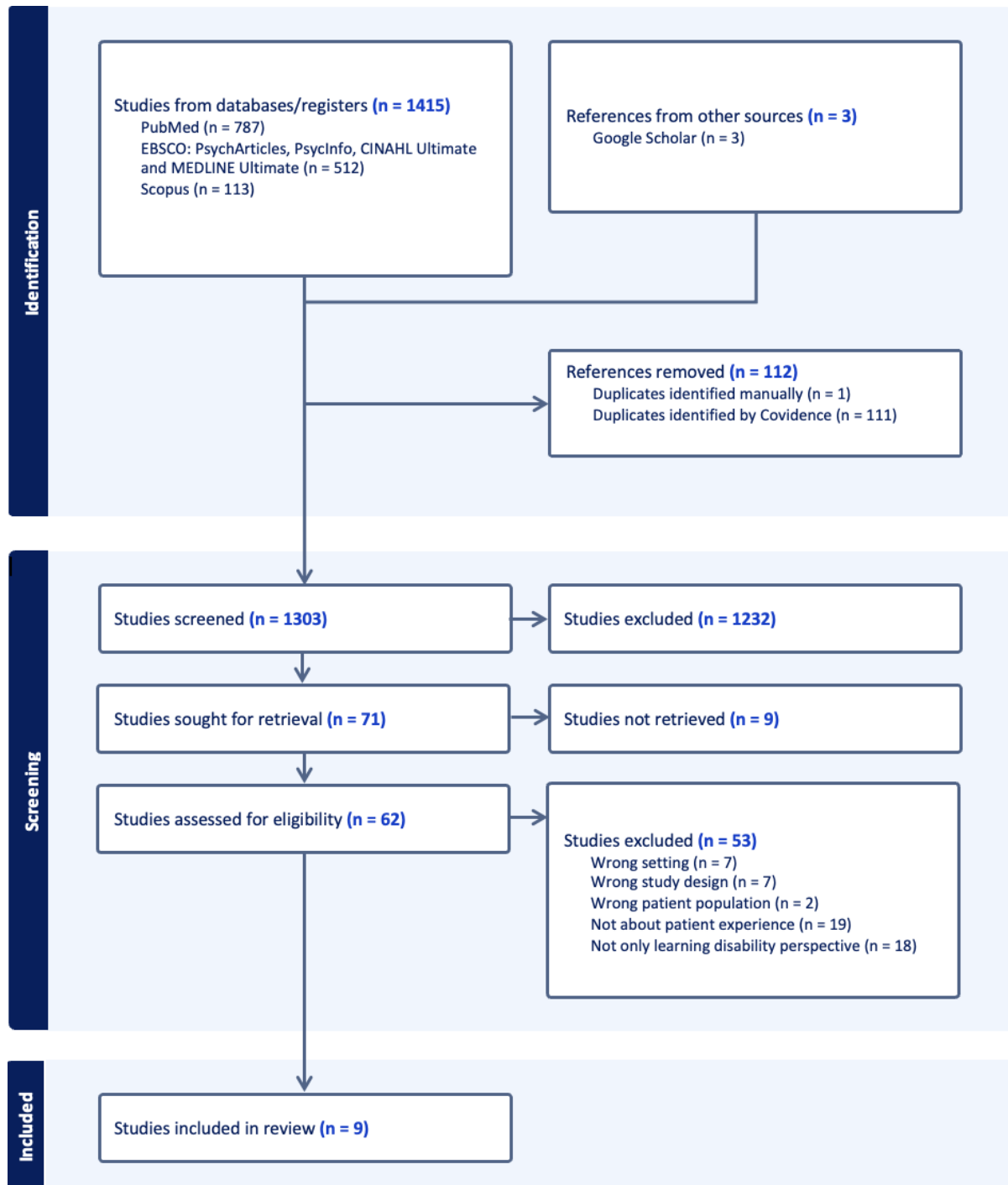


Covidence and one was identified manually, leaving 1,303 records for screening.

All retrieved records were initially screened at the title and abstract stage against the predetermined inclusion and exclusion criteria. Studies that appeared to meet the eligibility criteria at this stage were then sought for full-text retrieval, whereupon each paper was read in its entirety and assessed for final inclusion in the review. Title and abstract screening was conducted on all 1,303 records against the predetermined inclusion and exclusion criteria. Of these, 1,232 were excluded at this stage, leaving 71 studies sought for full-text retrieval. Nine studies could not be retrieved. As the review had identified enough studies for meaningful meta-ethnographic synthesis, and in the interests of transparency and replicability, a decision was made not to pursue these studies further through institutional library access. Thus, 62 studies proceeded to full-text assessment for eligibility. At full-text review, 53 studies were excluded for the following reasons: 19 were not about patient experience; 18 did not capture the learning disability perspective solely and directly; seven were conducted in the wrong setting; seven used the wrong study design, such as mixed methodology without sufficient qualitative data to be included; and two involved the wrong patient population. Following full-text review, nine studies met all inclusion criteria and were included in the final review and are detailed in Table 2.

**Figure 1**

*PRISMA Flowchart of the Systematic Review.*



### **1.3.3.7 Quality Assessment**

The methodological quality of each included study was assessed using the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2023), which comprises ten criteria covering the rigour, credibility, and relevance of qualitative research. Each criterion was rated on a five-point scale ranging from weak to strong, and an overall quality score out of ten was assigned to each study. The CASP appraisal was conducted for all nine included studies, and the results are summarised in Appendix A.

It is acknowledged in qualitative evidence synthesis that quality appraisal should not be used as a basis for excluding studies outright, but rather to contextualise the confidence with which findings can be drawn upon during synthesis (Noblit & Hare, 1988, p.16). In keeping with this position, all nine studies were retained for inclusion in the meta-ethnographic synthesis regardless of their quality score, with lower-scoring studies noted and their limitations taken into account when interpreting and drawing upon their findings.

In addition to the CASP checklist, each study was considered for its specific relevance to the review question. Particular attention was paid to the extent to which the direct perspectives of people with learning disabilities were represented in the data, the degree to which findings related to experiences of NHS physical and/or mental healthcare support, and whether the study context was sufficiently grounded in UK healthcare settings. These considerations ensured that quality appraisal was not conducted in isolation but remained closely aligned with the aims and scope of the review.

**Table 2***Study Overview Table and Quality Appraisal of Included Studies*

| <b>Author</b>        | <b>Research Aim</b>                                                                                                                          | <b>Sample Characteristics</b>                                                                                                                                                                                                                               | <b>Methodology</b>                                                                                                                                                                                                                                                      | <b>Key Findings</b>                                                                                                                                                                                                                                                                                                                                                                                                            | <b>Limitations</b>                                                                                                                                                                                                                                                                                                                                                                                                   | <b>CASP</b>   |
|----------------------|----------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|
| Baxter et al. (2023) | To explore the experiences of adults with learning disabilities who had been waiting for psychological therapy during the COVID-19 pandemic. | <ul style="list-style-type: none"> <li>• n = 7</li> <li>• Age: 23–63 years</li> <li>• Gender: 4 women, 3 men</li> <li>• Ethnicity: Not reported</li> <li>• LD: Confirmed diagnosis; mild-moderate (able to consent and communicate by telephone)</li> </ul> | <ul style="list-style-type: none"> <li>• Study type: Service evaluation</li> <li>• Setting: NHS community adult LD health service, North of England</li> <li>• Data collection: Telephone semi-structured interviews</li> <li>• Analysis: Framework analysis</li> </ul> | <ul style="list-style-type: none"> <li>• Four themes: Waiting has been 'painful'; Tolerating the wait; Use of coping strategies; Support and contact from the LD team</li> <li>• Waiting was distressing due to ongoing difficulties and lack of someone to talk to</li> <li>• Participants were understanding of delays caused by COVID-19</li> <li>• Regular contact and acknowledgement of the wait were desired</li> </ul> | <ul style="list-style-type: none"> <li>• Service evaluation; no ethical approval</li> <li>• Small sample size</li> <li>• Very short interview duration (5–15 mins)</li> <li>• Sole analyst; no member checking</li> <li>• Telephone format excluded those with severe communication difficulties</li> <li>• No accessible communication adaptations</li> <li>• Interview schedule not piloted; no service</li> </ul> | <b>4.5/10</b> |

| Author                    | Research Aim                                                                                                                                                               | Sample Characteristics                                                                                                                                                                                                                                     | Methodology                                                                                                                                                                                                                                           | Key Findings                                                                                                                                                                                                                                                                                                                                                         | Limitations                                                                                                                                                                                                                                                                                                         | CASP   |
|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|
|                           |                                                                                                                                                                            |                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                      | user involvement in design                                                                                                                                                                                                                                                                                          |        |
| Boyden et al. (2013)      | To evaluate a learning disability child and adolescent mental health service (LD-CAMHS), with the aim of producing quality standards to ensure service user needs are met. | <ul style="list-style-type: none"> <li>• n = 7</li> <li>• Age: 11–17 years</li> <li>• Gender: 5 male, 2 female</li> <li>• Ethnicity: Not reported</li> <li>• LD: Moderate to severe; some with additional needs or dual diagnoses (e.g. autism)</li> </ul> | <ul style="list-style-type: none"> <li>• Study type: Service evaluation</li> <li>• Setting: LD-CAMHS service, Chesterfield, North Derbyshire</li> <li>• Data collection: Semi-structured interviews</li> <li>• Analysis: Thematic analysis</li> </ul> | <ul style="list-style-type: none"> <li>• Four themes: experience of the service, communication, impact of therapeutic work, and difficulties encountered</li> <li>• Staff recommended to ensure accessible communication, a welcoming approach, and choice of location</li> <li>• Four service standards developed for future clinical delivery and audit</li> </ul> | <ul style="list-style-type: none"> <li>• Service evaluation context</li> <li>• Small sample size</li> <li>• Excludes individuals with profound LD or non-verbal communication needs</li> <li>• Younger children not represented</li> <li>• No data triangulation</li> <li>• Sole analyst; no reflexivity</li> </ul> | 5/10   |
| Cooper-Moss et al. (2024) | To explore the factors contributing to                                                                                                                                     | <ul style="list-style-type: none"> <li>• n = 20 (13 self-advocates,</li> </ul>                                                                                                                                                                             | <ul style="list-style-type: none"> <li>• Study type: Qualitative</li> </ul>                                                                                                                                                                           | <ul style="list-style-type: none"> <li>• Discrimination within healthcare settings</li> </ul>                                                                                                                                                                                                                                                                        | <ul style="list-style-type: none"> <li>• Self-advocate and carer perspectives not</li> </ul>                                                                                                                                                                                                                        | 6.5/10 |

| Author | Research Aim                                                                                                                                    | Sample Characteristics                                                                                                                                                                                                                                   | Methodology                                                                                                                                 | Key Findings                                                                                                                                                                                                                                                                                                                                    | Limitations                                                                                                                                                                                      | CASP |
|--------|-------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|
|        | barriers in healthcare access for people with a learning disability from ethnic minority backgrounds, and to identify how these can be reduced. | 5 carers, 2 unspecified)<br>• Self-advocates: Age 32–65; 7 male, 6 female; ethnicity: 9 Black, 1 mixed, 1 Chinese<br>• Carers: Age 44–50; 3 female, 2 male; ethnicity: 2 Pakistani, 1 Indian, 1 British Asian<br>• LD: Adults with learning disabilities | • Setting: Not specified (UK)<br>• Data collection: Experience-based co-design workshops (audio recorded)<br>• Analysis: Framework analysis | reported, with difficulty identifying its source<br>• Lack of reasonable adjustments and culturally sensitive support services<br>• Isolation and stigma within family and community networks<br>• COVID-19 worsened access and increased loneliness<br>• Effective communication and individualised care identified as key improvements needed | consistently differentiated<br>• Non-English speakers excluded, limited ethnic diversity among carer participants<br>• No accessible communication adaptations reported<br>• Lack of reflexivity |      |

| Author              | Research Aim                                                                                                             | Sample Characteristics                                                                                                                                                                                                                                                                                                            | Methodology                                                                                                                                                                                                                                              | Key Findings                                                                                                                                                                                                                                                                                                                                                                                                                           | Limitations                                                                                                                                                                                                                                                                                                                                                                                                            | CASP   |
|---------------------|--------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|
| Drozd et al. (2021) | To understand the orthopaedic and trauma hospital experiences from the perspective of people with learning disabilities. | <ul style="list-style-type: none"> <li>• n = 5 (4 with LD; 1 carer of person with PMID)</li> <li>• Age: 25–45 years</li> <li>• Gender: 3 female, 2 male</li> <li>• Ethnicity: Not reported</li> <li>• LD: Self-identified; includes one participant with profound and multiple intellectual disabilities (carer proxy)</li> </ul> | <ul style="list-style-type: none"> <li>• Study type: Qualitative</li> <li>• Setting: UK (not specified)</li> <li>• Data collection: One-to-one semi-structured interviews</li> <li>• Analysis: Interpretative Phenomenological Analysis (IPA)</li> </ul> | <ul style="list-style-type: none"> <li>• Themes: communication challenges, lack of person-centred care, pain management issues, lack of confidence in hospital staff, value of carer support, isolation and loneliness</li> <li>• Significant shortcomings in hospital care identified</li> <li>• Carer expertise was a key source of support and advocacy</li> <li>• First study to explore this specific clinical context</li> </ul> | <ul style="list-style-type: none"> <li>• Very small sample (only 4 directly interviewed with LD)</li> <li>• Inclusion of carer introduces methodological inconsistency</li> <li>• No accessible communication adaptations reported</li> <li>• Limited description of analytical process</li> <li>• Lack of reflexivity</li> <li>• Variable time between hospital experience and interview may affect recall</li> </ul> | 5.5/10 |
| Hall (2024)         | To explore how service users                                                                                             | <ul style="list-style-type: none"> <li>• n = 10</li> </ul>                                                                                                                                                                                                                                                                        | <ul style="list-style-type: none"> <li>• Study type: Service evaluation</li> </ul>                                                                                                                                                                       | <ul style="list-style-type: none"> <li>• Themes: long waits for therapy, emotional</li> </ul>                                                                                                                                                                                                                                                                                                                                          | <ul style="list-style-type: none"> <li>• Service evaluation; no ethical approval</li> </ul>                                                                                                                                                                                                                                                                                                                            | 4.5/10 |

| Author          | Research Aim                                                                                                                                                               | Sample Characteristics                                                                                                                                                                                                                  | Methodology                                                                                                                                                                                                           | Key Findings                                                                                                                                                                                                                                                                                                                                                                  | Limitations                                                                                                                                                                                                                                                              | CASP   |
|-----------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|
|                 | accessing a community learning disability team experience waiting for psychological therapy, and to inform standard operating procedures and recommendations for practice. | <ul style="list-style-type: none"> <li>• Age: Over 18 (specifics not reported)</li> <li>• Gender: Not reported</li> <li>• Ethnicity: Not reported</li> <li>• LD: Confirmed learning disability (specific level not reported)</li> </ul> | <ul style="list-style-type: none"> <li>• Setting: Outpatient secondary care community LD team, Yorkshire, UK</li> <li>• Data collection: Semi-structured interviews</li> <li>• Analysis: Thematic analysis</li> </ul> | <ul style="list-style-type: none"> <li>distress, relief upon being referred, difficulties with written letters, coping strategies (keeping busy, seeking support)</li> <li>• Waiting caused emotional distress and uncertainty</li> <li>• Accessibility of letters was a significant concern</li> <li>• Participants relied on social support and activity to cope</li> </ul> | <ul style="list-style-type: none"> <li>• Small sample size</li> <li>• Potential social desirability bias (interviewer = clinician within service)</li> <li>• Sole analyst; no independent review</li> <li>• Lack of reflexivity</li> <li>• No member checking</li> </ul> |        |
| Howieson (2015) | To examine the experiences of people with mild to moderate learning disabilities in                                                                                        | <ul style="list-style-type: none"> <li>• n = 7</li> <li>• Age: Over 16 years</li> <li>• Gender: 5 men, 2 women</li> </ul>                                                                                                               | <ul style="list-style-type: none"> <li>• Study type: Qualitative</li> <li>• Setting: Scotland, UK</li> <li>• Data collection: Two focus groups</li> </ul>                                                             | <ul style="list-style-type: none"> <li>• Three themes: 'Treat me right', 'Hidden in plain sight', 'Health care for all'</li> <li>• Participants emphasised need for</li> </ul>                                                                                                                                                                                                | <ul style="list-style-type: none"> <li>• Methodological inconsistency: IPA applied to focus group data (not standard; not justified)</li> </ul>                                                                                                                          | 5.5/10 |



| Author               | Research Aim                                                                                                                                               | Sample Characteristics                                                                                                                                                                                                         | Methodology                                                                                                                                                                                                                                        | Key Findings                                                                                                                                                                                                                                                                                           | Limitations                                                                                                                                                                                                                                                | CASP |
|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|
|                      | acute hospital services.                                                                                                                                   | <ul style="list-style-type: none"> <li>• Ethnicity: Not reported</li> <li>• LD: Mild to moderate</li> </ul>                                                                                                                    | <ul style="list-style-type: none"> <li>• Analysis: Interpretative Phenomenological Analysis (IPA)</li> </ul>                                                                                                                                       | dignity, respect, and accessible communication <ul style="list-style-type: none"> <li>• Hospital environments created anxiety and vulnerability</li> <li>• Staff attitudes and information delivery require improvement</li> </ul>                                                                     | <ul style="list-style-type: none"> <li>• Small sample size</li> <li>• Lack of reflexivity</li> <li>• Limited description of analytical process</li> <li>• Published in practice rather than research journal</li> </ul>                                    |      |
| Malouf et al. (2017) | To explore the experiences of women with learning disabilities in UK maternity care, with a focus on the support and reasonable adjustments they received. | <ul style="list-style-type: none"> <li>• n = 9</li> <li>• Age: 25–39 years (mean and median 30 years)</li> <li>• Gender: Female</li> <li>• Ethnicity: All White British</li> <li>• LD: 8 mild-to-moderate; 1 severe</li> </ul> | <ul style="list-style-type: none"> <li>• Study type: Qualitative</li> <li>• Setting: UK (multiple sites)</li> <li>• Data collection: In-depth semi-structured interviews (video and audio recorded)</li> <li>• Analysis: Interpretative</li> </ul> | <ul style="list-style-type: none"> <li>• With appropriate support, women with LD can become confident and successful parents</li> <li>• Maternity services should make reasonable adjustments to meet individual communication and learning needs</li> <li>• Women sought normalcy in their</li> </ul> | <ul style="list-style-type: none"> <li>• Maternity-specific focus limits transferability to broader NHS healthcare experiences</li> <li>• All participants White British; limits transferability</li> <li>• Convenience sample with gatekeepers</li> </ul> | 8/10 |

| Author                | Research Aim                                                                                                                                                                             | Sample Characteristics                                                                                                                                                                                                                                   | Methodology                                                                                                                                                                                                                                                              | Key Findings                                                                                                                                                                                                                                                                                                          | Limitations                                                                                                                                                                                                                                                                  | CASP |
|-----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|
|                       |                                                                                                                                                                                          |                                                                                                                                                                                                                                                          | Phenomenological Analysis (IPA)                                                                                                                                                                                                                                          | <ul style="list-style-type: none"> <li>experiences and often felt treated differently</li> <li>• Need for more inclusive, sensitive, and clearly explained maternity care</li> </ul>                                                                                                                                  | <ul style="list-style-type: none"> <li>• Perspectives of women whose children were removed are likely absent</li> <li>• No formal reflexivity statement</li> </ul>                                                                                                           |      |
| Mattock et al. (2020) | To create a space for service users with learning disabilities and co-occurring mental health problems to share their experiences of mental health services and what they found helpful. | <ul style="list-style-type: none"> <li>• n = 5</li> <li>• Age: 18–64 years</li> <li>• Gender: 4 women, 1 man</li> <li>• Ethnicity: 3 Caribbean, 1 White and Black Caribbean, 1 English</li> <li>• LD: Learning disabilities with co-occurring</li> </ul> | <ul style="list-style-type: none"> <li>• Study type: Qualitative (research paper)</li> <li>• Setting: Inner-London NHS community LD and mental health team</li> <li>• Data collection: One focus group (90 mins) with 5 service users and 4 staff/researchers</li> </ul> | <ul style="list-style-type: none"> <li>• Three themes: 'Relationships with others', 'Inclusion and communication', 'Challenges'</li> <li>• Service users felt supported but lacked control and wanted to be listened to</li> <li>• Power imbalances and limited involvement in care planning were reported</li> </ul> | <ul style="list-style-type: none"> <li>• Presence of clinical psychologists from the service in the focus group raises power imbalance concerns</li> <li>• Internal ethical approval only</li> <li>• Small sample; some participants contributed more than others</li> </ul> | 5/10 |

| Author                          | Research Aim                                                                                                             | Sample Characteristics                                                                                                                                                                                                             | Methodology                                                                                                                                                                                                                                                                  | Key Findings                                                                                                                                                                                                                                                                                                                       | Limitations                                                                                                                                                                                                                                    | CASP   |
|---------------------------------|--------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|
|                                 |                                                                                                                          | mental health problems                                                                                                                                                                                                             | <ul style="list-style-type: none"> <li>Analysis: Thematic analysis (Braun &amp; Clarke, 2006)</li> </ul>                                                                                                                                                                     | <ul style="list-style-type: none"> <li>Person-centred services and regular feedback mechanisms recommended</li> </ul>                                                                                                                                                                                                              | <ul style="list-style-type: none"> <li>Sole analyst (checked by facilitators only)</li> <li>No service user involvement in design or facilitation</li> <li>Lack of formal reflexivity</li> </ul>                                               |        |
| Truesdale-Kennedy et al. (2011) | To describe understanding of breast cancer and experiences of breast mammography among women with a learning disability. | <ul style="list-style-type: none"> <li>n = 19</li> <li>Age: 31–69 years (16 aged 50–69)</li> <li>Gender: Female</li> <li>Ethnicity: Not reported</li> <li>LD: Borderline to moderate; all had attended breast screening</li> </ul> | <ul style="list-style-type: none"> <li>Study type: Qualitative</li> <li>Setting: Three Health and Social Care Trusts, Northern Ireland, UK</li> <li>Data collection: Four focus groups</li> <li>Analysis: Thematic content analysis (Newell &amp; Burnard, 2006);</li> </ul> | <ul style="list-style-type: none"> <li>Limited knowledge of breast cancer; information primarily received from carers or nursing staff at time of invitation for screening</li> <li>Fear and anxiety due to lack of understanding of the screening process</li> <li>Embarrassment identified as a barrier to attendance</li> </ul> | <ul style="list-style-type: none"> <li>Recruitment exclusively from residential settings</li> <li>Perspectives of women who declined screening not captured</li> <li>Small sample; findings may not represent broader LD population</li> </ul> | 6.5/10 |

| Author | Research Aim | Sample Characteristics                                                         | Methodology            | Key Findings                                                                                                                                                                                      | Limitations                                                                                                                  | CASP |
|--------|--------------|--------------------------------------------------------------------------------|------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|------|
|        |              | in previous 12 months; all resided in residential settings in Northern Ireland | NVivo; peer debriefing | <ul style="list-style-type: none"> <li>• Accessible, multi-format information and structured education programmes recommended</li> <li>• Data saturation reached by fourth focus group</li> </ul> | <ul style="list-style-type: none"> <li>• Primarily descriptive analytical approach</li> <li>• Lack of reflexivity</li> </ul> |      |

### ***1.3.4 Data Extraction and Analysis***

Following is a breakdown of the seven steps of meta-ethnography as outlined by Noblit & Hare (1988, p. 26-29), and how they were applied in the present review. Although broken down into distinct steps, in reality these phases often overlap or run parallel to each other.

#### **1.3.4.1 Step 1-3: Getting Started; Deciding What is Relevant; and Reading the Studies**

In the first three steps of the meta-ethnographic synthesis the researcher is concerned with identifying an issue that requires further clarification or investigation, identifying something that is worthy of synthesis, selecting the studies to be included and once the studies have been selected, carefully reading the studies to begin to become familiar with them.

Whilst there is a research base concerned with the experiences of people with learning disabilities within specific services or contexts of the NHS, no overarching synthesis has yet been performed to collate this information across contexts or done so prioritising studies that centre exclusively on the voices of people with learning disabilities. This study aims to address this gap, with the eligibility criteria and research question developed to adequately capture such perspectives directly. Studies were included if they explored people with learning disabilities' experiences of NHS healthcare and did so by capturing the perceptions of this population directly. In contrast, studies that explored the healthcare experiences of people with learning disabilities through third party stakeholders, such as carers, family members and

health professionals, were excluded, as they did not capture the direct views of the population of interest.

#### **1.3.4.2 Step 4: Determining How the Studies are Related**

Where step three functions in a manner similar to coding, step four reflects the process of organising these codes into broader themes. This categorisation is typically iterative and may involve contributions from multiple researchers. Various organisational tools, such as diagrams or qualitative data analysis software, can be used to systematically bring concepts together and explore how they relate to, or differ from, one another. Towards the end of step four, the researcher can begin to make an initial assumption about the relationship between the studies (Luong et al., 2023; Noblit & Hare, 1988, p. 28).

For this synthesis the researcher used an Excel spreadsheet to organise the original themes from the nine studies included, and then worked and re-worked them in accordance with their relevance to the research question and their relation to each other.

#### **1.3.4.3 Step 5: Translating the Studies**

In step five, the researcher translates the studies by examining analogies, metaphors, themes, and concepts to develop an understanding of how different studies relate to one another. An effective translation preserves the central ideas and key concepts within each account while maintaining their relationships to other important ideas in that account.

In order to translate the studies into one another, the key concepts and initial themes identified during the familiarisation stage were systematically compared across individual studies, with the aim of identifying shared meanings and points of convergence that could be drawn together into a common set of synthesised themes. The interpretive process construct that were identified at this stage were: “the importance of relationships”, “social support”, “communication”, “reasonable adjustments”, “systemic exclusion”, “power”, “attitudes” and “emotional impact”. The researcher then aimed to identify how these terms related to each other (see Appendix B an example of the process of interpreting second-order constructs)

#### **1.3.4.4 Step 6: Synthesising Translations**

Following naturally on from the initial translations, synthesis involves developing an understanding that extends beyond the sum of individual parts. This involves seeking overarching explanations while also identifying areas of convergence, divergence, and gaps within the literature (Noblit & Hare, 2988, p. 28), see Appendix C for an example of the translation of second-order to third-order constructs.

The initial themes were then further organised into three constructs relating to participants' experiences across three different overarching themes: “Foundations of coping”, “Barriers to access” and “The experience of being cared for” (see Appendix D for an overview of the third order-constructs across the studies).

#### **1.3.4.5 Step 7: Expressing the Synthesis**

The final step involves reporting meta-ethnographic insights in a way that meaningfully develops understanding within the relevant field. Whilst the written form is the most common and favoured in academia, Noblit & Hare (1988, p. 30) also suggests researchers utilise creative forms of output to ensure the synthesis reaches the intended audience, and even further.

### ***1.3.5 Overview of Findings***

#### **1.3.5.1 Theme One: Foundations for Coping**

Across the included studies, the presence of positive, trusting relationships and reliable social support emerged as a fundamental condition for wellbeing, and for the ability to cope with both the challenges of living with a learning disability and the specific demands of navigating healthcare. This theme captures two mediating factors that enable participants to engage meaningfully with healthcare and the world around them. The theme is divided into two subthemes, the first being ‘the role of relationships’ and the second being ‘the role of social support’. Whilst relationships and social support are closely connected, they represent distinct phenomena within the evidence base and are therefore considered separately.

##### ***1.3.5.1.1 The Role of Relationships***

The quality and meaning of close interpersonal relationships emerged as a significant element of participants' experiences across multiple studies. What distinguished this subtheme from the broader concept of social support was the



emphasis participants placed on the experience of being seen and understood as an individual within a safe relationship.

In their study Mattock et al. (2020) captured this when participants described the experience of being listened to and understood as both rare and profoundly meaningful. Participants further identified the absence of this experience within healthcare and in their wider lives as a significant source of distress. One participant described the pain of not being heard by those around them, whilst another expressed surprise and relief at discovering in the focus group that other people shared similar difficulties to their own. The focus group functioned for participants as an unusual and valued relational space, in which they could connect with others.

Boyden et al. (2013) found that positive therapeutic relationships were central to young people's experience of LD-CAMHS, and being able to communicate with their therapist was described as one of the most beneficial aspects of the service. Participants shared that the warmth and accessibility of staff were key determinants of whether the experience of engaging with the service felt safe and worthwhile. This finding translates to Mattock et al.'s (2020) adult participants, who similarly described the quality of their relationship with specific staff members as a primary factor in shaping whether their experience of mental health services was positive or negative.

#### ***1.3.5.1.2 The Role of Social Support***

Whilst the previous subtheme addressed the quality and meaning of close interpersonal relationships, this subtheme focuses on the broader and more instrumental dimension of social support. This encompasses the practical and emotional assistance provided by family members, carers, support workers, and

healthcare teams and functions as a kind of scaffolding, enabling participants to access and navigate healthcare encounters that may otherwise have been too difficult or distressing to do alone.

Truesdale-Kennedy et al. (2011) found that the presence of a carer or nurse during breast mammography helped reduce participants' fear and anxiety about the procedure. They also found that women who had been supported to visit the screening unit in advance, to meet with staff, and to receive accessible preparatory information reported a more positive experience of the screening process than those who had not received this preparation. The support provided in these cases was both practical and emotional, and the combination of the two was experienced as transformative in terms of participants' ability to engage with the screening invitation. This finding translates across to Drozd et al. (2021), where carer presence and advocacy in orthopaedic and trauma hospital settings was described as very important in aiding participants communication with staff, interpreting the information and advocating for their needs.

In their respective studies, Baxter et al. (2023) and Hall (2024) found that social support from family members, support workers, and the learning disability team was the primary coping resource available to participants during the often lengthy and distressing wait for psychological therapy. Participants expressed a desire for regular contact and acknowledgement from the service during the wait. The value of practical support, such as help accessing the community, managing daily tasks, and maintaining routine, was also highlighted in Baxter et al. (2023) as an important buffer against the deterioration of mental health during periods of waiting, particularly in the context of the restrictions associated with the COVID-19 pandemic.

Malouf et al. (2017) found that with appropriate support from both informal networks and maternity services, women with learning disabilities were able to develop confidence and competence as parents, suggesting that social support is not merely a compensatory resource but one that enables growth and self-efficacy when it is reliably and sensitively provided.

This theme highlighted the importance and vital role of a person's relational and social support. Through positive relationships, people with learning disabilities described a sense of being seen and understood, as well as feeling safe and finding connection with others, all of which are likely important for their overall wellbeing and capacity to cope within the healthcare system. Furthermore, this theme explored the important role played by their support system in enabling them to engage with healthcare professionals, highlighting the value of supportive health professionals who are willing to provide person-centred and adaptive approaches.

#### **1.3.5.2 Theme Two: Barriers to Access**

The second theme addresses what participants described needing from services and systems in order for healthcare to be genuinely accessible. Across the included studies, participants encountered healthcare processes and communication practices that were not designed with their needs in mind. Three subthemes were identified within this theme addressing communication, the provision of reasonable adjustments, and the broader experience of systemic exclusion.

#### ***1.3.5.2.1 Communication***

The subtheme of communication emerged as the most consistently identified barrier to healthcare access across the evidence base, appearing in some form in all nine studies. Participants in the studies by Hall (2024) and Baxter et al. (2023) described difficulties reading and understanding appointment letters and written correspondence from their learning disability services, with several participants reporting that letters were difficult to understand or simply lost before they could be acted upon.

Truesdale-Kennedy et al. (2011) found that the participants received little to no accessible information about breast cancer or the mammography process prior to their screening appointment, with the majority reporting that the topic was only raised at the point of receiving their invitation letter. The inaccessibility of information, combined with the absence of preparatory communication about what the screening process would involve, was directly linked to the fear and anxiety that participants described as the primary barrier to attendance. This finding translates across to Malouf et al. (2017), where women with learning disabilities reported that information about their maternity care was not consistently explained in accessible terms, and that the absence of clear and tailored communication left them feeling uncertain and poorly equipped to make informed decisions about their care.

Furthermore, Howieson (2015) found that participants in acute hospital settings experienced communication failures and reported that staff frequently failed to adapt their communication style or the level of detail they provided to meet the needs of people with learning disabilities. Participants described not being told what

was happening to them, not having procedures explained in advance, and not being given the opportunity to ask questions or express their concerns. Similarly, Drozd et al. (2021) found that communication challenges were a central feature of participants' experiences in orthopaedic and trauma hospital settings, with staff demonstrating limited awareness of the adjustments needed to communicate effectively with people with learning disabilities.

Mattock et al. (2020) and Boyden et al. (2013) both found that participants valued being communicated with in a way that was accessible and responsive to their individual needs and capacities. In both studies, the experience of being spoken to in an appropriate and respectful manner was identified as a key determinant of whether participants felt safe, included, and able to engage with the service.

#### ***1.3.5.2.2 Adjustment***

Another consistent theme was the failure to make reasonable adjustments to the environment and service delivery. The evidence base suggests that reasonable adjustments were made inconsistently and often only in response to individual advocacy rather than as a matter of routine practice.

Malouf et al. (2017) found that reasonable adjustments in maternity care varied considerably between individual practitioners and services, and that the quality and appropriateness of the care women with learning disabilities received was largely determined by the initiative and awareness of the specific professionals they encountered rather than by any systematic or embedded commitment to equitable service delivery. This finding translates across to Drozd et al. (2021), where participants described a similarly inconsistent experience of person-centred care in

hospital settings, with some staff demonstrating genuine effort to meet their needs whilst others appeared unaware of, or indifferent to, the adjustments required.

Cooper-Moss et al. (2024) highlighted that for people with learning disabilities from global majority backgrounds, the need for culturally sensitive reasonable adjustments added a further and frequently unacknowledged dimension to the challenge of accessing equitable healthcare. Participants described a lack of support services that took account of their ethnic and cultural identities and identified the absence of culturally informed adjustments as a significant barrier to feeling genuinely included and understood within healthcare encounters.

Where reasonable adjustments were made, participants generally reported better experiences. For example, Truesdale-Kennedy et al. (2011) found that women who had participated in a breast awareness initiative that included a preparatory visit to the screening unit, accessible information materials, and additional time with staff reported a markedly more positive experience of mammography than those who had not received these adjustments. Boyden et al. (2013) found that young people in LD-CAMHS valued staff who communicated at an appropriate level, offered a welcoming and open approach, and provided some flexibility and options to participants. The development of accessible easy-read materials and the use of supported communication approaches were identified as necessary for good practice in several of the included studies, including Malouf et al. (2017), Drozd et al. (2021), and Howieson (2015), yet the absence of such materials and approaches was also commonly reported, suggesting that their provision remains inconsistent across NHS services.

#### ***1.3.5.2.3 Systemic Exclusion***

The third subtheme addresses the broader experience of systemic exclusion and aims to address the sense that the barriers encountered were not isolated failures but expressions of a healthcare system that had not been designed for people with learning disabilities.

Mattock et al. (2020) identified that participants continued to experience limited involvement in their care planning, inadequate information about their treatment, and insufficient opportunity to express their preferences and concerns. The limited involvement in care decisions was translated across several of the studies, including Cooper-Moss et al. (2024), Malouf et al. (2017), and Boyden et al. (2013).

Baxter et al. (2023) and Hall (2024) found that the experience of waiting for psychological therapy was made more difficult not only by the length of the wait itself but by the absence of any systematic process for maintaining contact with, providing information to, or acknowledging the experiences of people on the waiting list. Participants described feeling forgotten and unsupported during what were often lengthy and emotionally demanding periods of waiting and expressed a clear desire for the service to recognise and respond to their experience in a more proactive and person-centred way.

In their study Cooper-Moss et al. (2024) found that people with learning disabilities from global majority backgrounds reported encountering a healthcare system that failed to make adequate adjustments for their disability and demonstrated limited awareness of, or sensitivity to, their ethnic and cultural identities. Additionally, they found that COVID-19 had disproportionately worsened healthcare

access for this group, which added another dimension to the concept of systemic exclusion.

In summation, this theme revealed that the difficulties faced by people with learning disabilities when accessing healthcare are structural, rooted in preconceived institutional assumptions present in the system itself. Additionally, services appear to be structured around ableist assumptions, and reasonable adjustments may be an afterthought rather than something that is routinely offered. This is further underscored by the consistency of these reports across maternity care, acute hospital services, preventive screening, mental health provision, and waiting list management.

### **1.3.5.3 Theme Three: The Experience of Being Cared For**

The third theme addresses the subjective and interpersonal experience of being a person with a learning disability within a healthcare encounter. This theme explores what happens within the healthcare encounter itself, and in particular the ways in which the attitudes of healthcare professionals, the distribution of power within clinical relationships, and the emotional consequences of these experiences shape participants' sense of themselves and their relationship with NHS services. Three subthemes were identified within this theme, which address power dynamics, staff attitudes, and the emotional impact of healthcare experiences.

#### ***1.3.5.3.1 Power***

The issue of power emerged as a significant and consistent dimension of participants' experiences across the included studies, manifesting in the ways in which decisions about care were made, whether participants were active agents or passive



recipients within healthcare encounters, and in the broader structural relationship between people with learning disabilities and the healthcare professionals and systems.

The most direct expressions of power imbalance within the evidence base concerned decision-making about care and treatment. Mattock et al. (2020) found that participants had little understanding of or control over decisions about their medication, with several describing taking medication without knowing why it had been prescribed or what it was intended to do. This finding translates across to Cooper-Moss et al. (2024), where participants described healthcare and contraceptive decisions being made on their behalf by carers or professionals without adequate consultation. This was similarly expressed in the study by Malouf et al. (2017), where women with learning disabilities reported that their choices about maternity care were not always sought or respected, and that decisions about their pregnancies and parenting were sometimes made by others in ways that felt intrusive and disempowering.

Howieson (2015) found that participants in acute hospital settings described a need to be treated with dignity and respect, and identified the absence of this treatment as one of the most distressing aspects of their hospital experience. The theme of being treated as differently or less able than other patients emerged clearly from participants' accounts, and translated across to Drozd et al. (2021), where participants described feeling that their concerns and preferences were not taken seriously by hospital staff, and that their or their carers' opinions were frequently overlooked or dismissed. Furthermore, Boyden et al. (2013) found that young people

in LD-CAMHS valued being given a choice about aspects of their care, including the location of their appointments and the approach taken by their therapist.

#### ***1.3.5.3.2 Attitudes***

The attitudes of healthcare professionals towards people with learning disabilities encompasses a spectrum of experiences ranging from genuine kindness and person-centred engagement to dismissiveness, paternalism, and in some cases discrimination.

Howieson (2015) found that participants in acute hospital settings described encountering staff whose attitudes ranged from supportive to dismissive and lacking understanding of people with learning disabilities. The theme of being overlooked in healthcare translates across to Mattock et al. (2020), where participants described being talked over, ignored, or dismissed by healthcare professionals and others, and where the experience of being heard and attended to was identified as both rare and meaningful.

Drozd et al. (2021) found that participants in orthopaedic and trauma hospital settings described encounters with staff who demonstrated limited knowledge of and sensitivity to the needs of people with learning disabilities, with several participants describing experiences of perceived incompetence or indifference on the part of hospital staff.

Cooper-Moss et al. (2024) found that participants with learning disabilities from global majority backgrounds reported experiencing discrimination within healthcare settings. Participants also described difficulty in identifying whether this discrimination was rooted in their learning disability, their ethnicity, or the

intersection of the two. Additionally, they felt that their ethnic and cultural identities were not recognised or respected within healthcare relationships, and that the assumptions underpinning support were frequently stereotypical and inadequate.

It is important to note that across several of the included studies, participants also described encounters with healthcare professionals whose attitudes were described as positive, and these experiences stood out as meaningful and memorable because of their relative rarity. Truesdale-Kennedy et al. (2011) found that staff described as friendly and supportive at breast screening units significantly reduced participants' anxiety and increased their willingness to attend in future. Baxter et al. (2023) found that individual members of the learning disability team were described as helpful and supportive by participants, and Boyden et al. (2013) found that young people in LD-CAMHS valued staff who were welcoming and open when it came to communication.

#### ***1.3.5.3.3 Emotional Impact***

The final subtheme addresses the emotional consequences of the difficulties experienced in healthcare, particularly the psychological cost of navigating the healthcare system, staff attitudes, and the structural and communicative barriers. Across the included studies, the emotional impact of healthcare experiences on people with learning disabilities was both significant and multifaceted, encompassing fear, anxiety, distress, shame, loneliness, and a pervasive sense of “otherness” within healthcare settings.

Fear and anxiety were the most consistently reported emotional responses to healthcare encounters across the evidence base. Truesdale-Kennedy et al. (2011)

found that fear of the unknown, rooted in a lack of accessible information about the mammography process, was the dominant emotional experience associated with breast screening for many participants. Participants described anxiety about the screening equipment, about the procedure itself, and about the potential results, and several reported that the experience of entering an unfamiliar clinical environment without adequate preparation was deeply unsettling. This finding can additionally be seen in Howieson (2015), where participants in acute hospital settings described feelings of vulnerability and anxiety that were exacerbated by the unfamiliar environment, staff behaviour, and the absence of accessible information about what was happening to them and why.

Baxter et al. (2023) and Hall (2024) both found that the experience of waiting for psychological therapy was associated with significant emotional distress, characterised by feelings of isolation and uncertainty. Participants in both studies described the wait as emotionally painful, and several used language that conveyed a sense of being forgotten or abandoned by the service. These findings translate across to Mattock et al. (2020), where participants described the emotional impact of feeling neglected within mental health services, and identified the experience of being listened to and taken seriously as having a positive effect on their sense of wellbeing.

Malouf et al. (2017) found that women with learning disabilities in maternity care frequently described feeling scrutinised, judged, and treated differently from other mothers. The desire to be seen and treated as “normal” was a recurring theme in their accounts of healthcare. This was also present in Mattock et al. (2020), where participants described the emotional impact of encountering negative attitudes

towards their learning disability and mental health difficulties both within and outside of healthcare settings. One participant described the shame and distress of feeling that their mental health difficulties were not taken seriously, whilst another described the relief of encountering a professional who attempted to understand their experience.

Drozd et al. (2021) found that isolation and loneliness were prominent features of participants' experiences in orthopaedic and trauma hospital settings, with participants describing the difficulties of being in a strange environment and being supported by unfamiliar people. Baxter et al. (2023) and Hall (2024) found that social isolation and the absence of meaningful connection were key factors in the deterioration of emotional wellbeing during periods of waiting. Similarly, Mattock et al. (2020), where participants described the emotional toll of living without adequate support in their daily lives.

Notably, several studies contain accounts of emotional experiences that were positive and highlights the transformative potential of healthcare encounters that get it right. Truesdale-Kennedy et al. (2011) found that women who had completed breast screening described feeling proud and brave, and expressed a willingness to return for future screening. Malouf et al. (2017) found that appropriate support helped women with learning disabilities to develop confidence and competence as mothers. Baxter et al. (2023) found that participants demonstrated considerable resilience in their use of coping strategies during the wait for therapy and described moments of connection and support that were experienced as sustaining.

#### **1.3.5.4 Line of Argument Synthesis**

Having presented the three synthesised themes, it is now possible to articulate the line of argument that emerges from reading across the studies as a whole. The findings of this systematic literature review suggest that whilst people with learning disabilities demonstrate meaningful capacity for resilience and the formation of supportive relationships within healthcare contexts, this capacity is consistently and systematically undermined by a healthcare system that has not been designed for their needs. The relational and social resources that people with learning disabilities draw upon, captured in the theme of Foundations of Coping, represent a form of adaptive strength that enables them to navigate a system that frequently fails them. However, as the theme of Barriers to Access illustrates, the structural and attitudinal dimensions of that system, such as inaccessible communication and ableist assumptions embedded in service design, create conditions in which meaningful engagement is perpetually compromised. The third theme, The Experience of Being Cared For, reveals that when people with learning disabilities do access care, the quality of that experience is shaped less by their individual characteristics than by the attitudes, knowledge, and flexibility of the professionals they encounter. Together these three themes tell a story not of individual deficit but of systemic failure, in which the barriers faced by people with learning disabilities in healthcare settings are structural and therefore amenable to change. This line of argument has direct relevance to the primary research that follows, which explores whether a similar pattern of systemic exclusion operates in the context of climate change discourse.

### ***1.3.6 Discussion***

This review aimed to investigate the experiences of healthcare support in the UK as described by people with learning disabilities. Through a meta-ethnographic synthesis of nine studies the findings present a broadly consistent picture, with participants reporting negative experiences across markedly different healthcare settings, including maternity, orthopaedic, breast screening, mental health, and acute hospital care. Communication failures, insufficient reasonable adjustments, negative staff attitudes, and limited involvement in decision-making were reported by participants ranging from children aged eleven to adults aged sixty-nine, across mild to profound levels of disability, and across services spanning preventive screening to acute hospital care.

From this it can be hypothesised that the barriers identified may be structural in nature rather than specific to any single service or clinical specialty. These themes are consistent with existing literature around the healthcare inequality experienced by people with learning disabilities (Oulton et al., 2022; Cooper et al., 2025; Ali et al., 2013).

Accessibility of services was a recurrent theme, and of particular note was the challenges around written information, which was noted as an inaccessible communication tool. Inaccessible health information is not a new barrier, nor one that is unique to the NHS (Barrington et al., 2025). However, as one of the main methods of information sharing in the NHS, this suggests that a significant proportion of people with learning disabilities may be effectively excluded from meaningful engagement with services at the most basic administrative level.

The experience of participants of disempowerment in healthcare settings may reflect a pervasive and deeply embedded set of assumptions about their capacity, agency, and role in decisions about their own care. These assumptions sit in direct tension with both the legal requirements of the Mental Capacity Act 2005, which establishes a presumption of capacity and requires that all practicable steps be taken to support decision-making, and the stated values of person-centred practice that underpin NHS policy and guidance in relation to people with learning disabilities. Moreover these findings are consistent with other studies in NHS settings where participants report a lack of input in their care and being disempowered with regards to their care (Chinn et al., 2011)

The report that participants lacked confidence in the ability and willingness of staff to meet their needs is particularly significant, as it suggests that negative staff attitudes may not only be experienced as difficult in the moment but have lasting consequences for the trust and confidence that people with learning disabilities are able to place in NHS services more broadly. Staff knowledge and confidence in supporting people with learning disabilities has been identified as one of the factors impacting healthcare professionals' ability to sensitively and adequately support people with learning disabilities (Oulton et al., 2022). Additionally, the degree to which healthcare professionals consider it their responsibility to make adjustments to ensure equal care to people with learning disabilities (Rinaldi & Batsele, 2023). This highlights a barrier to staff in the form of a lack of training and resources available to help them to develop the skills necessary. Furthermore, people with learning disabilities from global majority backgrounds are of higher risk of 'double-



discrimination' (Roberts et al., 2025), which was highlighted by the finding that current models of support were experienced as stereotypical and culturally insensitive.

The experience of being cared for as a person with a learning disability within the NHS is frequently characterised by a lack of dignity, agency, and recognition, and the emotional cost of this is both significant and largely invisible to services.

However, the positive experiences present within the evidence base demonstrate that supportive healthcare encounters are possible for people with learning disabilities when healthcare professionals bring genuine respect, accessible communication, and a commitment to person-centred practice to their work. As stated by Chinn & Homeyard (2017), information that is tailored to the individual is more likely to meet the specific health information needs of people with learning disabilities. Thus, the development of different and creative approaches to producing accessible information has the potential to improve engagement across a wider range of people within this population.

These positive emotional experiences across studies suggests that people with learning disabilities are not passive victims of the healthcare system but active agents capable of growth, resilience, and meaningful engagement when the conditions for such engagement are in place. Despite assumptions around their ability to participate in research or express their needs, people with learning disabilities have clearly and consistently articulated both what makes healthcare inaccessible and what would make it better. Thus, there is a compelling moral and practical case for ensuring that these voices are placed at the centre of efforts to improve NHS service design and delivery for this population.

### ***1.3.7 Limitations***

Whilst this review has sought to adhere to rigorous methodological standards throughout, several limitations must be acknowledged that affect the confidence with which the synthesised findings can be interpreted and generalised.

Firstly, the nine studies included in this review vary considerably in their methodological quality, as evidenced by the CASP quality appraisal scores ranging from 4.5 to 8 out of 10. Whilst the decision was made to retain all nine studies in the review in keeping with the position that quality appraisal should inform rather than determine inclusion in qualitative evidence synthesis (Noblit & Hare, 1988), the variable quality of the evidence base means that the synthesised findings should be interpreted tentatively.

The included studies vary considerably in their clinical focus, encompassing maternity care, acute hospital services, orthopaedic and trauma care, breast screening, mental health services, and waiting list experiences. Whilst this diversity is a strength of the review in terms of the breadth of NHS healthcare contexts represented, it also means that the synthesised findings cannot be taken as representative of the full range of healthcare experiences of people with learning disabilities across all NHS settings. Notable gaps in the evidence base include primary care, including general practice and annual health checks, dental healthcare, and end of life and palliative care, all of which represent significant areas of NHS healthcare provision for people with learning disabilities that are not captured in the included studies.

The transferability of findings is further limited by the demographic characteristics of the samples across the included studies. Most participants were

described as having mild to moderate learning disabilities, with people with severe or profound learning disabilities largely excluded from participation due to communication requirements. This means that the synthesised findings may not adequately represent the experiences of people with more complex support needs, who are likely to face even greater barriers to accessible and equitable healthcare than those described in this review. Additionally, with the notable exception of Cooper-Moss et al. (2024) and Mattock et al. (2020), the ethnic diversity of participants across the included studies was limited, with several studies not reporting ethnicity at all and others recruiting exclusively or predominantly White British participants.

Systematic reviews conventionally involve at least two independent reviewers at each stage of the process to reduce the risk of bias in study selection and interpretation. The use of a single reviewer introduces the possibility of selection bias, in that studies meeting the inclusion criteria may have been inadvertently excluded, and of interpretive bias, in that the translation of concepts and the construction of synthesised themes reflects the perspective and judgements of one individual. Whilst every effort was made to maintain transparency and rigour throughout the review process, including the use of structured tools such as the CASP checklist and the PRISMA reporting framework, the absence of a second reviewer is a limitation that should be borne in mind when interpreting the findings of the synthesis.

As with all systematic reviews, the findings of this review are potentially subject to publication bias (Thornton & Lee, 2000), in that studies reporting positive or unambiguous findings may be more likely to have been published and therefore identified through the database searches than studies reporting more equivocal or

negative results. Equally, the opposite may also be true, with studies reporting negative experiences of healthcare potentially being more publishable given the recognised salience of healthcare inequalities experienced by people with learning disabilities. The inclusion of a manual Google Scholar search was intended in part to mitigate this risk by identifying relevant studies that may not have been indexed in the primary databases searched, but it is nonetheless possible that relevant unpublished or grey literature studies exist that were not captured by the search strategy and whose inclusion might have altered the findings of the synthesis.

### ***1.3.8 Conclusion***

This meta-synthesis investigates the healthcare experiences of people with learning disabilities. Despite a consensus across research, governance and policy that there needs to be reasonable adjustments and additional support to ensure better health outcomes for this population, this does not translate to the lived experience of people with learning disabilities. Across the themes of relational support, barriers to access, and the interpersonal dynamics of healthcare encounters, the findings are overwhelmingly negative, highlighting persistent gaps between policy intention and everyday practice. Although some positive experiences are noted, as the responses are largely negative, they highlight the need for further systemic improvements to ensure the health and wellbeing needs of this population are met.

The pattern of systemic exclusion documented across the healthcare literature is not confined to healthcare alone. The chapters that follow explore whether a comparable dynamic operates in the context of climate change discourse, and what

this means for a population that is often excluded from the conversations that shape their world.

## **1.4 Part Three: Climate Change and People with Learning Disabilities**

### ***1.4.1 Chapter Overview***

This section sets out to introduce the topic of climate change, and its impact from both a health and psychological perspective. It examines how and why people with learning disabilities may be disproportionately affected by the effects of climate change. It further goes on to highlight that despite this vulnerability, people with learning disabilities are largely left out of research about climate change, and conversations about it.

### ***1.4.2 Climate Change and Health***

Climate change refers to long-term alterations in global temperatures and weather patterns. Although such changes can occur naturally, for example due to variations in solar activity or major volcanic eruptions, human activity has been the primary driver since the 19th century (United Nations, n.d.), with current global temperatures rising more rapidly than at any other point in recorded human history. This is largely driven by the continued use of fossil fuels, alongside additional contributions from changes to ecosystems and landscapes, particularly those associated with agriculture and forestry. Without urgent reductions in carbon

emissions, global warming is likely to exceed the 1.5 °C threshold established in the Paris Climate Agreement, with current trajectories suggesting the possibility of warming exceeding 3 °C by the end of the century (Masson-Delmotte et al., 2021). The World Health Organisation has declared climate change as one of the biggest threats to human health and wellbeing in the next decades (World Health Organisation, 2021) with the scientific consensus that climate change will have significant impact on physical health (Costello et al., 2009), and mental health (Galea et al., 2008).

While climate change is often initially framed as a threat to wildlife and natural ecosystems, such as melting ice caps and polar bears, human well-being is deeply interconnected with ecological health in multiple ways. Whether through direct or indirect means, the effects of the rapidly changing climate are felt at a global emotional level as well as an ecological one. This is expressed most notably through collective grief, eco-anxiety and "solastalgia", which is the distress caused by environmental destruction (Lawrance et al., 2022). Furthermore, Dillman-Hasso (2021) has highlighted that climate change may compound its mental health impacts by degrading the natural environments that are known to provide psychological protection and restoration, suggesting that the mental health consequences of climate change extend beyond direct exposure to extreme weather events. Effective preparation for the impacts of climate change and real systemic change depends on developing a better understanding of the various ways it may influence people and societies, alongside the potential responses individuals and communities might demonstrate.

The socio-ecological impacts of climate change are already felt globally. Climate change is contributing to the increasing occurrences of extreme heat and wildfires and the emergence and spread of infectious diseases, which contribute to growing health emergencies. These effects put pressure on healthcare systems by affecting the health workforce and infrastructure, potentially limiting the capacity to deliver universal health coverage (Campbell-Lendrum et al., 2023). Furthermore, the escalating environmental pressures, such as drought and rising sea levels, are increasingly threatening the environmental and social determinants of both physical and mental health. These include access to clean air and water, sustainable food systems, and secure livelihoods, with some nations facing existential risks, including the prospect of forced displacement (Tai et al., 2014). Another major impact of climate change is food insecurity, with reduced food availability and resulting malnutrition potentially contributing to over half a million deaths globally by 2050 (Springmann et al., 2016).

The longer it takes for adaptations or mitigations to climate change to be implemented, the higher these risks become, and may threaten the decades of progress achieved in global health so far (Masson-Delmotte et al., 2021). Furthermore, as communities and countries look inwards at the felt effects of climate change, this may challenge the international commitment to global health for all (World Health Organisation, 2021).

Direct impacts on health are easily explored through the effects of extreme weather changes, such as excessive heat or hurricanes. Portier et al. (2010) reported in 2010 that extreme heat caused more weather-related deaths than any other weather

event in the United States. Furthermore, projections suggest that by the end of the century 48–74% of the global population may experience over 20 days a year of potentially lethal heat conditions, compared with about 30% today (Mora et al., 2017). This may disproportionately affect those with pre-existing health problems, such as cardiovascular, respiratory, and cerebrovascular diseases, as well as diabetes and asthma, as prolonged heat exposure may aggravate these conditions further (Portier et al., 2010).

Although climate change is a large-scale problem that needs policy and systemic changes to be made on a geopolitical scale, there is also a role to play for health professionals. In line with the health priorities outlined by the World Health Organisation, Campbell-Lendrum et al., (2023) identified three key ‘grand-challenges’ to address the threat climate change poses to health: promote actions that both reduce carbon emissions and improve health; build better, more resilient and environmentally sustainable health systems; implement public health measures to protect from the range of climate risks to health. They further detailed three functions for the health community in responding to the climate crisis, which include leadership and advocacy, evidence and monitoring and implementation.

#### **1.4.2.1 Mental Health Impact**

Though often treated in society as separate, physical and mental health are interconnected. As detailed above, extreme and sudden weather events have a high potential to harm physical health, however they may also cause immediate and severe psychological trauma. Direct and indirect effects of climate change have been found in the development and worsening of mental health difficulties, particularly



depression, suicide risk, anxiety, substance use disorders, post-traumatic stress disorder, and solastalgia (White et al., 2023).

Whilst considering the psychological impacts of climate change it is important to differentiate between the negative effects that climate-related disasters have on mental health, such as post-traumatic stress disorder, after effects such as floods or hurricanes, and broader impacts on psychological wellbeing, where ongoing climate pressures may undermine people's ability to experience positive emotions or maintain hope for the future. This distinction is important, as climate change has the potential to affect both aspects of psychological functioning.

Doherty (2018) detailed the challenge of fully characterising the mental health impacts of climate change, as these unfold across different geographical, temporal, and cultural contexts. They further suggest that the effect of climate change on mental health can be divided into three categories, direct impacts, indirect impacts and vicarious impacts. Direct impacts relate to disasters and acute environmental disruptions. An example of the direct psychological impact can be found in communities that have experienced catastrophic natural disasters, such as the prevalence of PTSD among those impacted by Hurricane Katrina, which was found to be around 20%, with even higher rates found in communities closer to the severe flooding (Galea et al., 2008). Another example highlighting the general link between disaster and distress is the increased rates of major depressive disorder found in Haiti following the 2010 earthquake, which was close to 30% (Cerdá et al., 2013).

Chronic climate events like prolonged droughts or flooding may disrupt livelihoods, increase food insecurity, intensify community tensions, and contribute to

forced migration, displacement, and conflicts over land use, which begin to affect economic systems and social infrastructure (Doherty, 2018). These in turn affect emotional wellbeing in a variety of ways, such as guilt or grief in relation to the changing environment, or anxiety and worry about climate change (Doherty & Clayton, 2011).

Vicarious impacts refer to the psychological distress or secondary trauma experienced by individuals who are geographically or socially removed from direct climate-related events. Some psychological responses may be experienced at a distance from the direct disaster events, such as anxiety or despair related to climate-related trauma, injustice, or ecological loss. Beyond its direct and indirect psychological effects, climate change is also likely to influence social and community relationships. While some impacts may arise directly from environmental changes, many are expected to occur indirectly through shifts in how people inhabit and use land. Changes in the suitability of regions for agriculture, aquaculture, and habitation may alter both individual experiences within specific locations and broader population distributions, with implications for interpersonal and intergroup relations. The extent of these impacts is shaped by wider social and environmental trends, and even when effects are concentrated within particular regions, economic consequences may extend beyond national borders, producing broader global repercussions.

Mental health will also likely be impacted by the degradation of the environment due to climate change, as this will affect the access to the benefits that nature provides for people's mental health. However, as suggested by Dilman-Hasso (2021) this area is under researched, highlighting that whilst climate change and

mental health is a burgeoning field of research there are still significant gaps in knowledge on its impact and correlation.

Psychologists have an important role in supporting adaptive responses to the psychological impacts of climate change and in addressing mental health difficulties linked to environmental disruption. Climate change is disproportionately affecting vulnerable individuals and communities, often reflecting broader social and economic inequalities (White et al., 2023; Ngcamu, 2023). Psychology can therefore help illuminate the impact on both local and global wellbeing, highlighting that climate change is not solely an environmental issue but also a psychological and social challenge with wide-reaching implications for mental health (Clayton & Manning, 2018). Furthermore, the Planetary Health Subgroup within the British Psychological Society's Clinical Psychology division identified three areas where clinical psychologists have a critical role to play: addressing the mental health impacts of climate change, such as anxiety and trauma; promoting healthier and more sustainable ways of living to mitigate and adapt to the climate change; and incorporating planetary health concepts into teaching, practice, and research (British Psychological Society, Division of Clinical Psychology, Planetary Health Subgroup, 2024).

Research has emerged indicating that climate change will have profound and widespread impacts on mental health, particularly for vulnerable populations, with a burgeoning field of research with particular interest in the impact on children and young people (Lawrance et al., 2022). In their recommendations for researchers, the

authors stress the importance of conducting research into the effects of climate change on the mental health of people from vulnerable populations.

### ***1.4.3 Disproportionate Impact on Marginalised Groups***

As discussed earlier in the chapter, the effects of the Earth's rapidly changing and unpredictable climate exacerbates existing societal inequalities. Although climate change is expected to affect all populations in various ways, certain groups are likely to face greater vulnerability than others. Women, children, individuals from marginalised communities, and Indigenous populations may experience a disproportionate impact on mental health as climate-related changes intensify (Manning & Clayton, 2018).

It is therefore important to pay greater attention to vulnerable populations who face increased risks of adverse health outcomes, which also includes low-income individuals, older adults, people with disabilities, children, racial and global majority groups, and those with substance use difficulties (Benevolenza & DeRigne, 2019). Most of the research exploring the direct impacts of climate related disasters on disenfranchised individuals has been conducted in the United States of America on populations affected by hurricanes and catastrophic storms. Research with survivors of Hurricane Katrina from socioeconomically disadvantaged populations highlighted that unequal resource distribution, constraints within educational and social support systems in the most affected areas, and longstanding institutional oppression contributed to increased vulnerability among African-American women (Hamilton-Mason et al., 2012). These themes suggested that perceived neglect, abandonment,

trauma, overlapping forms of institutional oppression, and feelings of being left behind by society were linked to heightened stress, distress, and uncertainty among participants and their families in the aftermath of Hurricane Katrina. Housing displacement was also found to be a significant contributor to adverse psychological outcomes, with those relocated to new communities or experiencing prolonged periods in temporary housing reporting significantly higher levels of psychological distress and perceived stress (Fussell & Lowe, 2014).

People with disabilities may be particularly vulnerable to the impacts of climate change, largely due to existing inequalities and their limited inclusion in adaptation and mitigation efforts (Gaskin et al., 2017). Evidence suggests that people with disabilities may be at greater risk of mortality during natural disasters, with some research indicating death rates up to four times higher than those of people without disabilities (Stein & Stein, 2022). Furthermore, Research by Davies and Hemmeter (2010) highlighted some of the barriers faced by individuals with disabilities to be in relation to disaster preparedness and evacuation, including inaccessible transport, lack of inclusive planning, disruption to essential medical supplies, and inadequate communication and shelter provision. Another challenge faced by vulnerable populations are their limited resources to cope with natural disasters, such as reduced financial capacity to prepare or evacuate. In their review Benevolenza and DeRigne (2019) highlighted the importance of tailored preparedness planning, specialised training, and disaster-relief efforts that prioritise the needs of these groups.

In their opinion piece, Jodoin et al., 2023 call for research in the field to be guided by the motto “*nothing about us without us*” and highlight the need for

research to be collaboratively generated and for the knowledge to be accessible to people with disabilities. The greater impact of climate change on people with disabilities highlights the need for stronger and more effective approaches that include disability in climate mitigation and adaptation efforts (Stein & Stein, 2013). Although there is growing recognition of the importance of addressing the impacts of climate change on people with disabilities, the existing research base remains limited. Much of the current literature focuses on vulnerability during natural disasters, with little attention given to broader impacts on everyday life or mental health. A recent scoping review highlighted this gap and emphasised the need for further research in this area (Lee, 2024).

Ensuring inclusion should remain central to climate change adaptation planning. Inclusive approaches emphasise engagement with a broad range of stakeholders, particularly vulnerable groups such as people living in poverty, Indigenous communities, and people with disabilities. Their meaningful participation in decision-making is important for both equity and effective outcomes (Pham & Saner, 2021).

#### ***1.4.4 People With Learning Disabilities and Climate Change***

From a disability human rights perspective, the disproportionate impact of climate change on people with disabilities is understood to result from overlapping cultural, social, economic, and structural forms of discrimination (Stein & Stein, 2013). Despite research showing that people with disabilities are more vulnerable to the climate crisis, there is still limited research specifically looking into the effects on

individuals with learning disabilities. The reason for this significant gap is unclear; however, a few suppositions and assumptions can be postulated based on research into truth-disclosure and inclusion in other areas, particularly around death and bereavement which has a substantial research base.

Historically there has been a tendency to protect people with learning and intellectual disabilities from “bad” or difficult news, such as illnesses or bereavements (Tuffrey-Wijne et al., 2017), with people with learning disabilities being less likely to be supported to understand that they themselves are dying or someone close to them is (Bernal & Tuffrey-Wijne, 2008; Ryan et al., 2011). Barriers to open communication experienced by staff supporting dying people with learning disabilities include a lack of confidence about discussing death. Another one is fear and reluctance to engage with issues related to death or dying, particularly worries about distressing clients (Tuffrey-Wijne et al., 2017; Tuffrey-Wijne, & Rose, 2017). This suggests that reluctance to engage in difficult conversations with people with learning disabilities may stem not only from concern about their reaction, but also from professionals' own discomfort with the topic itself.

Another concerning barrier to truth-disclosure are assumptions made around the abilities of people with learning disabilities. A literature review on learning disability and end-of-life decision-making by Kirkendall et al. (2017) found that individuals with learning disabilities were frequently assumed to lack decision-making capacity and, as a result, were often not informed of a terminal diagnosis. These assumptions are undoubtedly problematic as it excludes people with learning disabilities from being involved in their own care, and as a consequence decisions are

made by third parties who may have differing opinions to the ones of the person who is being cared for (Kirkendall et al., 2017).

Whereas the assumptions or judgements are often on the abilities of people with learning disabilities to understand information around climate change, the scrutiny rarely focuses on the general population and their ability or willingness to make accessible adaptations to this information. However, Manullang et al. (2021) examined science learning among six students with learning disabilities in Indonesia through photosynthesis experiments linked to climate change awareness. The study found that students were able to engage with the topic when teaching was adapted to their abilities, with appropriately challenging questions supporting understanding and analytical skills. The authors also emphasised the importance of teacher knowledge and inclusive teaching approaches to support environmental learning and participation.

Despite these fears and concerns around truth-disclosure, literature suggests that many people with intellectual disabilities want to be told the truth and that the truth needs to be disclosed simply and clearly (Tuffrey-Wijne & McEnhill, 2008). In a society where knowledge is power, the lack of accessible information is glaring and leaves people with learning disabilities at risk of being even more excluded and powerless to inform decisions. There is often limited access to resources and information for people with learning disabilities which further excludes them from better understanding the climate crisis and conversations about it (Kosanic et al., 2022). Organisations such as the United Nations Framework Convention on Climate Change (UNFCCC) and the Intergovernmental Panel on Climate Change do not



always provide documents in accessible formats online. As a result, people with visual, hearing, print, or intellectual disabilities who rely on accessible websites, captioned videos, adaptable presentations, or plain language materials may face barriers to accessing information needed to understand and exercise their rights (Stein & Stein, 2022)

A scoping review of the participation of people with learning disabilities in climate change research found that people with learning disabilities faced increased risks and barriers during and following natural disasters. It also highlighted their limited inclusion in government disaster planning and response, with inclusive education initiatives still relatively underdeveloped. Overall, people with intellectual disabilities were rarely positioned as leaders or collaborators in climate-related research or practice, and the literature largely focused on natural disasters rather than the wider climate crisis (Watfern & Carnemolla, 2025). This review further highlights the need for more research in this area. Gaining a better understanding of the perspectives of people with learning disabilities on inclusion in the conversations about the climate crisis, might provide valuable insights for clinicians on how to best support and advocate for people with learning disabilities.

#### ***1.4.5 Community Psychology, Climate Change and Research Gaps***

In community psychology, sustainability is commonly understood through an ecological perspective, which situates behaviour within broader social, cultural, economic, and political contexts (Riemer & Harré, 2017). This approach typically emphasises participatory methods, encouraging involvement in change processes

aimed at addressing these wider contextual influences (Hickman, Riemer & the YLEC Collaborative, 2016, cited in Riemer et al. 2020, p. 21). As has been highlighted in the earlier sections, there is a significant gap in climate change research and people with learning disabilities.

Community empowerment is a key priority within community psychology. Research suggests that public participation in environmental decision-making, for example debates around nuclear or industrial waste sites, is often shaped by broader social power dynamics. These power relations can influence both access to resources and the extent to which different groups are able to influence agendas and decision-making processes (Culley & Angelique, 2011; Culley & Hughey, 2008). Where people with learning disabilities are all but excluded from climate change research, it is important to consider the importance of community empowerment as well as inclusion.

Literature on inclusive climate change adaptation (CCA) often focuses on local and community contexts while recognising the importance of national, regional, and international coordination. Bottom-up initiatives are typically supported by national policy, strategic direction, and government funding, with international commitments and national strategies needing to be translated into locally relevant action where adaptation is primarily implemented (Pham & Saner, 2021).

Empowering people with disabilities as key participants in climate action is important for strengthening resilience at individual, community, and societal levels. Despite this, they have often been underrepresented within environmental movements, reflecting forms of eco-ableism, where expectations about ability

contribute to exclusion (Stein & Stein, 2022). Furthermore, climate resilience education has the potential to empower people with disabilities to take an active role in protecting their families and communities. For instance, within the Pamismas project in rural Indonesia, people with disabilities received training to serve as monitoring group members, enabling them to contribute to decisions regarding water access design and placement (Pham & Saner, 2021). There is a growing need to properly involve disadvantaged groups in adaptation efforts, not only to uphold human rights but also to help ensure sustainable development in industrialised countries.

#### ***1.4.6 Rationale and Aim for the Current Study***

As there is such limited research into people with learning disabilities and climate change, there is a significant risk that they are further excluded from conversations about it, or that assumptions are made about their interest or ability to partake in or inform the knowledge base. This would represent a continuation of the pattern of exclusion highlighted throughout this introduction, in a context where people with learning disabilities are likely to be among those most affected by the consequences of climate change.

Due to the lack of research in this area, and in accordance with the inclusive and community psychology ethos that underpins this thesis, it is important to begin with the perspectives of the population in question, rather than making assumptions on their behalf. The aim of the current study is therefore to explore the perspectives of people with learning disabilities on the climate crisis, including their understanding of

it, and if and how they might want to be involved in conversations and actions to help with climate change. In doing so, this research seeks to contribute to an emerging and important area of inquiry, and to affirm that people with learning disabilities have both the right and the capacity to participate in one of the most significant conversations of our time.

## **2. Methods**

### **2.1 Chapter Overview**

This chapter outlines the methodology of the study, beginning with some reflections on personal positioning in relation to the subject matter and an exploration of the philosophical and epistemological stance of the research. It further sets the scene by describing the elements of the study design, such as the recruitment, data collection, data analysis and ethical considerations. Finally, this chapter goes on to explore potential and appropriate avenues for dissemination of this research.

### **2.2 Personal Positional Reflection**

As qualitative research inherently demands some form of interpretative analysis, it is a given that the findings will be somewhat informed by the subjective opinions of the researcher carrying out the analysis. Thus, throughout the process of this study, the researcher remained mindful of their own relationship with the subject matter and with the client group, to ensure that they did not infer too much of their own stance to the participants and their responses. The researcher is the product of the

land of fjords and mountains, a country which is hailed for its natural beauty and closeness to nature, also a country whose wealth and welfare is built largely upon oil and gas development and investment. This duality and hypocrisy affected the researchers' passionate engagement with the impacts of climate change, whilst acknowledging that the wealth generated from fossil fuels is an indisputable part of the reason they are able to study in a different country than the one they were born in and to undertake this doctorate. Thus, the researchers' relationship with and feelings about the subject and engagement with climate change is important to note and be mindful of as the findings are discussed. Furthermore, as the researcher does not have a learning disability, they were positioned as an 'outsider' to the main element of the study, namely the experience of having a learning disability, and were therefore in a position of power.

In an attempt to increase awareness of the internal processes, potential biases, prejudices and own opinions, the researcher kept a reflexivity diary throughout the process of this research. Reflections were noted down, particularly after interviews and during data analysis. These reflections helped support and inform the thematic analysis, particularly during the coding process and with emerging themes.

## **2.3 Philosophical Perspective and Epistemological Position**

Lincoln et al. (2011, p.97-98) frame research paradigms as reflecting a philosophy of science that engages with fundamental questions across four domains: ontology, epistemology, axiology (ethics), and methodology.

Ontology concerns a researcher's understanding and assumptions about the form and nature of reality. It includes questions of whether reality exists independently of the researcher and whether or the extent to which it can be seen as something concrete and observable (Riemer et al., 2020, p. 258). Epistemology involves the study and theory of knowledge, addressing both the processes through which knowledge is acquired and the criteria by which its validity and value is judged, and how knowledge relates to others including the researcher (Howitt & Cramer, 2011, p. 298). Axiology is concerned with ethical questions pertinent to the research (Windchief et al., 2023). Lastly, methodology is an umbrella-term used to describe research approaches, methods and procedures. The method and approach to the research chosen is influenced by the researcher's assumptions about ontology, epistemology and axiology.

For many years the dominant stance in qualitative and quantitative research was *positivism*, which was first articulated by the French philosopher and mathematician Auguste Comte in the nineteenth century. Comte stressed the importance of observable evidence as the basis for the reliable development of knowledge (Mill, 1961, p.4). In psychology, positivism reflects a law of universality, suggesting that knowledge can be viewed as facts that can be empirically tested, confirmed or disconfirmed. However, principles in human nature and behaviour are not necessarily translated globally or across time or they exist outside of culture and context culture and context. In the second half of the 20th century other epistemological paradigms emerged, and most research now grounds itself within the

ontology and epistemology of the *post-positivist* paradigm which is based on *critical realism*.

The present study is positioned within a critical realist framework. Critical realism holds that an objective reality exists independently of human perception, whilst simultaneously acknowledging that our access to that reality is mediated through experience, language, and social structures (Riemer et al., 2020, p.261). This represents a middle ground between the objectivism of positivism and the stronger relativism associated with constructivism and is therefore well-suited to applied research of the kind undertaken here. This position also resonates with the ethos of community psychology, which similarly holds that social inequalities and barriers to participation are real and consequential phenomena that can be identified, critically examined, and challenged. Thus, this research adopts a critical realist ontological position as it argues that inclusion, and by extension exclusion, is a real and consequential phenomenon, not merely a social construction. The marginalisation of people with learning disabilities from important societal conversations, such as those concerning climate change, reflects real structural and systemic barriers that exist independently of how they are perceived or described individually. Central to this ontological position is the notion that there is a reality to inclusion: that is, if the existing literature demonstrates that current approaches to inclusion are inadequate or failing, as outlined in the introduction chapter, then it follows that a more meaningful and equitable form of inclusion exists, even if it remains unattainable in practice. In other words, the existence of a demonstrably wrong way of “doing” inclusion implies

that there is a right way, or at least a better way, towards which research and practice can strive.

Epistemologically, the study adopts a post-positivist stance, consistent with critical realism. Whilst a single, fully objective account of participants' experiences cannot be attained, their accounts are nonetheless considered to provide meaningful and credible insight into what genuine inclusion looks and feels like, and what currently prevents it. The existence of this deeper reality, even if it can only ever be partially apprehended, is what lends the study its critical edge: the findings are not simply one construction of inclusion among many equally valid alternatives, but rather an approximation of a truth about inclusion that, whilst perhaps never fully reachable, is nonetheless real and worth striving towards. The researcher's role is therefore not simply to report participants' perspectives, but to interpret them in relation to the broader structural and social context in which they are situated.

This philosophical position is considered compatible with Braun and Clarke's (2022a, pp.169-170) reflexive thematic analysis, which acknowledges the active role of the researcher in constructing meaning from data, whilst retaining a commitment to producing rigorous and credible findings that reflect participants' experiences in a meaningful way. It also aligns with the broader social justice orientation of the present study, which seeks not merely to describe the current landscape of inclusion, but to contribute to an understanding of what more equitable and meaningful inclusion in climate activation might look like.



## **2.4 Study Design**

### ***2.4.1 Setting***

The research was conducted at a community day centre for people with learning disabilities in East-England. Details about the day centre have been withheld to protect the anonymity of the participants. The day centre offers a wide range of activities, clubs and trips that support the wellbeing and independence of their service users. Their service and its offer is based on their values stating that every individual has the right to lead a fulfilling, inclusive and independent life. The service further places a strong emphasis on collaborative and community-focused projects and aims to maintain a visible presence in the local community and support their service users to participate in research projects.

### ***2.4.2 Co-production***

The day centre has a long history of collaborating closely with the University of Essex as part of the Doctorate of Clinical Psychology second year module on Learning Disability. In the early stages of the planning of the project, the researcher arranged a visit to the day centre with the thesis supervisor to consult with a group of service users and staff members about the research. A group of service users volunteered to sit down and talk about the research topic and share their thoughts on it. The conversation introduced the topic of climate change, and the service users were asked about their opinions and perspectives. The service users expressed an interest in the topic and shared varied degrees of understanding, and towards the end it was

agreed that it would be helpful to carry out a research project about climate change, as it was felt that service users would likely have opinions on the topic and want to be involved in it. Additionally, the staff team agreed that it might be beneficial for the day centre and for its service users to build on the themes and ideas identified in this research to create their own project, with ideas about developing a resource or video. This initial consultation not only confirmed the relevance and accessibility of the research topic for this population but also shaped the decision to adopt a two-phase research design that would ensure participants remained actively involved throughout the process, from the generation of findings to their review and dissemination.

A key methodological decision that also emerged from this initial consultation concerned whether to provide participants with a brief introduction to climate change prior to each interview. During the consultation visit, service users demonstrated varied degrees of familiarity with the topic, with some participants appearing unfamiliar with the term climate change itself whilst others demonstrated a more developed understanding. This raised an important ethical and methodological tension requiring careful consideration.

Providing a briefing prior to interview risked introducing a degree of priming that could shape participants' responses, potentially compromising the naturalistic quality of the data and raising questions about whether subsequent accounts reflected participants' own pre-existing knowledge and views. However, proceeding without any introductory information risked a different and arguably more significant problem. For participants unfamiliar with the term climate change, attempting to conduct a meaningful interview without any shared grounding risked placing them in

a disempowering position, and was inconsistent with the accessible and inclusive ethos of the study. It also risked generating data that reflected confusion with terminology rather than participants' genuine perspectives.

Following reflection and discussion with the thesis supervisor, the decision was made to provide a brief, accessible description of climate change at the start of each interview. This was kept deliberately concise and informational rather than interpretive and was consistent across all participants. The aim was not to teach participants about climate change but to ensure all participants had access to a basic shared understanding before being invited to share their own views, consistent with guidance on accessible research methods with people with learning disabilities (Hollomotz, 2018; McFarland et al., 2024). The potential influence of the briefing on participants' responses is acknowledged as a limitation of the study and discussed further in the limitations section.

The research utilised qualitative methods to gain an insight into participants' understanding of and engagement with the climate crisis. In an attempt to encourage participants to take an active part and to regain some of the power in the researcher - researched dynamic, the principles of participatory action research were adapted and considered. Although it does not claim to be participatory action research, the project infuses some of the principles through consultation with the community studied, a feedback session to discuss the findings of the research and providing an accessible summary. Thus, the project had two phases: The main phase during which the research was carried out, the data was analysed, and themes were generated and discussed; and the secondary phase in which the findings were shared with

participants and feedback was gained on the themes generated, to see if it felt true to their experiences. During the feedback session it was also discussed with participants whether they wished to create a project based on the research. Following this the researcher provided a short and accessible summary of the research, as agreed with the participants, that was made available for the community day centre and the participants to inform a climate change project, that could be carried out independently of the researcher. Due to the constraints of the thesis submission timeline, the researcher was not able to be directly involved with the projects that followed.

## **2.5 Recruitment**

### ***2.5.1 Sampling***

As all participants attended the day centre, the research utilised voluntary and purposive sampling, which is encouraged when researching specific communities and populations to garner a greater depth of understanding (Palinkas et al., 2015).

Recruitment was supported by the managers and staff at the day centre, who shared information about the project in their weekly meeting with service users. Following this meeting they identified service users who were interested and eligible to participate. The researcher aimed to recruit between 12-15 participants for the study, to ensure sample size saturation as suggested for qualitative research by Hennink & Kaiser (2022), and in total fourteen participants were recruited.

### ***2.5.2 Inclusion/Exclusion Criteria***

Participants' suitability for the research was considered with staff from the day centre who had extensive knowledge of the service users and was based on the following criteria. An age limit was set so participants had to be over 18 years old. Participants about whom safeguarding concerns had been raised at the time of the study and/ or were experiencing emotional distress at the time of recruitment were excluded. This was to ensure their emotional safety and to not add any additional distress. Due to the nature of the interviews, participants needed to be able to communicate verbally and engage with the interview questions.

Lastly, participants' ability to take part were dependent on their cognitive abilities and their ability to give informed consent. Participants' capacity to consent to the research was guided and assessed by staff at the day centre prior to being approached by the researcher and invited to take part in the research. During the interviews, the researcher applied their clinical expertise to further assess each participant's capacity to consent. This was based on the Mental Capacity Act (MCA, 2005), which asserts that anybody aged 16 years old and over regardless of whether they have a learning disability has the right to make their own decisions wherever possible. It further states that a person must be assumed to have capacity unless established otherwise and that they are not to be treated as unable to make a decision unless all practicable steps to help them do so have been taken without success. In keeping with this principle, capacity was never assumed to be absent on the basis of a participant's learning disability alone. The researcher took practicable steps during the

pre-interview stage and the interview to support each participant's understanding and decision-making.

## **2.6 Measures**

### ***2.6.1 Study Overview***

As previously mentioned, the study was divided into two stages, and these are detailed later in the chapter. The research component of this project was largely contained within stage one, which used qualitative methods to explore the topic of climate change with people with learning disabilities and their abilities to engage with it. Stage two was developed with a community psychology and participatory action lens, to take the research findings back to the participant for their feedback and provide a platform from which they could decide what they wished to do with the findings.

### ***2.6.2 Interview Schedule***

One of the aims of qualitative research is to develop richer, more nuanced understandings of human experience. Semi-structured interviews are among the most widely used methods for achieving this goal. Although an interview schedule is simply a list of interview questions and related topics, planning and organising a successful interview depends on the researcher thinking deeply about the topics and questions to ensure they gather the information that is sought. In their opinion piece, Bearman (2019) suggests three steps to create and structure a successful interview schedule: (1) considering which core event or series of events illustrate phenomena of

interest, (2) ordering questions to optimise an intuitive and conversational flow and (3) refining the schedule through a series of review and piloting. These were considered when the interview schedule for this project was created, however their emphasis on open-ended questions and reliance on “conversational flow” had to be moderated slightly due to the varied conversational abilities of the participants. Thus, adaptive methods were employed to support participants’ different abilities and understanding throughout the interview, including close-ended follow-up questions, closer readings of contextual clues and using the images in the participant information sheet to remind participants of the topic (McFarland et al., 2024)

The central phenomenon of interest was participants' general understanding of climate change and their capacity to engage meaningfully with the topic, and an interview schedule was developed to reflect this (Appendix E). As discussed in Section 2.4.2, the decision to provide participants with a brief introduction to climate change prior to interview was made following the initial consultation and reflected both ethical and methodological considerations. To orient participants to the interview, the researcher began with a brief introduction and welcome to the study and reminded them of their right to withdraw at any point should they wish to do so. Next the researcher provided each participant with a simplified introduction of climate change. The introductory overview of climate change was standardised across all participants to ensure consistency and was delivered verbally by the researcher whilst being supported by the participant information sheet, which contained accessible images and simplified text on the subject. Where necessary, adaptations were made to suit individual participants' communication needs and levels of

understanding, for example by simplifying language further, repeating key points, or drawing participants' attention to specific images on the information sheet. This served to establish a shared foundational understanding across all participants, which could facilitate deeper discussion as the interview progressed. It also afforded the researcher an early insight into each participant's level of comprehension of the topic, enabling them to adapt their approach accordingly.

Five broad areas were explored through the interview questions: participants' general understanding of climate change; their emotional responses to it; their personal experiences of and engagement with the topic; their preferred methods of and experiences of learning about climate change; and their potential and actual involvement within their communities. Every section incorporated prompts designed to encourage participants to consider the topic from a variety of perspectives, including in relation to their own personal experiences of climate change, such as changes in weather patterns and local environmental initiatives. Throughout the interview, the researcher routinely monitored participants' comfort levels and sought verbal confirmation that they wished to continue. Each interview concluded with a debrief, during which the researcher checked in with participants regarding their wellbeing and outlined the subsequent stages of the research process, including analysis and write-up.

For the follow-up focus group meeting, a deliberately loose structure was developed (Appendix F). This encompassed a brief recapitulation of the study aims, a summary of the emerging findings, and a discussion regarding potential future directions. Rather than adhering to a rigid schedule, the conversation was guided



predominantly by interviewer prompts drawn from the information shared by participants, with the aim of eliciting their reflections and feedback on the research. The follow-up session concluded with a summary of the discussion, both to ensure that the researcher had accurately understood participants' responses, and to inform participants that they would receive an easy-read summary of the completed research project.

## **2.7 Procedure**

In the initial stages of the project, the thesis supervisor, who collaborated with the day centre as part of the University of Essex, Doctorate of Clinical Psychology Training Programme in the past, provided an email introduction to the service manager. An initial meeting was held with the day centre service manager and the community inclusion coordinator to discuss the scope of the project. As part of the arrangement of this, the researcher and thesis supervisor also met with service users for the initial consultation with experts by experience, as detailed in the co-production section above.

Following this the researcher provided the community inclusion coordinator with the easy-read information sheet, which they shared in the weekly service user meeting to gauge interest for the research and identify potential participants. If they wished, participants were encouraged to familiarise themselves with the information sheet in their own time. However, the researcher and community centre staff were available in case participants had any questions. After a cooling off period, those who expressed an interest in participating were contacted and an interview appointment

was arranged. Before the interview, the participants were provided with an easy-read consent form with which to familiarise themselves and was completed collaboratively with the researcher prior to the commencement of the interview. The staff at the community centre were also available to support the participant with the consent form and clarify where needed. The interview only went ahead once the researcher was confident the participant understood the information and could give informed consent. Both the interview and the follow-up meeting was conducted at the day centre to accommodate and make it more comfortable for participants, and to reduce attrition. As stated previously, this project had two stages which are detailed below.

### ***2.7.1 Stage One***

Stage one entailed the main part of the research, including the data collection and analysis. Semi-structured individual interviews were conducted to explore participants' understanding of climate change and climate related engagement. The interviews were audio recorded and the researcher also took notes during the interviews to supplement the recording (Appendix G). These notes served several purposes: capturing certain responses verbatim, particularly where participants had a speech impediment or other communication differences that might affect the clarity of the audio recording and risk important contributions being lost during transcription; recording non-verbal responses and contextual observations that would not be captured by the audio recording alone; and noting emerging analytical thoughts and reflections that could inform the subsequent analysis. The recordings were then analysed using reflexive thematic analysis.

### ***2.7.2 Stage Two***

Stage two followed once the data had been analysed and disseminated. The researcher and the community inclusion coordinator at the day centre initiated a focus group with participants. However, for accessibility the phrase “follow-up meeting” was used instead and details of it were shared with participants in the service user meeting. This was voluntary and described to participants as a chance for them to discuss the findings of the research and think of a future project based on the findings. Due to the informal nature of the follow-up meeting, it was not audio recorded. This decision was made deliberately in order to preserve the informal and participatory ethos of the session, as it was felt that the presence of recording equipment might have inhibited participants' contributions or altered the nature of the interaction. The researcher instead noted down the important points and reflections afterwards. It is acknowledged that the absence of an audio recording represents a limitation of the data collected during the follow-up meeting, as the researcher's notes necessarily constitute a partial and interpreted record of the discussion rather than a verbatim account. As such, the findings from stage two should be understood as reflecting the researcher's best attempt to capture the essence of participants' responses and reflections and may be subject to a greater degree of interpretive influence than the data collected during the recorded individual interviews in stage one.

## **2.8 Data Collection**

Data was collected through individual interviews, using semi-structured questions. The interviews lasted between 29-63 minutes. The duration of this was

subject to variation and moderation in response to the individual needs of each participant, for instance through the provision of breaks or by adjusting the length of the session accordingly.

### ***2.8.1 Transcription***

The interviews were audio-recorded via a one-sided Microsoft Teams meeting, with the camera disabled throughout. Although Microsoft Teams generates an automatic transcript, each audio recording was additionally uploaded to Microsoft Word, which produced a second, more accurate transcription. Both transcripts were used as reference aids as the researcher manually transcribed each interview. The speech was rendered in standard written form with the notation of paralinguistic features such as pauses, intonation, or overlapping speech (Johnson et al., 2025), see Appendix H for an example. This process of listening to the audio recordings whilst simultaneously checking the accuracy of the transcripts also served as an initial phase of familiarisation with the data, in line with the first stage of Braun and Clarke's (2006) thematic analysis framework.

The transcription process was further supported by the researcher's reflective and at times verbatim notes from each interview, which frequently provided contextual information and aided comprehension in instances where neither the transcript nor the audio recording yielded a sufficiently coherent account of what had been said. Each transcript was anonymised by assigning participants a numerical identifier, for example Participant 1, and so forth. Once each transcript had been

completed within a Word document, it was exported to an Excel spreadsheet to facilitate further analysis.

## **2.9 Data Analysis**

### ***2.9.1 Qualitative Methods***

There are many methods available to choose from when conducting qualitative research. One such option is grounded theory, which is a qualitative research methodology, originally developed by Glaser and Strauss (1967), in which theory is inductively generated from data rather than being established prior to data collection. Rather than beginning with a hypothesis to test, the researcher collects and analyses data simultaneously in an iterative process, allowing theoretical insights to emerge organically from the data itself (Charmaz, 1996). Grounded theory was not considered appropriate for the present study, as the primary aim was not to generate new theory, but rather to explore and describe participants' understandings of and engagement with climate change. Additionally, grounded theory's methodological requirements, such as theoretical sampling and collecting data iteratively until saturation is reached, would have posed practical challenges given the relatively small and specific participant group (Aldiabat & Le Navenec, 2018).

Another approach that was considered for this research was interpretive phenomenological analysis (IPA), which was developed in the UK in the 1990s (Eatough & Smith, 2017). IPA was not considered the most appropriate methodology for the present study for several reasons. Whilst IPA's focus on an individual's lived

experiences and meaning-making is a strength, its idiographic approach requires a detailed, case-by-case analysis of each participant before broader patterns are considered across the dataset. Given that the present study was concerned with identifying shared patterns of understanding and engagement with climate change across participants, rather than examining the depth of everyone's experience in isolation, this level of idiographic analysis was not deemed necessary. Furthermore, IPA typically employs very small, homogeneous samples, and its philosophical foundations in phenomenology represent a level of theoretical commitment that was not required for the purposes of the present study. Thus, Braun and Clarke's (2006) reflexive thematic analysis was considered more fitting for the present study for several reasons.

### ***2.9.2 Thematic Analysis***

Thematic analysis offers a robust and accessible method for qualitative analysis, that at its very basic level is a method for developing, analysing and interpreting patterns across a qualitative dataset. This involves a systematic process of data coding to develop themes (Braun & Clarke, 2022a, p.4). Thematic analysis is affectionately considered a *family* of methods. Unlike grounded theory and IPA, it offers a flexible and accessible analytical framework that is not bound to a specific theoretical tradition or epistemological position, allowing it to be applied across a range of research questions and contexts. Its emphasis on the researcher's active role in interpreting and constructing meaning from the data was also considered particularly appropriate given the nature of the present study, in which the researcher's

reflexivity and positionality were central considerations (Braun & Clarke, 2022b). Thus, thematic analysis is well-suited to the applied research questions explored in the present study, as it enables rich and meaningful descriptions of patterns across the dataset, without the requirement to generate new theory or conduct an in-depth analysis of each individual case. The interview transcripts were analysed using thematic analysis (Braun & Clarke, 2006) and the suggested six stage approach was used as a framework for the data analysis.

### ***2.9.3 Analysis***

The six phases of Braun and Clarke's (2006) reflexive thematic analysis were adopted to guide the analytic process. Although the following account presents these phases in an ordered and structured way, it is important to note that in practice the process of this analysis was not always linear:

#### **2.9.3.1 Phase 1: Familiarising Yourself with the Dataset**

This stage started during transcription as the researcher began to familiarise themselves with each interview whilst checking the accuracy of the transcripts. Following this the researcher read and re-read each transcript, making notes and highlighting areas of specific interest. The researcher also wrote a short summary of each interview in the reflective diary, particularly including impressions and contextual clues that may not be explicit in the data.

### **2.9.3.2 Phase 2: Coding**

The researcher worked through each dataset systematically to identify segments of data of potential interest or relevance and gave each a code label (see Appendix I for example). The researcher applied both semantic codes, describing explicit or surface meanings, and latent codes, describing more conceptual and implicit meaning. The researcher did this in an Excel spreadsheet by adding the semantic or latent code to the column next to each quote. The code labels were then collated on a separate sheet on the spreadsheet.

### **2.9.3.3 Phase 3: Generating Initial Themes.**

The code labels generated in phase two were then analysed to identify initial themes. This was an active process and was done in Excel where code labels that seemed to share core ideas or concepts were grouped and re-grouped to find broader shared meanings, generating candidate themes.

### **2.9.3.4 Phase 4: Developing and Reviewing Themes.**

To identify the final themes the researcher assessed the fit of the provisional candidate themes to the data and the viability of the analysis and made comparison with the full dataset. The researcher reviewed whether the themes highlighted the most important patterns across the dataset and in relation to the research questions. During this phase some candidate themes were discarded or collapsed together for a better fit, to identify the central organising concept of the themes.



#### **2.9.3.5 Phase 5: Refining, Defining and Naming Themes.**

This fine-tuning of the themes was experienced as a dynamic process that really took shape during the initial write-up which brought together the raw data, e.g. selected quotes, and the themes. To aid this process the researcher reflected on the core concept beneath each theme and how it contributed to the overall story of the data.

#### **2.9.3.6 Phase 6: Writing Up.**

The process of writing began considerably earlier than this phase might suggest and played a central role in integrating the research themes within the broader scope of the study. This process was further supported by regular thesis supervision sessions, during which emerging themes, ideas, and reflections were discussed and refined.

Following the data analysis, an engagement and planning meeting was offered to participants to share the themes identified by the researcher and to garner feedback. This engagement and planning meeting corresponds to stage two of the research design outlined in the procedure section above and represented the participatory dimension of the study in which the findings were taken back to participants for their reflection and feedback, in keeping with the community psychology principles underpinning the research. The information from the focus group is presented separately in the results section.

### ***2.9.4 Data Storage and Confidentiality***

Confidentiality refers to the researcher's obligation to protect the privacy of participants and the information they share, ensuring that any data collected is stored securely and is only accessible to those directly involved in the research process. All documents retained as part of this research, such as the completed consent forms and demographic information collected, were stored on a private password protected hard drive.

Participants were informed that the interview would be audio-recorded, and it was made clear that the recordings would be accessible only to the researcher, would be stored securely and deleted upon completion of the project. Transcripts were produced promptly following each interview, and all identifiable information was removed to ensure participant anonymity. The anonymised transcripts were subsequently stored securely on the researcher's password-protected hard drive, and plan to be deleted upon completion of the project. Raw data will be retained by the University of Essex for the duration of the project. All data management procedures utilised by this research are compliant with the EU General Data Protection Regulation (GDPR) and the UK Data Protection Act (2018).

## **2.10 Ethical Considerations**

As this research was carried out outside of the NHS, NHS ethics was not necessary. However, ethical approval was sought from the University of Essex before proceeding with the research, as had been done by previous students who have carried out research with the same community centre. Due to necessary considerations around

the participants' potential vulnerability, this research was subject to evaluation by an ethics sub-committee. The ethical approval from the University of Essex for this project was gained in January 2025 and the ethical number is ETH2324-1938 (Appendix J). Whilst the possibility of a follow-up meeting had been briefly noted in the original ethics application, it had not been sufficiently detailed or explored at that stage to fall within the scope of the original approval. An amendment was therefore sought to incorporate this component of the research, which was subsequently approved by the University of Essex ethics sub-committee in November 2025, ethical number ETH2526-0166 (Appendix K).

The local authority, as the commissioning body for the community centre, was also consulted with regards to the proposed research and their permission to proceed. They confirmed they did not operate their own ethical approval processes and would defer to the decision made by the University of Essex (Appendix L).

### ***2.10.1 Consent***

The ability to make a decision is an important consideration in research involving vulnerable populations (Mental Capacity Act, Code of Practice, 2007). When assessing a prospective participant's capacity to consent, researchers must consider several factors, including the presence of an impairment or disturbance that affects the individual's ability to think, whether this impairment is permanent, temporary, or fluctuating, the nature of the decision being made, and the timing of the decision. Importantly, capacity is not an all-or-nothing concept as an individual may have capacity to make certain decisions but not others, and capacity may vary across

time and context. In many research settings, it is the researcher themselves who is responsible for assessing capacity, and this assessment may need to be revisited at different stages of the project. Where capacity is in question, researchers are encouraged to take steps to enhance a prospective participant's ability to reach a decision independently. Such steps may include providing information in accessible formats, breaking down complex information into smaller components, allowing additional time for decision-making, adjusting the timing or location of the consent process, and encouraging discussion with trusted others such as family or friends. The Mental Capacity Act 2005 provides a framework to support researchers in forming a reasonable belief about whether an individual has the capacity to consent to participation (British Psychological Society, 2020)

Furthermore, researchers should remain mindful of the risk of stigmatisation and ensure that the dignity and autonomy of all participants are fully upheld throughout the research process. When working with vulnerable populations, for whom understanding may be more challenging, psychologists have a responsibility to ensure that participants are given sufficient opportunity to understand the nature, purpose, and anticipated outcomes of their involvement in the research, so that they are able to provide consent to the fullest extent that their capabilities allow. Wherever possible, methods that maximise the ability of vulnerable individuals to give informed consent, and that respect their agency and self-determination, should be employed (British Psychological Society, 2021).

The researcher created an easy-read participant information sheet (Appendix M) and an easy-read consent form (Appendix N), to accommodate participants and

make the information more accessible. To ensure participant understanding and informed consent, those who were deemed to meet the criteria for the research were provided with the information about the study by staff at the community day centre prior to contact with the researcher. At the start of each interview, the researcher offered to review and explain the participant information sheet with each individual. Whilst some participants welcomed and required this support, others demonstrated a sufficient understanding of the research and required less assistance. Only after having confirmed participants' understanding of the information sheet did the researcher move on to ask for consent to commence the interview. The researcher supported the participants to go through and complete the consent form as needed. Once the consent form had been completed, the audio recording was initiated. Participants' consent was reviewed throughout the interview; the researcher was particularly aware of any verbal or non-verbal cues that might indicate discomfort. If the researcher observed any signs of discomfort, anxiety, or distress, they would check in with the participant and offer the opportunity to end the interview if they wished to do so.

### ***2.10.2Risks***

The British Psychological Society states that an important consideration in psychological research is the potential of physical or psychological harm, discomfort or stress to human participants. Although it can be difficult to identify all potential risks to participants at the outset of the research, it is important that the researcher strives to identify and assess all possible risks and develops protocols for risk

management, and to ensure appropriate levels of ethical approval is sought (British Psychological Society, 2021).

Climate change is a topic that can produce feelings of distress due to the uncertainty and dangerous implications for human existence. As the research involved participants from a vulnerable population, careful consideration was taken with regards to the wording of questions, material used and the delivery of information. Specific terminologies were changed such as the phrases “climate emergency” and “climate crisis”, not because they are inaccurate or to deceive participants, but as they were deemed unnecessarily anxiety or fear provoking. It was agreed that, should a participant become distressed at any point during the interview process, the researcher would promptly notify a member of staff at the day centre.

Another risk mitigation measure involved working closely with community centre staff to identify participants who were not experiencing emotional or physical distress, or any safeguarding concerns, at the time of the research. This was intended to ensure that participants were not placed in an unnecessarily vulnerable position or caused undue distress as a result of their involvement in the study. All participants were offered the option to have a member of staff accompany them in the interview.

Out of the fourteen participants, one participant displayed signs of distress during their interview. This was towards the end of their interview and the participant clarified that their distress was not due to the nature of the topic discussed, but frustration with their own difficulties comprehending the topic. The participant had opted to have a member of staff with them in the interview, who consoled them and helped them articulate how they were feeling. Reassurance and an offer of terminating

the interview was provided, however the participant declined and requested a few minutes break before continuing and then completing the interview.

## **2.11 Evaluating the Research Quality**

Due to the flexibility and numerous variations of thematic analysis, creating a universal standard for evaluating and ensuring research quality is challenging. However, Braun and Clarke (2022a, pp.268-269) have provided guidance on how researchers can evaluate their own research based on 15-points across five processes: transcription, coding and theme development, analysis and interpretation, overall, and written report. The researcher utilised this checklist to assess the quality of the research, whilst bearing in mind the warning from Braun and Clarke (2022a, p.268) that it is only useful if accompanied by thoughtful engagement and understanding. As such they recommend the researcher supplements the checklist with reflexive journaling, allowing enough time for analysis, gaining insight from supervisors or peers, naming themes carefully, drawing inspiration from good, published examples and demonstrating quality through an 'audit trail'. This is discussed in further detail in the discussion chapter.

## **2.12 Dissemination**

Following the completion of the Doctorate in Clinical Psychology, this thesis will be available at the University of Essex online research repository. Upon completion of the study, participants will be provided with an easy-read summary of the research findings. Furthermore, the thesis has been accepted for presentation at the

British Psychological Society's Faculty for People with Intellectual Disabilities Annual Conference in April 2026. Lastly, the following journals have been identified as potentially appropriate for the publication of the thesis and will be considered in the future: The Journal of Environmental Psychology; The Journal of Intellectual Disabilities; British Journal of Learning Disabilities; Journal of Environmental and Sustainability Psychology; Journal of Applied Research in Intellectual Disabilities.

## **3. Results**

### **3.1 Chapter Overview**

This chapter provides an overview of the research findings. First a description of the participant characteristics will be provided to help contextualise the results. Following this the results from phase one and phase two are described. Phase one covers the process of data gathering through 14 individual semi-structured interviews with participants and the subsequent thematic analysis of the interview transcripts. The same participants were invited to take part in phase two which involved one follow-up meeting discussing a brief overview of the findings of the interviews, and any potential action or projects the participants wished to carry forward based on this discussion.



### 3.2 Participant Characteristics

The 14 participants were recruited from a community day centre for people with learning disabilities in the East of England, and an overview has been provided in Table 3. Participants' ages ranged from 25 to 75, with a mean age of 48 years old, this excludes one participant who did not remember their age and thus could not supply it. Out of the 14 participants, six identified their biological sex as male (43%) and eight identified their biological sex as female (57%). All identified their ethnicity as white-British. All participants were recruited from and were regular attendees of the community day centre. Despite the option being available, only one participant opted to have a support worker join them in the interview, the rest attended alone. Throughout the results section participants are referred to numerically (1-14) and personal information has been removed to protect their identities and maintain confidentiality. Furthermore, the gender-neutral pronouns 'they' and 'them' are used when describing participants.

**Table 3***Overview of Participant Characteristics*

| Participant number | Age          | Biological Sex | Ethnicity | Phase one | Phase two |
|--------------------|--------------|----------------|-----------|-----------|-----------|
| Participant 1      | 35           | Male           | White     | ✓         | ✓         |
| Participant 2      | 45           | Male           | White     | ✓         | ✓         |
| Participant 3      | 25           | Female         | White     | ✓         | ✗         |
| Participant 4      | 75           | Female         | White     | ✓         | ✓         |
| Participant 5      | 30           | Male           | White     | ✓         | ✗         |
| Participant 6      | 52           | Female         | White     | ✓         | ✓         |
| Participant 7      | 53           | Female         | White     | ✓         | ✓         |
| Participant 8      | 60           | Female         | White     | ✓         | ✗         |
| Participant 9      | 53           | Male           | White     | ✓         | ✓         |
| Participant 10     | 32           | Female         | White     | ✓         | ✓         |
| Participant 11     | 25           | Male           | White     | ✓         | ✗         |
| Participant 12     | Not reported | Female         | White     | ✓         | ✓         |
| Participant 13     | 50           | Male           | White     | ✓         | ✗         |
| Participant 14     | 33           | Female         | White     | ✓         | ✓         |

### 3.3 Phase One

In phase one of the project, individual semi-structured interviews were conducted with the participants, and these were analysed to identify themes in line with the research aim. A six-phase reflexive thematic analysis (Braun and Clarke, 2006) was used to identify themes and patterns of meaning across the dataset. This process was described in detail in the method chapter and involves familiarisation with the data, coding, generating initial themes, developing and reviewing themes,

refining, defining and naming themes and finally producing the report through the write up (Braun & Clarke, 2022a, pp. 35-36).

### ***3.3.1 Overview of Findings***

The majority of participants, bar one, shared that they had enjoyed the interview process and would be happy to speak about climate change again. One participant became upset towards the end of the interview and stated that this was due to the frustration felt with their own difficulty understanding the concept of climate change and clarified that the distress was not related to the topic of climate change itself. Despite this and offers to end early, the participant wished to complete the interview and instead utilised a few breaks to be able to do so.

People with learning disabilities often present with various communication difficulties, and as such the participants in this study often answered questions with short sentences or with “yes/no” responses. Given that part of the interview process involved the researcher clarifying participants' intended meanings, for instance by offering choices or reflecting back what had been said, the analytic process was similarly shaped by this dynamic. As a result, rather than relying on one or two extended quotations to illustrate a given point, the researcher draws upon a combination of shorter quotations and, where relevant, includes their own follow-up questions within the extracts, in order to more effectively highlight the themes. APA Style guidance states that when formatting quotations from research participants, quotations of fewer than 40 words should be presented in quotation marks within text, whereas quotes longer than 40 words should be presented in an indented block below

the text (American Psychological Association, n.d.). Due to the nature of the data the researcher deviates from this rule of presentation to accurately represent and capture the meaning of participants. When context was not needed for the quotes shorter than 40 words they are represented in text, however when context was needed, they are presented on a separate line with the researchers prompts. Finally, it is important to acknowledge that the analysis represents the researcher's perception and interpretation of the themes within the data.

Prior to the development of the project an initial consultation was held with attendees at the community centre to gauge their interest and potential knowledge of climate change. Staff at the community centre identified interested participants who were invited to attend, and an informal group was created on the day. The consultation lasted approximately 20-30 minutes and was not audio recorded; however, the researcher made some written notes for later reference. Based on the varied levels of knowledge displayed in the informal group the researcher decided to provide a brief description of climate change at the start of each interview. This was done to provide some common ground knowledge for all participants.

During the familiarisation and the coding process of the analysis it emerged that the participants were split into two categories – those who had some understanding of climate change and those who did not. Of the 14 participants, seven shared that they knew what climate change was before the interview and seven had not heard of it and did not know what it was. As the coding process progressed it became clear that the level of understanding of climate change varied significantly between participants, and was spread across a spectrum: at one end of the spectrum

there were those who did not know or understand the concept of ‘climate change’; in the middle those who associated climate change with weather changes and certain specific activities such as litter picking or gardening; and at the other end of the spectrum were those who had a more comprehensive or complex understanding of climate change, e.g. talking about biodiversity and government incentives. This was further developed into the first major theme, ‘Understanding climate change’, which detailed the variation of understanding and in knowledge, and has been illustrated in Figure 2. A second theme that emerged during analysis was about the information available about climate change and climate initiatives; how accessible these were and to what degree participants were interested in taking part in groups or activities specifically about climate change, and participant’s own perspectives on their lack of inclusion in these topics. A visual representation of the position of people with learning disabilities on the “outside” of climate discourse has been illustrated in Figure 3. In keeping with the accessible and participatory ethos of the study, easy read versions of both figures have been developed to ensure that the findings are presented in a format accessible to the participants themselves and to people with learning disabilities more broadly (see Appendix O and Appendix P). An overview of the themes and subthemes are presented in Table 4.

**Table 4***Overview of Themes and Subordinate Themes*

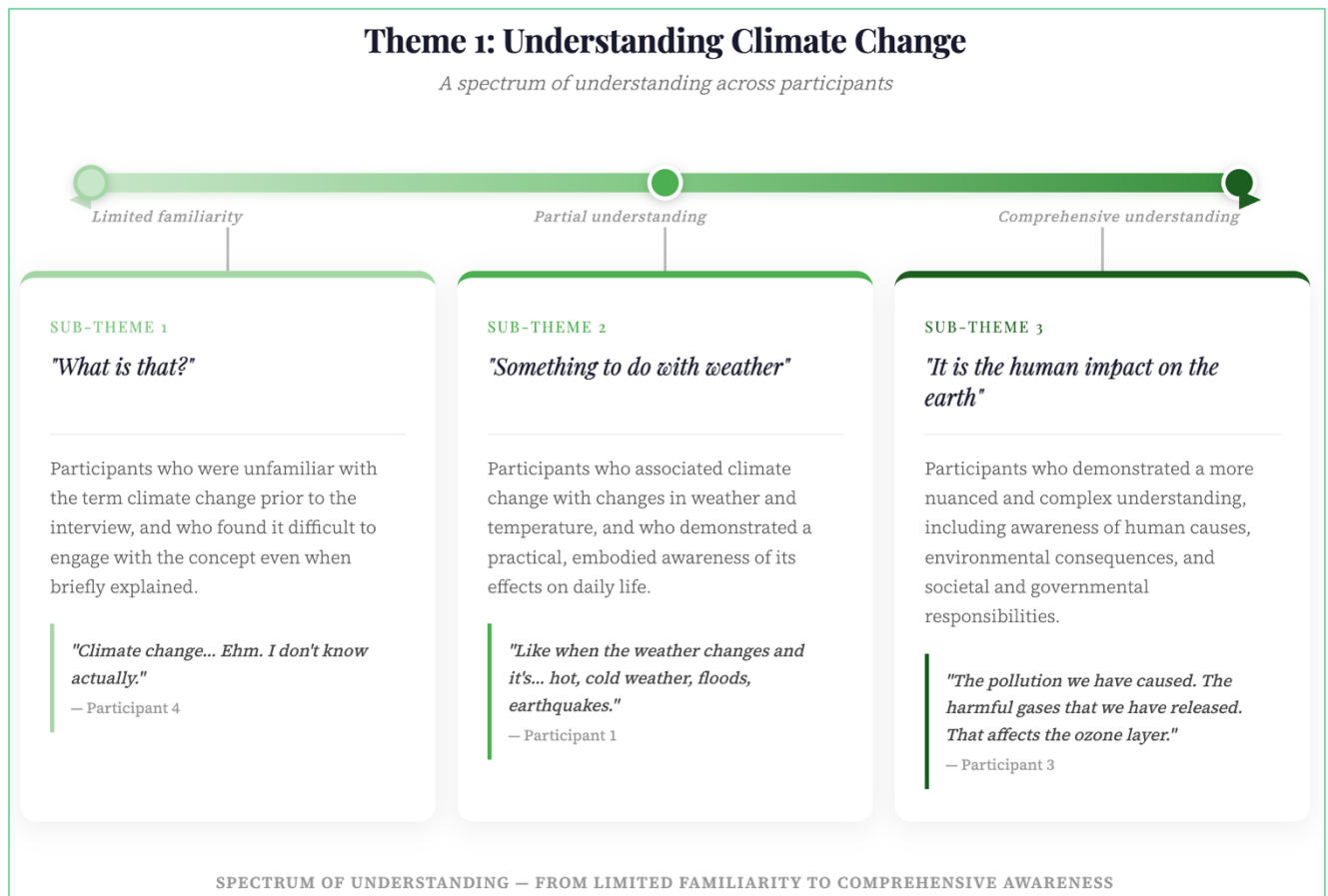
| Themes                       | Subordinate Themes                    |
|------------------------------|---------------------------------------|
|                              | “What is that?”                       |
| Understanding climate change | “Something to do with weather”        |
|                              | “It is the human impact on the Earth” |
| Inaccessible climate change  | “It’s on the news”                    |
|                              | “Come tell me about it”               |
|                              | “People think they don’t understand”  |

### **3.3.1.1 Theme One: Understanding Climate Change.**

A large part of the data reflected participants’ varied degree of understanding and sensemaking of the concept of climate change. Although half of the participants were relatively or totally unfamiliar with climate change, there were instances during the interviews where participants were noted to make associations between activities or topics related to climate change, without explicitly naming it as such. Theme one explored the different levels, or the spectrum, of understanding that emerged during analysis and the nuances within and overlap across them. This spectrum of understanding moves from one end to another, starting with “what is that?”, then moving onto what is noted as the middle point “something about the weather”, and finally to “it is the human impact on the Earth”.

**Figure 2**

*Illustration of Theme One*



**3.3.1.1.1 "What is That?"**

Some participants shared that they had never heard about climate change before, and some expressed curiosity about the term whereas others appeared ambivalent. Many of the participants who were unfamiliar with the concept of climate change found it difficult to engage with the concept whilst it was being briefly explained at the introduction of the interview or when asked about it straight after.

"Climate change ... Ehm. I don't know actually." (Participant 4)

*“I don't know and I can guess.” (Participant 5)* then when prompted further, the participant guessed it was about *“How to... be good.”*, and after another prompt added *“Listen carefully.”*

“What's climate change mean?” (Participant 7)

For some participants climate change remained a difficult concept to understand and as the interview progressed struggled to grasp the concept. Participant 14 highlighted how even after having been introduced to the concept of climate change it continued to be difficult to retain or understand.

Interviewer: Could you explain to me in your own words what climate change is? ... Well, would you be able to say what climate change is?

Participant 14: No, no.

Interviewer: So, we were just talking about it.

Participant 14: It's about the weather getting hotter or colder, yeah. And I can't possibly explain that.

Notably, despite many participants demonstrating evident difficulty engaging with the concept of climate change, even when explained in simplified terms relating to weather and weather changes, several went on to make spontaneous and relevant associations later in the interview, such as Participant 12 who shared that people could get involved through recycling *“They can, they can recycle milk bottles.”*



Another example of spontaneous association is presented in the conversation with Participant 11 below:

Interviewer: Is there anything else you can do to help with climate change?

Participant 11: I can help trees.

Interviewer: Can you help trees? How can you help trees?

Participant 11: I can plant trees. Yeah. I love garden as well.

Similarly, Participant 5's response to the same question showed clear association between climate change and with certain environmentally associated practical activities:

*Participant 5: That one (points to a picture of gardening).*

Interviewer: Help planting things?

Participant 5: Yeah.

#### ***3.3.1.1.2 "Something to Do with Weather."***

For many participants climate change was immediately associated with weather and the different kinds of weather that can be experienced. A number of participants who had initially indicated an unfamiliarity with climate change, and who were provided with a brief recapitulation of the introductory explanation, subsequently made connections between climate change and changes in the weather. These associations were particularly linked with the outside temperature.

“Yeah. Hot. Cold.” (Participant 10)

“When we get bad weather like winter.” (participant 7)

*“It's getting hotter.”* When further prompted stated *“It's getting cold.”*

(Participant 12)

“Like. When the weather changes and it's... that hot, cold weather, floods, earthquakes.” (Participant 1)

“Like when... like when it's really hot?” (Participant 9)

Many participants then naturally went on to speak about practical ways to stay safe and healthy during periods of extreme weather, for example drinking enough water and staying out of the sun during heatwaves.

“So trying to drink more fluid, but don't often. You might get dehydrated. I went to hospital a little while ago. They had to do bloods and stuff and look at the skin and jaundice.” (Participant 9)

“That's why you have to drink plenty of water to keep yourself hydrated.”

(Participant 7)

“The weather... you need to know what the weather is. Keep... keep covering with sun cream.” (Participant 4)

These responses suggest that whilst some participants may not have been able to articulate a technical understanding of climate change, they nonetheless demonstrated a practical and embodied awareness of its consequences, particularly in relation to the direct impact of extreme weather on their own health and daily lives. In this sense, personal safety knowledge can itself be understood as a form of climate change understanding, one that is grounded in lived experience rather than abstract conceptual knowledge.

#### ***3.3.1.1.3 “It’s the Human Impact on the Earth.”***

Several participants demonstrated a more nuanced and complex understanding of the concept of climate change. These understandings ranged from values based and action-oriented understandings such as displayed by Participant 6 below, to the personal and larger scale human impact on the climate, and to reflections on societal and governmental responsibilities.

“To save the planet” (Participant 6)

“I, when he's on my, I saw the icebergs melting.” (Participant 13)

“When you. Yeah, it's like it's warm. (...) Not when it gets so hot in Western humans, but when the atmosphere is sort of. (...) Yeah, stays in the people. (pause) No, not air, no more. But when it gets too muggy, there's no air, not me, I can't actually breathe and something.” (Participant 9)

“That's what we're doing to the Earth. (...) What we have done. (...) The pollution we have caused. The harmful gases that we have released. That affects the ozone layer that's caused a hole in it.” (Participant 3)

Participants also spoke about the current and future implications of climate change, e.g. health difficulties, resource inequality and potential for future loss of life. Many expressed concern for how animals and future generations would be affected if the climate continues to be exploited as it has been.

“The animals get tangled up in the nets and they'll just die and that will ruin the ecosystems.” (Participant 3)

“Well, the water. (...) Ehm. It's getting affected. (...) Well, people in other countries where you're... Yeah, you know they are drinking the wrong water. (...) They're not drinking. After hours, five hours, five hours. They forget to clean it.” (Participant 13)

“Yeah, yeah, yeah. But it's still a possibility for the next generation, like if you've got kids they have kids, you got (...) Got to think about what the next generation is gonna be like.” (Participant 3) When further prompted on what the potential consequences could be if climate conditions continue to worsen, they elaborated “Then a lot more people would die, and there'd be a lot more people poor in this world. Because they can't have water because of the droughts. You can always see it now, yeah.” (Participant 3)

Participants also spoke about governments needing to take more responsibility for climate change and needing to work together and put in place more initiatives to incentivise climate action. One participant particularly highlighted the bottle recycling scheme in Holland called ‘Statiegeld’.

“Like there are so many projects I think the government should... I'm like, I mean, dead bottles and hot weather. Like in Holland.” When asked to elaborate on government incentives Participant 9 further shared “It's a good idea for that or when you go back to the supermarket, you get lucky and you're bottling, you're going to get some like maybe 20p to 30p back per bottle or something.” (Participant 9)

This theme reflected the considerable variation in participants' knowledge and understanding of climate change as a topic. Whilst some participants were unfamiliar with the term prior to the interview and found it difficult to engage with throughout, others demonstrated a more developed awareness of the subject. Despite this variation

many still contributed interesting and unprompted associations, and described relevant ways they could take personal action, such as planting trees or gardening. Other participants had heard about climate change prior to taking part in the research, and whilst they did not have a technical or scientific understanding of it, they made clear associations between it and weather changes.

Many participants also spoke about the direct impacts that weather changes had on their lives and on those close to them, such as heatwaves being dangerous for people with asthma or breathing difficulties. Thus, they were able to engage with more tangible and personal aspects of climate change and potential areas they could get or were already involved, such as recycling and litter picking. Lastly, some participants showed a deeper understanding of the concept of climate change, and many had a knowledge of the reasons for climate change and some of the socio-political aspects of it, for example government responsibilities and future consequences. The subthemes described suggested that there are different levels to understanding climate change. Through their statements participants clearly displayed an interest in and ability to engage with the topic, even though their ability to engage with the abstract and more complex aspects varied significantly from participant.

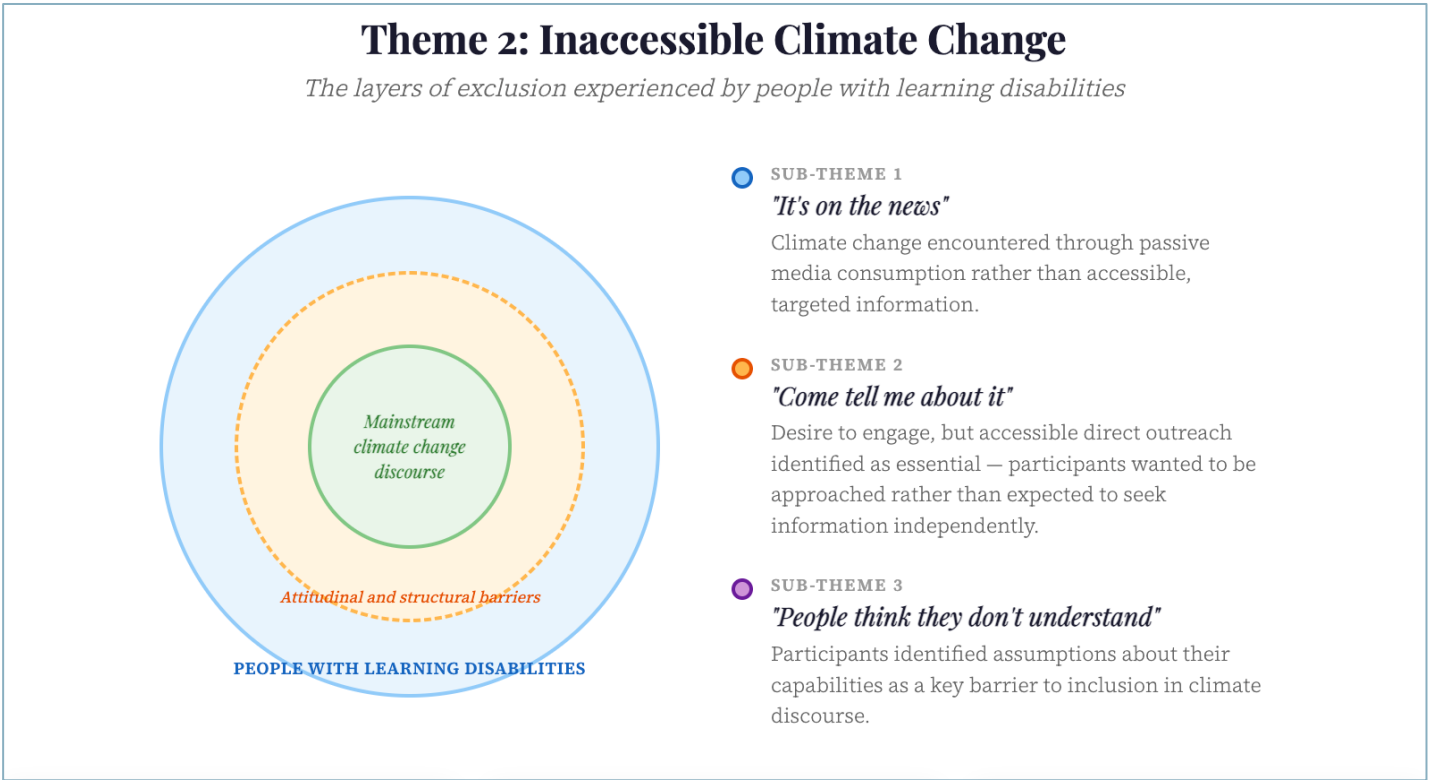
### **3.3.1.2 Theme Two: Inaccessible Climate Change.**

This theme explores the accessibility of information about climate change, as well as the extent to which initiatives that individuals or groups can engage with to address climate change are accessible to people with learning disabilities. Three subordinate themes were identified within this theme. The first, "It's on the news", considers the sources through which participants encountered and learned about

climate change. The second, "Come tell me about it", explores how participants wished to engage with climate action initiatives, and the extent to which they felt motivated to do so. The final subordinate theme, "People think they don't understand", examined participants' own perspectives on why people with learning disabilities have been, and continue to be, excluded from conversations about climate change.

**Figure 3.**

*Illustration of Theme Two*



**3.3.1.2.1 "It's on the news."**

Largely, participants who knew about climate change had heard about it via media outlets and cited this as their main source of on-going discourse about climate change. The most frequently mentioned of these was the news as described by

Participant 6, *“No. It says it in the newspapers. Yeah. It says it in there.”*, and by Participant 1 who shared, *“On the news. Yeah.”* and when prompted further elaborated, *“Both of them. Yeah. TV and radio, yeah.”*. Another often cited resource was the weather news as shared by Participant 2 *“On the news. On the weather.”*. Participant 9 also shared that their main source of information was the news and elaborated that they heard about it from world leaders, *“In the media, it’s in newspapers. On social media. And ehm... politicians in one of the worlds, lot of countries, some countries”*.

Participant 1 noted that climate change was a topic that was also shared on social media platforms but that it had to be actively sought out. *“You can read about it online, yet nothing... Facebook mainly, yeah.”*. Participant 3 described needing to do their own research as there was little discourse about it in everyday life *“You do a lot of your research, yeah. See it on Facebook sometimes if you're lucky.”*. Few participants reported discussing climate change with others. Participant 9, however, alluded to encountering the topic through a variety of channels, describing how they learned about it through newspapers and through general conversations with others. *“Newspapers. When people talk about it. People talking about it just in general.”* (Participant 9)

The level of engagement with this information varied from passively taking it in to actively seeking out more information. One participant shared that they had heard about David Attenborough’s documentary about the world’s oceans and marine life, ‘Oceans with David Attenborough’, *“David Attenborough did an epic film about the... the environment. It was to do with the all the oceans.”* (Participant 6). Despite



not having watched the programme themselves, Participant 6 shared that they knew it was important to save the oceans and wanted to learn more about it, *“Yeah, because of the pollution that they've been like, yeah, all the horrible stuff in the... in the oceans. Oil spills. So I want to look after them as well.”* This exchange illustrates a pattern observed across several participants, whereby engagement with climate change information was often passive and mediated through others rather than direct and self-initiated, with participants absorbing fragments of climate discourse through media and conversation without necessarily having the opportunity or means to seek out more detailed or accessible information independently.

#### ***3.3.1.2.2 “Come Tell Me About It”***

This subtheme explored participants' interest in getting involved in climate action and conversations, and thoughts on how this could be made more accessible to them. Generally, participants described really enjoying taking part in activities and groups and several had clear ideas of what they would like to learn more about and why. For some participants, learning about climate change represented an opportunity to develop a deeper understanding of its socio-political implications, whilst for others it offered a means of connecting with like-minded individuals on a topic that is rarely discussed.

“Guess to understand a bit more. Understand how the government should work with these countries that are doing all the pollution, trying to cut down the pollution down a bit more. Not some of these countries shouldn't (...) should work with the government to find solutions.” (Participant 9)

“Would be nice to talk to people to learn. Yeah, because sometimes you do feel quite alone. You know when you're the only one and you try to debate with your friends and they're not interested.” (Participant 3)

Many participants shared that they would be interested to learn more about climate change, but that accessing the information was a barrier to engaging with it and that it would be most helpful for someone to come and tell them about it. This was clearly expressed by Participant 10 when they said, *“To come in to tell me about it, yeah.”* as they felt that being approached directly would be more helpful than being expected to seek out opportunities independently. Participant 1 further described this when saying, *“Not really, I’d like someone to tell me about it. I know quite a lot about it ... it’s on the news you know (...) I don’t think I know about it, you know about it.”*, highlighting the inaccessibility of the information that is out there on climate change.

Participant 3 expanded on this point, describing the lack of accessible information as a barrier, noting that accessing such information was not as easy as it should be, and suggesting that dedicated support to be taught on the subject would be beneficial.

“Not as easy what it should be. You might see it in leaflets and might see it in photos yeah. There's good more could be done. It could be taught like (community centre). There could be a class about, yeah.” (Participant 3)

Whilst many participants felt uncertain about how they could get involved, Participant 9 articulated a clear vision for a project they would like to be involved in, one that would seek to improve the understanding of climate change among people with learning disabilities.

“Yeah. It's like if we did like a like the video. We got some come in one of the big wigs in a government or something similar next to them. And she sat down and talked to us and all that. It's like a little promo video or something like that.” (Participant 9)

One participant expressed enthusiasm about joining a group or activity and indicated a desire to be "helpful" to the researcher. However, it was unclear whether they had fully understood that the purpose of such an activity would be centred around climate action, and whether this would genuinely be of interest to them.

Participant 11: Yeah, sure. I don't mind. What? Why me? I can help.

Interviewer: I'm just checking if you're interested.

Participant: Yeah, of course. I don't mind. I don't mind.

Interviewer: Sounds like you like being involved in...

Participant 11: Yeah, I love things. I love things helping.

In contrast to those who expressed a desire to engage further with climate change, some participants indicated that they had little interest in actively

participating in climate action activities or groups, such as Participant 10 who responded “*No, not particularly*” when asked. A few described a feeling of helplessness and that there was nothing they could do to improve the situation that would make an impact, as detailed below in the conversation with Participant 13:

Interviewer: Would you like to learn more about how you can help with climate change?

Participant 13: No.

Interviewer: Why is that? Why wouldn't you want to?

Participant 13: Can't be bothered.

Interviewer: Yeah. Okay. Is there anything that you can do to help stop climate change?

Participant 13: There's nothing I can do except I don't know being in charge of the UN or whatever in who's in charge of it.

Interviewer: Oh, okay. So you feel there's nothing you can do.

Participant 13: No.

Interviewer: Because you're not one of the really top people like in the event?

Participant 13: That's one of the top people that helps... only the top people will sort it out.

Interviewer: Are there any small things that you can do to help reduce the impact on the climate?

Participant 13: I'm hoping it changes soon.

### ***3.3.1.2.3 “People Think They Don’t Understand”***

Whilst the question of inclusion had been a central concept from the outset of the research, this subordinate theme only emerged in its own right in the final stages of the data analysis. This theme addressed the felt sense participants shared that people with learning disabilities were not involved in climate change discourse when they often should be and that they often had valuable insights to share, as was highlighted in the conversation excerpt below from Participant 10:

Interviewer: Do you think people with learning disabilities are included in these conversations?

Participant 10: Not really.

Interviewer: No? Why do you think that is?

Participant 10: I don't know, to be honest.

Interviewer: No? Do you think if people with learning disabilities were to be included, do you think that would be helpful?

Participant 10: Yeah.

Interviewer: If someone was making like rules or guidelines.

Participant 10: Yeah.

Interviewer: Do you think people with learning disabilities should be asked about that?

Participant 10: Yeah, definitely.

Some participants further went on to describe what appeared to be a systemic and purposeful exclusion on a socio-political level when reflecting on why people with learning disabilities are not included in conversations about climate change, such as described by Participant 9: *“Because, I don't know really. I think the government don't really see us. The government don't seem to want (...) I don't think they want to know.”*

As is illustrated in the following interview excerpt, Participant 3 suggested that this exclusion stemmed from stigmatisation and assumptions made about the capabilities of people with learning disabilities. Furthermore, Participant 3 described how this created an additional barrier, suggesting that individuals may feel reluctant to put themselves forward and would instead prefer to be approached directly:

Interviewer: Do you think people... People with learning disabilities or disabilities are included in conversations about climate change.

Participant 3: Not really. Cause some people think they don't understand.

Interviewer: It's really difficult. It's difficult to be part of a change when you're not included in the...

Participant 3: No, cause some people think it's above them. People think “Oh they won't know anything about climate change”.

Interviewer: So they, they assume that people won't know, so they don't ask?

Participant 3: Mhmm (head nods)

Interviewer: OK. If someone was to. I don't know be making rules or making any preparations for climate change. Do you think it would be helpful for people with learning disabilities to be asked about it?

Participant 3: Yeah. Yeah, cause some people with learning disabilities don't just wanna put themselves forward sometimes. It's harder to put themselves forward as they want to be asked.

Similarly, Participant 13 suggested that people with learning disabilities were excluded from climate discourse because those with the power to enact change perceive the issue as time-sensitive and therefore do not prioritise the inclusion of others in these conversations:

Interviewer: Yeah. So we need to get everybody's view about it. (...) Do you think people with learning disabilities are asked about climate change?

Participant 13: No.

Interviewer: Why do you think they're not asked about that?

Participant 13: They don't want to ask about it. I don't think they're asked about it. Because they don't want to. They know this is "I've got to do this by a certain time."

Interviewer: They don't want to ask people about it.

Participant 13: Well, they would rather sort that out. Themselves.

Interviewer: They'd rather sort that out themselves. Do you think that's (...)

Do you think people with learning disabilities have opinions about climate change?

Participant 13: I think we do.

Additionally, and as can be seen in the excerpts above and in the one below from Participant 6, amongst those participants who demonstrated a greater awareness of climate change, there was a prevailing sense that people with learning disabilities were not being included in these conversations. Alongside this, however, there was also a strong feeling that, were they to be included, they would have meaningful contributions to make:

Interviewer: So if people were going to talk to you about it, you would find that OK?

Participant 6: Yeah.

Interviewer: Do you think people (...) If someone is going to ask your opinion on it, would you feel able to answer?

Participant 6: Yes.

In contrast to the views expressed by the majority of participants, Participant 14 felt that people with learning disabilities were already included in conversations about climate change. However, in keeping with the general consensus, they agreed that this inclusion should continue and be maintained:



Interviewer: Do you think people with learning disabilities are included in those conversations or not?

Participant 14: No

Interviewer: No, you don't think they're included or you think they are included?

Participant 14: Oh, included. They are included.

Interviewer: That's good. You think they should be included?

Participant 14: Yeah.

Whilst Participant 14's response offers an interesting counterpoint to the views expressed by the majority of participants, it is worth considering what this divergence might reflect. It is possible that Participant 14 had a different understanding of what inclusion means in practice, for example interpreting the general visibility of climate change in media and public discourse as a form of inclusion, rather than the active and meaningful participation in decision-making and conversation that other participants described as absent. Alternatively, it may reflect the variation in individual experience, whereby some people with learning disabilities have encountered contexts in which their views on topics such as climate change have been genuinely sought and valued. Either way, Participant 14's response does not undermine the broader pattern identified in this subtheme but rather serves as a reminder that the experience of exclusion is not uniform across all people with learning disabilities, and that

individual differences in experience and interpretation must be acknowledged within the synthesis.

To summarise, the second theme explored the ways in which climate change discourse is experienced as exclusionary and inaccessible by people with learning disabilities, examining both how participants encountered information about the topic and the extent to which climate action felt available and relevant to them. Most participants described a passive, mediated engagement with climate change through news and weather forecasts, and there was a general sense that climate-related initiatives were largely inaccessible and would be more meaningful if developed collaboratively with people with learning disabilities, rather than assuming that individuals would seek them out independently. Participants also reflected thoughtfully on their own exclusion from these conversations, identifying attitudinal assumptions about their capabilities as a key barrier, and expressing a clear desire to be approached and invited into climate discourse rather than being expected to put themselves forward.

### **3.4 Phase Two**

All fourteen participants who took part in the interviews were invited to join the feedback group, of whom nine agreed to participate. Attendance was highly dependent on whether participants were present at the day centre on the day the feedback session was held, and the five who did not take part were not in that day so it is unclear if more of the participants would have been interested in attending. It should be noted that as attendance at the feedback session was self-selecting in nature,

the views expressed during the discussion cannot be considered fully representative of all fourteen participants who took part in the original interviews. The feedback session was not recorded; however, the researcher took a few notes during the conversation and immediately afterwards to be able retain and reflect on the information shared.

Whilst this feedback session shares some parallels with the practice of participant validation, it is more accurately characterised as a form of respondent feedback and transparency practice. It should be noted that this feedback session was not intended to serve as a form of participant validation, as the researcher did not seek to modify the themes on the basis of the discussion. Rather than seeking participants' confirmation or disconfirmation of the themes as a measure of validity, the session was intended to honour participants' involvement in the research by sharing the findings with them and creating a space in which their responses and reflections could be heard. Thus, the session was informed and inspired by the underlying principles of community psychology research and participatory action research, rather than fully adopting the practice.

All participants had been informed and provided consent prior to the commencement of the session and were reassured that they could leave or stop the session should they wish to. The feedback session was loosely and informally structured in three sections; firstly the introductions in which the researcher set the scene and reminded participants of climate change and the purpose of the research; secondly, the researcher then went on to share the findings from the research and opened up for a discussion and reflections; and finally the researcher set the scene for

a conversation about whether there were any potential projects the participants and the community centre could take forward based on the research.

When sharing the findings the researcher started by explaining that the understanding of climate change was quite varied and shared the three different dimensions mentioned in the findings above, to which there was general agreement amongst the group. When it was mentioned that some people had been unfamiliar with climate change before the interview one participant mentioned unprompted that it was “*something to do with weather*”. This prompted a discussion about the impact of significantly hot and cold weather, and the precautions participants took such as “*wrapping up warm*” when it was cold and putting on sunscreen in the hot weather. When sharing the findings about the inaccessibility of climate change information, there was general agreement among the participants that climate change was difficult to understand and that it would be helpful to have someone speak to them about it. Many participants shared that they felt climate change information was accessible through the news and the weather, and some felt it was communicated in a way that was easy to understand, whereas others mentioned that the difficult language, particularly “*the jargon*” that is used around climate change can make it quite difficult to understand what is being said. Participants also agreed that they did not get taught enough about it, and that they were not told enough about it.

The conversation then moved to think about climate initiatives and climate action that people can take, and generally participants stated that they wanted to take part in some way but agreed that it was hard to know what to do and what was relevant. A discussion was had about the everyday things that people do that they

might not know are related to climate change, and when reminded of things they do daily, such as recycling, participants were able to name other activities. For example, participants spoke about reusing things, buying second-hand and vintage clothing, and one shared an example of a cafe they used to work at which reduced food waste by using used coffee beans to fertilise plants. One participant mentioned that they helped their carer with their recycling and rubbish, *“because that's useful to everyone”*. Several participants also spoke about using transportation alternatives to driving, listing a variety such as walking, cycling, and taking buses.

One of the things that was suggested to improve the inaccessibility of climate change information was having people come and talk with the participants about climate change, and some participants also suggested doing topical activities and groups. Many felt that this would make it a bit easier to understand. Another thing that was mentioned was potential for excursions to places, with one participant suggesting going to a news building to see where they do the weather and news reporting.

All the participants seemed to enjoy taking part in the discussion, and all spoke up or said something during the session. No one became distressed or upset by the topic, even when the discussion centred on the impact of climate change and the potential effects on quality of life. Towards the end of the focus group, the participants were reminded of the rationale behind the research, and particularly that people with disabilities are often not included in these conversations. Although it seemed like many had not previously considered that they were not generally

informed about or included in conversations about climate change, participants generally agreed with this and one stated “*oh... that is true*”.

It was agreed that participants will be provided with a short summary of the research, with information of the rationale for the research and the findings (Appendix Q). Many participants were excited about the prospect of having the information and a piece of documentation for what they had taken part in. Although participants were keen to get involved in climate action it was difficult to generate ideas around what they wanted to do. What was ultimately agreed on was that the in-house newsletter at the community centre, which some of the participants were actively involved in, would run a piece on or include something about climate change in it to increase awareness, and further projects could be carried out later should the participants or the community centre wish to do so.

### **3.5 Reflections**

To conclude the results chapter, it feels important to include some of the reflections the researcher had during the data analysis process and write-up. Whilst the researcher argues that the content and information provided by participants was rich and an important addition to an otherwise silent conversation, the richness looked somewhat different to that of “traditional” qualitative research. Due to the nature of the population group, which, as explored earlier in this chapter, offered a variation of types of responses and communication abilities, the researcher relied to a lesser degree on paragraph analysis and more on short or mono-syllabic responses and context clues from the interview. These clues were accessed by routinely checking the

transcripts in accordance with the audio recording of the interviews and by conferring with the notes taken in each interview, and reflections written down after. During the analytical process, the researcher frequently drew upon their own interpretations of the implicit meaning behind participants' accounts, and at times what remained unsaid. This at times felt uncomfortable, as the researcher was mindful of the risk of misrepresenting participants or inferring meaning that was not genuinely present in the data. Whilst these limitations are acknowledged, the researcher believes that the richness of the data lies not only in what was said, but in the contextual, relational, and embodied knowledge that participants brought to the interviews, and that the interpretive approach taken was both necessary and appropriate for capturing the depth and texture of their experiences.

## **4. Discussion**

### **4.1 Chapter Overview**

This chapter discusses the findings of this research and how they relate to the existing literature and theory and offers interpretations of these in light of the research questions. It then offers a critical reflection on the second phase of the research, which involved an informal focus group with participants. The discussion that follows situates these findings within the broader context of inclusion, participation, and the systemic exclusion of people with learning disabilities from important societal conversations. It further suggests that the evidence gathered here has implications not only for climate research and activism, but for how researchers, clinicians, and

policymakers think about the capacity and right of people with learning disabilities to participate in and contribute to public discourse more broadly. Finally, the chapter ends with the researcher's personal reflections, and a summary highlighting the study's contributions and significance.

## **4.2 Research Aims and Summary of Findings**

The primary aim of this research was to qualitatively explore people with learning disabilities' interest in, and ability to engage with, conversations around climate change. The purpose of this was two-fold: firstly, to explore the perspectives of people with learning disabilities on the climate crisis, and their understanding of it; secondly to understand if and how people with learning disabilities might want to be involved in conversations and actions to help with climate change. In doing so, this study sheds light on an area of research that is otherwise largely overlooked within climate and disability research.

Participants were recruited from a community day centre. Fourteen took part in phase one of this research which entailed individual interviews. Nine of these then went on to take part in phase two, participating in an informal feedback group to discuss the findings of the research and to think of ways they might want to get involved, or projects they might want to carry forward after the research had ended.

Reflexive thematic analysis was used following this phase to analyse the interview transcripts. From this, two overarching themes, and six subordinate themes were identified in relation to the research aims above. Through these themes it became clear that participants were able to engage in conversations about climate



change at different levels of understanding and complexity. These levels were divided into three stages, from little to no understanding of climate change, to some knowledge and making clear associations with weather specific phenomena, and finally to having a grasp on more abstract and complex ideas, such as pollution and protecting ecosystems. The second group of themes identified related to how accessible climate change is as a concept and covered three topic areas; where participants heard about it, if and how they might want to engage with it in the future, and why they thought people with learning disabilities were not included in these conversations. Throughout the interview process it was clear that participants were willing to and able to engage with conversations about climate change, but that flexibility and adaptability was necessary to support them to do so at their level of ability.

### **4.3 Interpretation of Findings**

Given the paucity of existing research at the intersection of climate change and learning disability, the discussion that follows necessarily draws on a broader range of literature than is conventional in a doctoral thesis. Rather than situating the findings within an established body of directly comparable research, it draws on adjacent theoretical frameworks and empirical work from the fields of disability studies, community psychology, climate communication, and health inequalities to contextualise and interpret the findings as fully as possible.

### ***4.3.1 Theme One: Understanding Climate Change***

This theme captured how varied participants' ability to engage with and understand the topic of climate change was. This variation was organised across a spectrum of understanding, illustrated in Figure 2 in the results section, from little to no familiarity with the concept to a more complex and comprehensive awareness of its causes and consequences. The following sections describe the three subthemes that together map this spectrum of understanding: "What is that?", "Something to do with the weather", and "Human impact on the Earth."

#### **4.3.1.1 “What Is That?”**

As illustrated in the results, some of the participants had never heard about climate change before and struggled to retain the brief descriptions or reminders provided during the interview. Whilst this might initially appear to suggest a fundamental limitation in participants' ability to engage with the topic, it is argued here that this interpretation risks conflating unfamiliarity with inability, a distinction that is central to the social model of disability and to the inclusive ethos underpinning this research (Oliver & Barnes, 2012, pp. 17-18; Reeve, 2019). The difficulty participants experienced in engaging with climate change as an abstract concept is consistent with the broader literature on the exclusion of people with learning disabilities from complex societal and potentially distressing conversations, which, as discussed in the introduction, has historically been justified on the grounds of presumed inability rather than demonstrated evidence of it (Tuffrey-Wijne & Rose, 2017; Milner & Frawley, 2019). Whilst there is likely to be some variation in

participants ability that may be linked with their cognitive or communicative abilities, it was not the case in this research that those participants who presented with a more profound learning disability thus had poorer knowledge of, or ability to engage with, climate change. From a community psychology perspective, the absence of prior knowledge is more meaningfully understood as a reflection of structural exclusion, specifically the failure of climate discourse to be communicated in accessible formats and directed towards this population, than as evidence of individual deficit. This interpretation is supported by the finding, noted in the results, that several participants who were initially unable to define or engage with the concept of climate change went on to make spontaneous and relevant associations later in the interview, such as identifying recycling and tree planting as ways to help.

This suggests that the knowledge and awareness required to engage meaningfully with climate change may already exist in some form for many people with learning disabilities, but that it is not connected to the language and framing through which climate change is conventionally discussed. The recognition that climate knowledge takes many forms is not a new area of inquiry. Embodied community knowledge encompasses lived experiences, tacit knowledge, and intergenerational transmission, with indigenous communities having long modelled and championed this relational and place-based understanding of the natural world. These forms of knowledge arise from socially situated practices where activities and their purposes are meaningfully connected to the lives of participants and have been proposed as an alternative approach to making climate change more accessible to the general population (Donkers, 2022). The implication is that with appropriate

scaffolding, accessible communication, and deliberate outreach, the gap between this latent awareness and meaningful participation in climate discourse may be considerably smaller than a surface reading of the findings might suggest.

#### **4.3.1.2 “Something to Do with Weather”**

For many participants the term climate change was closely associated with weather and weather changes, with several making immediate and confident connections between the concept and their own direct experiences of temperature extremes, floods, and seasonal shifts. Rather than framing this as a limited or partial understanding, it is argued here that this represents a distinct and valid form of climate knowledge, one that is grounded in lived and embodied experience rather than abstract scientific or political framing. This distinction is theoretically significant, as it challenges the implicit assumption that understanding climate change requires fluency in the technical and policy-oriented language through which it is most commonly discussed, and suggests instead that people with learning disabilities may engage with climate change through a different but no less meaningful epistemological register. This is consistent with Devine-Wright's (2013) argument that place attachment is one of the strongest predictors of climate change engagement, and that individuals engage most readily with climate change when it is connected to places and experiences that are personally and emotionally meaningful to them. This suggests that the weather-based associations described by participants in this study represent not a limitation of understanding, but a legitimate and potentially powerful foundation for deeper engagement with the topic.

This grounding in personal and local experience can be understood as both a potential barrier to, and a meaningful entry point for, engagement with climate change. As a barrier, an exclusively weather-focused understanding may make it more difficult for individuals to connect their personal experiences to the broader systemic and political dimensions of climate change, such as the role of fossil fuels, governmental responsibility, or global inequality, which require a degree of abstraction that moves beyond the immediately observable. However, as an entry point, the personal and tangible nature of weather-based associations offers a powerful and ready-made foundation from which deeper engagement with climate change could be cultivated, particularly if information and activities were designed to begin with participants' existing experiential knowledge and build outward from there. This is consistent with community psychology principles of starting where the community is (Riemer et al., 2020, pp.4-6), and with the broader argument that accessible and inclusive climate communication should be grounded in the lived realities of the people it seeks to engage rather than in the technical lexicon of climate science and policy.

It is also worth acknowledging a contextual factor that may have shaped the specific nature of participants' weather-related associations. The interviews were conducted during the summer, a period during which the United Kingdom was experiencing notably hot weather. It is possible that this temporal context made temperature and heat particularly salient for participants and may have influenced the frequency and nature of the weather-related associations they made. Whilst it would be speculative to draw firm conclusions from this observation, it is noted here in the

spirit of methodological transparency and raises an interesting question about the extent to which climate change understanding and engagement may be situationally activated by immediate environmental experience, a phenomenon that could itself be a productive avenue for future research.

#### **4.3.1.3 “Human Impact on the Earth”**

Several participants demonstrated a significant and sophisticated level of knowledge about climate change, articulating awareness of its human causes, environmental consequences, and the responsibilities of governments and individuals to respond. This theme challenges the assumption that people with learning disabilities may be unable to meaningfully engage with climate change due to a lack of understanding or ability, as many participants demonstrated a significant level of knowledge about the topic and were able to articulate this clearly. Instead, it supports a social model of interpretation, which suggests the apparent absence of climate knowledge among some participants is understood not as a lack of ability but as a predictable consequence of structural disablism in the form of exclusion from accessible information and discourse (Reeve, 2019, p. 44). The depth and breadth of understanding demonstrated by participants in this subtheme is particularly significant given that, as established in the systematic literature review, people with learning disabilities are routinely excluded from conversations considered too complex for them to engage with (Tuffrey-Wijne et al., 2010; Wiese et al., 2013), and climate change is rarely if ever communicated in formats designed to be accessible to this population. Addressing this gap is not without solutions; Watfern and Carnemolla (2025) suggest that utilising inclusive communication tools such as social stories or

easy read formats might be helpful and practical steps to improve access to climate change discourse.

That several participants were nonetheless able to engage with the topic at this level of sophistication once again suggests that the barriers to engagement are informational and structural rather than cognitive, and that with appropriate access to accessible and inclusive climate communication, the contributions of people with learning disabilities to climate discourse could be considerably greater than is currently assumed. One might question whether these participants may have actively sought out information about climate change or perhaps been exposed to it via their family members or carers. An alternative interpretation is that there may be adequate information available out there for people with learning disabilities, but only some individuals seek this out. However, the evidence suggests otherwise. Climate change communication presents significant accessibility challenges even for the general population, relying heavily on technical jargon, abstract scientific framing, and emotionless registers that create barriers to engagement regardless of cognitive ability (Coombs Fine, 2022; Guenther et al., 2023). If the general population struggles to engage meaningfully with climate information in its current form, it is reasonable to suggest that these barriers are likely to be considerably more pronounced for people with learning disabilities, for whom this kind of language and framing presents additional and well-documented challenges. The variation in knowledge observed across participants in this study may therefore reflect not individual differences in motivation or information-seeking behaviour, but the uneven and largely inaccessible landscape of climate communication itself, within which some individuals will

inevitably encounter more accessible entry points than others through chance rather than design.

This theme highlighted the depth of knowledge demonstrated by some participants, as well as the breadth and sophistication of their thinking on the subject. One participant highlighted the responsibility of the government to establish initiatives that incentivise climate action, making specific reference to bottle return schemes operating in Holland and Scandinavian countries. Notably, in January 2025 the UK government announced plans to introduce such a scheme, namely the Deposit Return Scheme. Set to begin in October 2027, this will offer consumers a financial incentive to return single-use bottles and cans to local collection points, for example in supermarkets (Department for Environment, Food & Rural Affairs, 2025). The fact that a participant with a learning disability independently identified and articulated a policy solution that the UK government subsequently adopted serves as a striking illustration of the central argument of this thesis, namely that people with learning disabilities are not only capable of engaging with climate change but have informed, relevant, and valuable perspectives to contribute to the conversations and decisions that will shape the collective response to the climate crisis.

It is also worth noting that the variation in climate change understanding observed across participants in this study is unlikely to be unique to people with learning disabilities. Research consistently indicates that knowledge and engagement with climate change varies considerably across the general population, with many individuals demonstrating limited, partial, or misconceived understandings of its causes and consequences regardless of intellectual ability (Yang et al., 2020; Pew



Research Center, 2016). What distinguishes the experience of people with learning disabilities is not the variation itself, but the assumptions that accompany it. Whilst limited climate knowledge in the general population is rarely interpreted as evidence of an inherent inability to engage with the topic, the same variation in people with learning disabilities risks being read through a deficit lens, as confirmation of a presumed incapacity rather than as a reflection of differential access to information and opportunity. This double standard is significant, as it suggests that the exclusion of people with learning disabilities from climate discourse is not justified by evidence of their inability to engage, but is instead driven by assumptions that are applied selectively and inequitably to this population. Furthermore, whilst the general population is not typically expected to demonstrate a particular level of climate knowledge before being considered a legitimate participant in climate conversations, it may be that people with learning disabilities face an implicit threshold of understanding that must be met before their inclusion is considered appropriate or worthwhile. This may represent a form of epistemic injustice, in which the knowledge and perspectives of a particular group are systematically devalued or dismissed not because of their content but based on assumptions about the group itself (Fricker, 2007).

Taken together, the three subthemes within theme one paint a nuanced and compelling picture of the relationship between people with learning disabilities and climate change understanding. Whilst the level and nature of that understanding varied considerably across participants, what is consistent across all three subthemes is that participants were willing and able to engage with the topic in ways that were

meaningful, relevant, and at times sophisticated. The variation observed may not just reflect differences in capacity but also differences in exposure, access, and opportunity. This pattern is directly relevant to the second overarching theme, which explores the structural and attitudinal barriers that have prevented people with learning disabilities from accessing climate change information and participating in climate discourse. If the first theme establishes that the knowledge and capacity for engagement exists within this population, theme two begins to explain why that capacity has remained largely left out, and what would need to change for people with learning disabilities to be genuinely and meaningfully included in conversations about one of the most pressing issues of our time.

#### ***4.3.2 Theme Two: Inaccessible Climate Change***

Following on from the first theme, the second theme explores the structural and attitudinal dimensions that limit engagement. As illustrated in the concentric circles diagram presented in the results section (See Figure 3), the findings of this theme suggest that people with learning disabilities occupy a position on the periphery of mainstream climate discourse, separated from it not necessarily by inability but by a series of overlapping and mutually reinforcing barriers. These barriers are informational, communicative, and attitudinal in nature and not unique to climate change. Instead, they are consistent with the broader pattern of exclusion from complex societal conversations documented in the systematic literature review and discussed in the introduction chapter. These barriers include, but are not limited to, a lack of accessible communication, assumptions about ability or resilience and a lack

of flexible and adaptive approaches tailored to people with learning disabilities.

However, the specific context of climate change, with its reliance on jargon, abstract future scenarios, and predominantly expert-led discourse, likely make these barriers more pronounced and consequential. Particularly given the disproportionate impact that climate change may have on people with learning disabilities.

The three subthemes that follow address how participants encountered climate change information, how they wished to engage with it, and their own reflections on why people with learning disabilities are excluded from climate discourse.

#### ***4.3.2.1 “It’s on the News”***

For most participants, climate change was something they encountered through mainstream media, primarily the news and weather forecast, and often passively. The close relationship between these two sources is itself interesting and is consistent with the finding in theme one that many participants associated climate change primarily with weather and weather changes. For participants whose understanding of climate change was grounded in observable weather phenomena, it is perhaps unsurprising that the weather forecast represented their most accessible and familiar point of contact with the topic, as it provided a tangible and locally relevant framing of climate-related information that connected directly to their lived experience.

However, whilst mainstream media represents a point of contact with climate change for many participants, it raises important questions about the accessibility and adequacy of this as a primary or sole source of information. Mainstream news and weather coverage is not designed with the diverse communication needs of people

with learning disabilities in mind, and the language, pace, and format of broadcast media may present significant barriers to comprehension for many individuals within this population. This is consistent with the broader literature on health information accessibility, which has consistently found that people with learning disabilities face significant barriers in accessing information that has not been specifically adapted for their needs, and that individually tailored information is considerably more likely to meet their specific requirements (Drozd et al., 2021; Mattock et al., 2020). The reliance on mainstream media as the primary channel through which climate change reaches people with learning disabilities therefore raises a fundamental question about equity of access, namely whether it is reasonable to expect people with learning disabilities to independently seek out and navigate information that has not been designed with their needs in mind.

This question becomes particularly pressing considering the absence of accessible climate change resources from major national and international organisations. As noted in the introduction, despite longstanding recommendations that climate information be made accessible to diverse populations, organisations such as the United Nations do not currently provide easy-read versions of their key climate communications or policy documents. This gap is significant, as it suggests that the inaccessibility of climate change information for people with learning disabilities is not merely a practical oversight but reflects a deeper failure to recognise this population as a legitimate and intended audience for climate discourse. It is worth noting that the question of whether mainstream media is designed with diverse audiences in mind extends beyond people with learning disabilities and connects to

broader debates about the accessibility and inclusivity of climate communication across socioeconomic, cultural, and educational lines (Pearson et al., 2017; Stamm et al., 2000; Yang et al., 2020). However, for people with learning disabilities, whose communication needs are both more specific and more consistently overlooked, this failure is important to note and its consequences particularly significant.

The implication is not simply that more accessible information is needed (though it clearly is) but that the absence of such information is itself a form of structural exclusion that actively positions people with learning disabilities as outside the intended audience for climate discourse. This is consistent with the community psychology perspective underpinning this thesis, which argues that barriers to participation reflect limitations in systems and structures rather than deficits within individuals (Prilleltensky, 2001). This also ties in with the social model of disability, which locates the problem of exclusion in the design of the environment rather than in the characteristics of the person (Reeve, 2019; Shakespeare, 2013). Addressing this structural gap would require not only the production of accessible climate information in easy-read and other adapted formats, but a fundamental shift in how climate communicators and organisations conceptualise their audience. Moving from an implicit assumption of a uniform and scientifically informed public towards a genuinely inclusive model of communication that starts from the diverse needs and existing knowledge of the communities it seeks to engage.

#### **4.3.2.2 “Come Tell Me About It”**

Many participants expressed a clear desire to engage with climate change and climate action but described the inaccessibility of information and the absence of

direct outreach as significant barriers to doing so. The name of this subtheme, which is drawn directly from a participant's own words, captures something important about the nature of this barrier. Namely that it is not a lack of interest or motivation that prevents engagement, but often it is a lack of accessible routes into the conversation. This finding contradicts assumptions that people with learning disabilities are disinterested or indifferent to climate change and instead suggests that the problem is located within the design and delivery of climate communication and outreach.

A particularly striking observation within this subtheme was that some participants described actively engaging in climate-related behaviours on a routine basis, such as recycling, growing fruit and vegetables, and reducing food waste, without being aware that these activities were connected to climate change or to environmental sustainability more broadly. This finding is analytically significant for several reasons. Firstly, it suggests that the gap between people with learning disabilities and climate action may be smaller in practice than the absence of formal climate knowledge might imply, and that meaningful climate engagement may already be occurring within this population. However, these actions may not be recognised as such, either by participants themselves or by the wider climate community. It also raises an important question about how climate action is defined and measured. If conventional approaches to assessing climate engagement rely on individuals' ability to explicitly connect their behaviours to a named concept such as climate change or sustainability, then people with learning disabilities may be overlooked as climate actors, their contributions rendered invisible by a framework that does not prioritise embodied and practical action.

This connects to the broader argument developed in theme one, that experiential and place-based knowledge represent a valid and meaningful form of climate engagement that is grounded in lived reality rather than scientific or political framing. The everyday climate actions described by participants can be understood as a form of existing community knowledge and practice that climate communicators and organisations could build upon, rather than starting from an assumption of ignorance or disengagement. As Devine-Wright (2013) argued, engagement with climate change is most effectively cultivated when it begins from what is personally and locally meaningful to individuals, and the practical, everyday behaviours already present in participants' lives represent precisely this kind of meaningful foundation.

The preference expressed by many participants for being approached and invited into climate conversations, rather than being expected to seek out information independently, is also consistent with the broader literature on inclusion and participation in research and public discourse involving people with learning disabilities. As discussed in the introduction, Booth and Booth (1996) argued that barriers to participation reflect limitations in research and communication methods rather than deficits within individuals. The findings of this subtheme extend this principle to the specific context of climate engagement, suggesting that the responsibility for bridging the gap between climate discourse and people with learning disabilities lies with communicators, organisations, and policymakers rather than with the individuals themselves. The implication is that a small investment in accessible outreach, whether through easy-read materials, community-based climate activities, or partnerships with organisations already working with people with

learning disabilities such as community day centres, could yield an increase in meaningful engagement from a population that is at present almost entirely absent from the climate conversation.

#### **4.3.2.3 “People Think They Don’t Understand”**

The third and final subtheme within the second theme is perhaps the most theoretically significant of all the findings in this study, as it moves beyond describing the barriers participants face and into participants' own critical analysis of why those barriers exist. As described in the results, participants demonstrated a clear awareness that people with learning disabilities are routinely excluded from conversations about climate change. Furthermore, they were able to articulate the attitudinal assumptions that underpin that exclusion with a lot of insight. The fact that participants could not only identify their own exclusion but explain its mechanisms, namely that others assume they will not understand and therefore do not ask, is itself a powerful refutation of the deficit assumptions that have historically justified their exclusion (Langdon et al., 2025; Milner & Frawley, 2019; Tuffrey-Wijne & Rose, 2017).

This finding invites a direct reflection on the assumptions that informed the early stages of this research. Prior to beginning the study, several questions were held about whether climate change would prove too distressing a topic for people with learning disabilities to engage with; whether participants would be able to meaningfully engage with the concept at all; and whether they would have any interest in taking part in these conversations. The findings of this subtheme, and indeed of the study as a whole, suggest that each of these concerns, whilst raised in good faith and in keeping with the tendency towards protection that has characterised



much research ethics involving vulnerable populations, reflected the kind of assumptions that participants themselves identified as the source of their exclusion. In this sense, the research process itself became a site of reflexive learning, in which the researcher's initial assumptions were challenged and revised by the evidence gathered from participants.

This raises a broader and important question that sits at the heart of the present study: are people with learning disabilities being systematically underestimated, or are people from the general population being simultaneously overestimated? As noted in the discussion of the first theme, research consistently indicates that climate change knowledge and engagement vary considerably across the general population, with many individuals demonstrating limited or partial understanding of its causes and consequences. The general population is not, however, subjected to the same scrutiny or assumptions about their capacity to engage, nor is their inclusion in climate discourse made conditional on demonstrating a sufficient level of understanding. The selective application of capacity-based assumptions to people with learning disabilities, whilst leaving equivalent limitations in the general population unquestioned, reflects a form of systemic bias that is both ethically problematic and practically counterproductive. This bias can result in the exclusion of a population that, as this study has demonstrated, has both the interest and the ability to contribute meaningfully to climate conversations.

It is also important to acknowledge, however, that the picture is not uniformly one of foiled engagement. Several participants expressed a genuine sense of hopelessness in relation to climate change, feeling that the scale of the problem was

beyond their influence and that meaningful action was reserved for those in positions of power. This experience of climate-related hopelessness or helplessness is not unique to people with learning disabilities and has been extensively documented in the broader climate psychology literature under concepts such as climate anxiety, eco-distress, and climate fatalism (Taylor, 2022, p. 151; Runkle et al., 2025). However, for people with learning disabilities, who already experience significant marginalisation and reduced agency across many domains of their lives, this sense of powerlessness may be particularly acute and particularly difficult to address without sustained and meaningful opportunities for genuine participation and influence. This may be further compounded by the finding that climate change progressively degrades the natural environments that are known to provide psychological protection and restoration, creating an additional indirect pathway through which climate change affects mental health and wellbeing (Dillman-Hasso, 2021). This underscores the importance of not only making climate information accessible to people with learning disabilities, but of creating genuine opportunities for their involvement in climate action and decision-making in ways that are empowering rather than tokenistic.

Moreover, this information needs to build on the existing knowledge, values, and motivations that this study has shown to be present within this population. Particularly as there is research suggesting that supporting people with their climate related emotions and helping them to move toward hopeful engagement, is beneficial both for them and for the health of the planet (Betro', 2024; Ward, 2026)

Ultimately, the findings of this subtheme, and of theme two, suggest that people with learning disabilities are not absent from climate discourse because they

lack the capacity, interest, or knowledge to participate. They are absent because the systems, structures, and attitudes that shape climate communication and action have not been designed with them in mind. Furthermore, they are excluded because assumptions about their abilities often take the place of direct inquiry into their perspectives. As Participant 3 observed with striking clarity, people assume that climate change is above them and that they will not know anything about it. The evidence gathered in this study suggests that this assumption is not only inaccurate but actively harmful; also, that addressing it is both a moral imperative and a practical opportunity for the climate movement to engage with a community whose voices, perspectives, and everyday climate actions have gone unheard and unacknowledged.

#### **4.4 Phase Two Reflections**

Although the possibility of providing the community centre with the research findings to inform a project of their own making had been briefly considered during the planning stage, this research does not claim to qualify as participatory action research. Phase two emerged partly from practical considerations arising during the data collection process but evolved into something that felt both methodologically and ethically important in its own right and is therefore worth reflecting on in some depth here.

Whilst collecting the interviews it became apparent that expecting participants to engage for a prescribed length of time was unrealistic, particularly given that climate change was a topic with which some participants had little to no prior familiarity. Interview durations varied considerably across participants, and it became

clear that the length of a participant's contribution was shaped not by the depth or quality of their engagement but by a range of factors including their prior knowledge of the topic, their communication style, and their capacity to sustain concentration over time. This observation raises a broader and important methodological question that is rarely asked explicitly in qualitative research involving people with learning disabilities, namely whether the value of a participant's contribution should be judged by their ability to engage for a particular length of time. To apply such a criterion uncritically is to privilege a particular model of research participation that is implicitly designed around the abilities and communication styles of non-disabled participants, and that sits in direct tension with the accessible and inclusive ethos that this research sought to embody.

It is also worth noting that the participant whose interview was longest was the only participant to become emotionally dysregulated during the research process. Whilst their distress was attributed to frustration with their own difficulty comprehending the topic rather than to the subject matter itself, as described in the results section, it is worth reflecting on whether the length of the interview may have been a contributing factor to their experience of distress. This is noted not as a criticism of the participant but as a reflexive observation about the potential costs of applying standardised expectations of research participation to a population whose needs and abilities vary considerably and unpredictably.

These reflections point towards a broader argument about what inclusive research practice with people with learning disabilities requires in terms of flexibility, adaptability, and a willingness to interrogate the assumptions embedded in

conventional research design. If the goal of inclusive research is to genuinely capture the perspectives of people with learning disabilities in a way that honours their contributions and respects their needs, then the formats and criteria through which that research is conducted must be designed with those needs in mind from the outset, rather than being adapted as an afterthought when the standard approach proves unworkable. The doctoral training context in which this research was conducted presents particular challenges in this regard, as the structural requirements of a professional training programme may not always sit comfortably alongside the flexible and responsive approach that genuinely inclusive research demands. This tension is acknowledged here not as a criticism of the training context but as an unresolved dilemma that future researchers and training programmes working with marginalised populations may benefit from reflecting on and addressing explicitly.

## **4.5 Adaptations, Dilemmas and Ethical Considerations**

Several ethical questions arose for the researcher throughout the process of designing and conducting this study, and it is worth reflecting on these honestly as they illuminate some of the tensions inherent in conducting research with people with learning disabilities within a conventional academic framework.

One of the central methodological adaptations made in this study was the decision to provide participants with a brief standardised introduction to climate change at the start of each interview. This decision was made on the basis of the initial consultation with service users, which revealed considerable variation in prior knowledge of the topic, and was intended to ensure that all participants had access to

a shared foundational understanding before the interview began. Whilst this adaptation was made with good intentions and in the spirit of accessibility, it raises an interesting ethical question about the extent to which providing information prior to data collection may have influenced participants' subsequent responses. In conventional qualitative research this might be considered a form of priming that risks compromising the authenticity of participants' accounts. However, in the context of research with people with learning disabilities, withholding accessible information about the topic in order to preserve methodological purity would itself represent an exclusionary practice, effectively penalising participants for a lack of prior exposure to information that had never been made accessible to them in the first place. The decision to provide the introduction is therefore defended here not as a methodological compromise but as a necessary and ethically justified adaptation that reflects the accessible and inclusive values of the research.

A related dilemma concerned the use of closed and leading questions during the interviews. As described in the methods chapter, the varied communication abilities of participants meant that the researcher frequently needed to offer choices, reflect responses back, or suggest possible answers in order to support participants to express their views. Whilst these adaptations were necessary and appropriate given the communication needs of participants, they inevitably raise questions about the degree to which responses were shaped by the researcher's prompts rather than generated independently by participants. This tension is acknowledged honestly here and is consistent with the reflexive observations made at the end of the results chapter. It is argued, however, that the alternative, namely, to rigidly adhere to open-

ended questioning in a way that left participants unable to engage or express themselves, would have been both methodologically and ethically worse, producing either silence or disengagement rather than the rich and varied data that the adapted approach yielded. The ethical principle at stake here is one that runs throughout this thesis, namely that the responsibility for creating the conditions for meaningful participation lies with the researcher rather than with participants, and that adapting the research process to meet the communication needs of the participants, is not a concession to methodological rigour but an expression of it.

## **4.6 Implications of This Study**

### ***4.6.1 Clinical Implications***

The findings of this study have several implications for clinicians and practitioners working with people with learning disabilities. Fundamentally, they suggest that climate change is a topic that people with learning disabilities are both interested in and capable of engaging with, and that clinicians should not assume otherwise. As the systematic literature review established, people with learning disabilities are routinely excluded from conversations considered too complex or distressing for them to engage with, and the findings of this study suggest that climate change has been treated in a similar way, with assumptions about inability acting as a barrier for genuine inquiry into participants' perspectives (Tuffrey-Wijne & Rose, 2017). Clinicians working with people with learning disabilities, such as clinical psychologists and other health professionals, are well placed to challenge these

assumptions in their practice and to create opportunities for people with learning disabilities to engage with climate change in accessible and supported ways.

Further implications of these findings relate to how clinicians recognise and respond to climate-related distress in people with learning disabilities. Several participants in this study expressed a sense of hopelessness and helplessness in relation to climate change, reflecting a pattern that has been documented in the broader population under concepts such as climate anxiety and eco-distress. Whilst this literature has grown considerably in recent years, it has not yet engaged meaningfully with the specific experiences of people with learning disabilities, who may be particularly vulnerable to the psychological impacts of climate change given the additional marginalisation and reduced agency they experience across many domains of their lives (Emerson & Baines, 2011). This distress may be further impacted by the lack of consistent, clear and accessible information, which risks creating uncertainty and ambiguity for people with learning disabilities at a time when clarity and reassurance may be particularly important. Clinical services should be equipped to recognise and respond to climate related distress in this population in accessible and appropriate ways.

This study also speaks directly to the role of psychologists in addressing climate change more broadly. Whomsley (2021) identifies five distinct roles for psychologists in responding to the climate crisis, including changing human behaviours that contribute to climate change, fostering human connection with the natural world, advising on governance and leadership, providing psychological support for those affected by climate change, and preparing communities for



adaptation. Whilst this framework was not developed with people with learning disabilities specifically in mind, it provides a useful structure for thinking about the particular responsibilities of clinical psychologists working with this population. As a group that is both disproportionately affected by the health consequences of climate change (Emerson & Baines, 2011; Marmot et al., 2020) and systematically excluded from the conversations and actions designed to address it (Watfern & Carnemolla, 2025), people with learning disabilities represent a population for whom psychologists have a specific and largely unrecognised responsibility. Clinical psychologists are well placed to advocate for the inclusion of this population in climate discourse, to develop and deliver accessible psychological interventions for climate related distress, and to contribute to the growing body of research on the intersection of disability, climate change, and mental health. The findings of this study suggest that this is not only a clinical responsibility but a social justice imperative, consistent with the broader values of community psychology and the commitment to working alongside marginalised populations that underpins the present research.

Community day centres and other learning disability services could play an important role in incorporating climate change into their programmes of activities and community projects, using the accessible and participatory model demonstrated in this study as a template. The newsletter project initiated by participants at the end of phase two of this research offers a small but meaningful example of what community-led climate engagement might look like in practice, and services should be encouraged to build on and develop similar initiatives in partnership with the people they support.

This is consistent with the NHS Long Term Plan's commitment to improving the health and wellbeing of people with learning disabilities through greater community inclusion and participation (NHS England, 2019).

Finally, the findings reinforce the broader clinical principle that accessible communication is not an optional adjustment but a fundamental requirement of good practice with people with learning disabilities. Under the Equality Act (2010), healthcare and social care providers are legally required to make reasonable adjustments to ensure that people with disabilities can access services and information on an equal basis with others, and the findings of this study suggest that this obligation extends to the provision of accessible information about climate change and its health impacts.

#### ***4.6.2 Political Implications***

The findings of this study have direct implications for climate policy and the design of climate initiatives at local, national, and international levels. People with learning disabilities represent a significant proportion of the population and are likely to be disproportionately affected by the consequences of climate change, yet their perspectives are almost entirely absent from climate policy discussions. Health inequalities experienced by people with learning disabilities are likely to be exacerbated by the health impacts of climate change, including increased exposure to extreme heat, air pollution, and the mental health consequences of environmental disruption (Marmot et al., 2020). Addressing this requires not only that climate policy takes account of the specific vulnerabilities of people with learning disabilities, but

that people with learning disabilities are actively included in the policy conversations through which responses to climate change are designed and implemented.

The United Nations Convention on the Rights of Persons with Disabilities establishes the right of people with disabilities to participate in public and political life on an equal basis with others (United Nations, 2006). Whilst this study does not argue to be representative of the whole learning disability population, the findings of this study suggest that this right is not currently being upheld in the context of climate discourse, and that meaningful steps are needed at both national and international levels to address this gap. Organisations such as the United Nations, the UK government, and local authorities should be encouraged to produce easy-read versions of their key climate communications, policies and initiatives, as the current absence of such materials represents a significant and unjustifiable gap in accessible public communication.

The findings also support the case for including people with learning disabilities as experts by experience in the design and delivery of climate initiatives, in the same way that they are increasingly included in NHS interview panels and as co-facilitators of professional training programmes. The participant in this study who independently identified the bottle return scheme as a policy solution illustrates vividly the value of including this population in policy conversations and serves as a concrete and compelling example of the contribution that people with learning disabilities are able to make when invited to participate.

### ***4.6.3 Activism Implications***

The findings of this study have implications not only for clinical practice and policy but for the climate movement itself. Suggesting that the climate movement has a responsibility to examine its own inclusivity and to ask whether its campaigns, communications, and organising strategies are designed in ways that are accessible and inclusive. Current climate information is largely inaccessible (Coombs Fine, 2022; Watfern & Carnemolla, 2025), which represents both a missed opportunity and an ethical failure on the part of a movement that claims to speak on behalf of all people and future generations. In keeping with the community psychology principle that meaningful change requires the active involvement and leadership of those most affected by the issues being addressed (Riemer et al., 2020), climate activists and organisations should actively seek to include people with learning disabilities in their campaigns and initiatives rather than treating them as a passive audience or risk not considering them at all.

Though this would require effort through the development of accessible climate resources, and outreach such as community groups and engagement strategies. This study suggests that people with learning disabilities can be engaged and are motivated, if they are simply approached and invited in. Procedures like these are consistent with the community psychology principle that barriers to participation reflect limitations in systems and methods rather than deficits within individuals (Booth & Booth, 1996). A relatively modest investment in accessible outreach, whether through easy-read materials, community-based climate activities, or partnerships with organisations already working with people with learning disabilities,

could yield an increase in meaningful engagement from a population that is currently almost entirely absent from the climate conversation.

The concept of climate justice, which argues that the impacts of climate change fall disproportionately on the most marginalised and vulnerable communities, should be extended explicitly to include people with learning disabilities (Chávez et al., 2008). Their exclusion from climate discourse is itself a form of injustice that the climate justice movement should be willing to name and address, and the development of disability-led climate activism, in which people with learning disabilities are supported to design and lead their own climate campaigns and projects, represents an important and as yet largely unrealised opportunity. The Capabilities Approach, discussed in the introduction to this thesis, provides a useful framework for thinking about what this might look like in practice, arguing that meaningful inclusion requires not only the removal of barriers but the active cultivation of the capabilities that enable people to engage in socially valued roles and activities on their own terms (Shinn, 2015). In this sense, the implications of this study extend beyond the specific question of climate change and learning disability and speak to the broader and enduring question of what genuine inclusion requires of the systems, organisations, and movements that claim to speak for everyone.

## **4.7 Limitations**

One limitation that warrants reflection concerns the relational context in which the interviews were conducted. Participants were recruited from a community day centre where they had established relationships with staff and with each other, yet the

researcher was largely unknown to them prior to the interviews. Hollomotz (2018) argues that researchers working with people with learning disabilities are likely to elicit richer and more authentic responses when they have taken time to establish a relationship with participants prior to data collection. This may provide the researcher with valuable familiarity with a participant's communication style, preferences, and ways of expressing themselves, which can significantly enhance the quality and depth of the data gathered. In the present study, the researcher had limited prior contact with participants beyond the initial consultation visit, and it is possible that a more extended period of familiarisation, perhaps through attendance at day centre activities or informal conversations prior to the interviews, would have enabled participants to feel more comfortable and communicate more freely. This is acknowledged as a meaningful limitation, and future research in this area would benefit from incorporating a more substantial relationship-building phase prior to data collection, even where this presents practical challenges within the constraints of a doctoral training programme.

A second and related limitation concerns the potential influence of the information provided to participants at the start of each interview. As described in the methods chapter, a standardised introduction to climate change was provided to all participants, accompanied by the participant information sheet which included images representing climate change and climate action. Whilst this was a necessary and ethically justified adaptation intended to establish a shared foundational understanding across participants, it is possible that the specific images and language used in this introduction inadvertently shaped the associations and responses that

participants subsequently made during the interview. For example, the prominence of weather-related imagery may have contributed to the frequency with which participants associated climate change with weather, and it is difficult to determine with certainty the extent to which this association reflected participants' pre-existing understanding or was influenced by the framing of the introduction. This is an inherent tension in accessible research design that may never be fully resolved, but future studies might consider using a wider range of images and a more open-ended introductory format to minimise the risk of inadvertently directing participants' responses.

Conversely, and perhaps paradoxically, a third limitation is that participants may have been able to engage more fully and give more varied responses if they had been provided with a richer array of creative and visual resources during the interviews themselves. The present study relied primarily on verbal communication, supplemented by the images in the participant information sheet, as the medium for data collection. However, there is a well-established body of literature suggesting that creative and participatory methods, including the use of photographs, drawings, objects, and other visual or tactile materials, can significantly enhance the ability of people with learning disabilities to express complex thoughts, feelings, and experiences that may be difficult to articulate verbally (Aldridge, 2007; Nind & Vinha, 2016). It is possible that the use of such methods in the present study would have enabled participants to engage with the more abstract dimensions of climate change in ways that verbal questioning alone could not fully support and may have produced a richer and more varied dataset. Future research in this area might therefore

consider incorporating a broader range of creative and multimodal methods alongside or in place of conventional interviewing, both as a means of enhancing accessibility and as a way of generating forms of data that more fully reflect the diversity of participants' knowledge, experiences, and perspectives.

The sample was drawn entirely from a single community day centre in East England, which limits the transferability of the findings to other settings and service contexts. Participants who attend a community day centre may differ meaningfully from those who do not access such services, and future research should seek to recruit from a wider range of settings, including supported living and community environments, to capture a more diverse range of perspectives.

Another significant limitation concerns the ethnic composition of the sample, as all fourteen participants identified as White British. The perspectives of people with learning disabilities from global majority ethnic backgrounds, who may face additional and intersecting barriers to climate engagement arising from the combined effects of disability, ethnicity, and structural racism, are entirely absent from the findings. This is acknowledged as an important gap that future research should seek to address.

The inclusion criteria, which required participants to communicate verbally, meant that people with more significant learning disabilities who use alternative or non-verbal communication are not represented in the findings. This is a limitation shared by much qualitative research in this area, and developing methodologies capable of capturing the perspectives of this group remains an important priority for future research.



As discussed earlier in this chapter, the interviews were conducted during a period of notably hot weather in the United Kingdom, which may have influenced the nature of participants' weather-related associations with climate change. Additionally, the research was conducted during a period of heightened public discourse about climate change, and participants' awareness of the topic may have been shaped by this broader context in ways that may not be generalisable to other time periods.

The study focused exclusively on the perspectives of people with learning disabilities and did not incorporate the views of staff, carers, or family members. Whilst this was a deliberate choice that reflects the aim of centring participants' voices directly, future research might adopt a more holistic design that incorporates multiple perspectives whilst ensuring that the voices of people with learning disabilities remain central.

Finally, the exploratory and descriptive nature of the study means that the findings generate hypotheses and directions for future research rather than definitive conclusions. The novelty of the research area, whilst a strength in that it breaks new ground, also means that the findings cannot yet be fully situated within an established body of knowledge, and it is hoped that future research will build progressively on the contributions made here.

## **4.8 Evaluating Research Quality: Braun and Clarke's Fifteen-Point Checklist**

As noted in the methods chapter, Braun and Clarke (2022a, p.269) provide a fifteen-point checklist for evaluating the quality of reflexive thematic analysis across

five domains: transcription, coding and theme development, analysis and interpretation, the written report, and overall quality. In keeping with their caveat that this checklist is only useful when accompanied by thoughtful engagement rather than mechanical application, the following section reflects honestly on the quality of the present study against each of these domains, acknowledging both its strengths and its limitations.

#### ***4.8.1 Transcription***

The transcription process in this study was carried out carefully and systematically, with each interview audio recording manually transcribed by the researcher using two automated transcripts as reference aids. An orthographic approach was adopted, rendering speech in standard written form with the notation of some paralinguistic features to provide context or nuance to responses, such as when the participant nodded in response to a question rather than confirming verbally. Whilst this decision was appropriate given the aims of the analysis, it is acknowledged that some nuance in participants' communication, including tone, hesitation, and non-verbal expression, may have been lost in the transcription process. The researcher's interview notes were used to supplement the transcripts where the audio recording or automated transcription was unclear, particularly in instances where participants had speech differences that affected the clarity of the recording. This multi-layered approach to transcription is considered a strength of the study, and the process of manually checking each transcript against the audio recording served as an important early stage of familiarisation with the data.

### ***4.8.2 Coding and Theme Development***

Coding was conducted systematically and iteratively across the full dataset, with both semantic and latent codes applied to identify surface and conceptual meanings within participants' accounts. The use of an Excel spreadsheet to organise and group codes into candidate themes enabled a transparent and traceable analytical process, providing a partial audit trail of the decisions made during theme development. Codes were reviewed and revised across multiple passes of the data, and candidate themes were tested against the full dataset before being finalised. It is acknowledged, however, that the coding and theme development process was conducted by a single researcher without independent verification, which represents a meaningful limitation on the rigour of this stage of the analysis. Whilst peer debriefing through supervision sessions partially mitigated this limitation, the absence of a second coder means that the thematic structure reflects one interpretive perspective rather than a collaboratively verified account of the data.

### ***4.8.3 Analysis and Interpretation***

The analysis sought to move beyond descriptive summary towards interpretive engagement with the data, drawing on the theoretical frameworks of the social model of disability, community psychology, and critical realism to develop themes that offered insight into the structural and attitudinal dimensions of participants' experiences rather than simply cataloguing their responses. The researcher remained mindful throughout the analytical process of the risk of over-interpreting or misrepresenting participants' accounts, particularly given the communication

adaptations employed during the interviews, and this concern is reflected in the reflexive observations included at the end of the results chapter. The decision to draw on contextual clues, non-verbal responses, and interview notes alongside the transcripts in interpreting participants' accounts is acknowledged as an interpretive choice that introduces a degree of researcher subjectivity into the analysis and is defended here on the grounds that it was both necessary and methodologically consistent with the reflexive and inclusive approach of the study.

#### ***4.8.4 Written Report***

The written report seeks to present the findings in a way that is transparent, accessible, and analytically coherent, using participants' own words as the primary evidential basis for the themes identified. The decision to deviate from APA Style guidance on quotation formatting, as explained in the results chapter, was made in order to represent participants' contributions accurately and in a way that preserved the relational and communicative context in which they were produced. The use of shorter quotes and interviewer prompts within extracts, whilst unconventional, is argued to be more faithful to the nature of the data than the presentation of decontextualised extended quotations would have been. The inclusion of visual representations of the themes, namely the spectrum diagram for theme one and the concentric circles diagram for theme two, was intended to enhance the accessibility and clarity of the findings for the reader, and to reflect the participatory and inclusive values of the research in the presentation of its outputs.

#### ***4.8.5 Overall Quality***

Overall, the present study demonstrates a number of the markers of quality identified by Braun and Clarke (2022a, pp.268-275), including a clearly articulated and consistently applied theoretical framework, a transparent and iterative analytical process, a reflexive awareness of the researcher's positionality and its influence on the research, and a commitment to representing participants' voices with accuracy and respect. The limitations identified elsewhere in this chapter, including the single researcher design, the adapted interview format, and the homogeneity of the sample, are acknowledged as meaningful constraints on the rigour and transferability of the findings. However, it is argued that these limitations are largely inherent to the specific challenges of conducting qualitative research with people with learning disabilities within the constraints of a doctoral training programme, and that they do not fundamentally undermine the credibility or value of the findings. The supplementary quality assurance measures employed throughout the research process, including reflexive journaling, regular supervision, careful cross-referencing of data sources during transcription, and the phase two feedback session in which participants were given the opportunity to respond to the findings, together provide a reasonable basis for confidence in the trustworthiness and integrity of the analysis.

#### **4.9 Researcher Reflections**

The process of conducting and writing-up this research has been at different times very challenging, very rewarding and all-consuming. As I begin to reflect on

this process as a whole and the end of this professional milestone, I am left thinking about the personal and professional impact this has had.

Throughout this project I have been mindful of my position towards climate change discourse. It is not a topic I stumbled upon by accident nor one that I feel neutral towards. As a Norwegian citizen I grew up surrounded by forests and fjords and within a culture that places a strong emphasis on the importance of being outdoors and appreciating the natural environment. Thus, my love for all things ‘nature’ was instilled at a very young age, and I still remember the first time I heard about climate change in school when I was eight and that the wrongness of it rang true even then. My engagement with climate change has followed me since and grown stronger and more passionate as our environment has suffered. The irony that my mother-country is both a country renowned for its natural beauty and also as one of the most profitable oil nations in the world, is a source of a lot of shame and frustration for me. It has therefore been especially meaningful to be able to contribute to research on climate change, within my professional field and whilst getting to work with and appreciate a population so often overlooked.

My position on climate change is, as will perhaps be apparent from the preceding discussions, one of deep concern about the continued destruction and exploitation of the natural world and the people living in it. Whilst I feel very passionately about this, it was important for me to not infer the same values and opinions onto the participants in this study, and to be mindful of the power I held as the researcher to potentially influence the participants’ answers or to erroneously infer my values into participants’ responses.

Whilst it is likely that the findings of this research have been influenced to some degree by my own stance, every effort was made throughout the research process to remain curious, open, and reflexively aware of this risk. This included the maintenance of a reflexivity diary, regular supervision, and a conscious commitment to representing participants' perspectives on their own terms rather than through the lens of my own values and assumptions.

Whilst my positioning with regards to the topic of discussion was one of being very much on the “inside” of the discourse, my positioning with the participant group was one of being an outsider. This was not just due to my lack of a learning disability, which was briefly mentioned in the methods chapter, but also as someone with little experience of working with people with learning disabilities. Prior to taking on this research project, my professional experience of working with people with learning disabilities was somewhat limited and varied in context, which, whilst a bit of an unknown, was one of the motivating factors for working with this population. Going into this research I did not quite know what to expect, and a part of me feared that the participants would have little to say on the topic or feel uncomfortable with it, and that the research question would be null and void. However, the participants in this study challenged my fears and assumptions by being curious, open, interested and often very knowledgeable. They further challenged my notions about what climate knowledge looks and sounds like, and how it is communicated and understood. This variety further cemented, and maybe made even more sincere, my values and belief that everyone should be invited into conversations and be able to make their own decision about whether they wish to take part.

In hindsight, I wish I had spent a bit more time reflecting on the population and particularly the areas of adaptation that I could put in place earlier in the project development. Particularly when thinking about the interview, I am left wondering if including more alternatives and aids for communication and information sharing may have supported the participants to engage even more in the conversation. Whilst the participants and I were able to adapt quite well, I think the research may have benefitted from more varied aids and resources.

What I have learned throughout this experience I intend to take forward into my clinical practice. This includes a greater awareness of the importance of accessible communication and the value of taking the time to understand and adapt to an individual's specific communication needs, rather than expecting them to adapt to a standardised format. More broadly, this research has deepened my commitment to working alongside marginalised populations in a way that starts from a genuine curiosity about their perspectives and a belief in their capacity to contribute meaningfully to conversations from which they have too often been excluded. People with learning disabilities have taught me a great deal throughout this process, and I hope that in some small way this research begins to repay that debt.

## **4.10 Conclusion and Final Implications**

This study set out to examine the perspectives of people with learning disabilities on climate change, which to the researchers' knowledge is the first known exploration of this area. The introduction highlights the lack of involvement of people with learning disabilities in climate change, despite the probable disproportionate



effects and risks it poses to this population. The findings suggest clearly that people with learning disabilities are both willing and able to engage with the climate change debate and movement, and that the variation in understanding observed across participants reflects not differences in capacity but differences in exposure, access, and opportunity. Participants demonstrated knowledge and engagement ranging from practical and embodied associations with everyday environmental behaviours, to sophisticated awareness of the human causes, global consequences, and political dimensions of the climate crisis. They also articulated with insight and clarity their own exclusion from climate discourse and the attitudinal assumptions that underpin it. Thus, directly challenging the deficit model of learning disability and lending support to a social model interpretation in which the barriers to engagement are located in systems and structures rather than in individuals.

The implications of these findings extend across clinical practice, policy, and activism, and speak to the broader and enduring question of who is considered a legitimate participant in these conversations. The study argues that people with learning disabilities are not absent from climate discourse because they lack the capacity or interest to participate, but because the systems and attitudes that shape climate communication and action have not been designed to include them. Meaningful change will require systemic responses and a shared commitment to inclusion across disciplines, not least within psychology and research themselves. Clinically, this means equipping practitioners with the awareness and tools to facilitate climate conversations with people with learning disabilities, to recognise and respond to climate related distress in accessible ways, and to advocate for the

production of accessible climate information within the services and organisations they work alongside. For researchers, it means prioritising co-produced and participatory methodologies that place people with learning disabilities not only as participants but as active contributors to the questions asked and the knowledge generated. These responses need to go beyond tokenism to place the voices and perspectives of people with learning disabilities at the centre of efforts to understand and respond to one of the defining challenges of our time.

In a world that is changing rapidly and inequitably, that is not simply a research recommendation. It is a matter of justice.

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# Appendix

## Appendix A

### Systematic Literature Review CASP Checklist

| Author(s)                        | 1.<br>Clear<br>statement<br>of aims | 2.<br>Qualitative<br>methodology | 3.<br>Research<br>design | 4.<br>Recruitment<br>strategy | 5.<br>Data<br>collection | 6.<br>Researcher/<br>Participant<br>relationship | 7.<br>Ethical<br>considerations | 8.<br>Data<br>analysis | 9.<br>Findings     | 10.<br>Research<br>Value | Overall<br>rating |
|----------------------------------|-------------------------------------|----------------------------------|--------------------------|-------------------------------|--------------------------|--------------------------------------------------|---------------------------------|------------------------|--------------------|--------------------------|-------------------|
| Baxter et al., (2023)            | Strong                              | Moderate                         | Weak to moderate         | Weak to moderate              | Weak to moderate         | Weak                                             | Moderate                        | Weak to moderate       | Moderate           | Moderate                 | 4.5/10            |
| Boyden et al., (2013)            | Strong                              | Moderate to strong               | Moderate to strong       | Weak to moderate              | Moderate                 | Weak                                             | Weak to moderate                | Weak to moderate       | Moderate           | Moderate                 | 5/10              |
| Cooper-Moss et al., (2024)       | Strong                              | Moderate to strong               | Moderate to strong       | Moderate                      | Moderate                 | Weak to moderate                                 | Moderate                        | Moderate               | Moderate to strong | Moderate to strong       | 6.5/10            |
| Drozd et al., (2021)             | Strong                              | Moderate to strong               | Moderate to strong       | Weak to moderate              | Moderate                 | Weak                                             | Weak to moderate                | Weak to moderate       | Moderate           | Moderate                 | 5.5/10            |
| Hall (2024)                      | Strong                              | Moderate                         | Moderate                 | Weak to moderate              | Moderate                 | Weak to moderate                                 | Weak                            | Weak to moderate       | Moderate           | Moderate                 | 4.5/10            |
| Howieson (2015)                  | Strong                              | Moderate                         | Moderate                 | Weak to moderate              | Moderate                 | Weak                                             | Moderate                        | Weak to moderate       | Moderate to strong | Moderate                 | 5.5/10            |
| Malouf et al., (2017)            | Strong                              | Strong                           | Strong                   | Strong                        | Strong                   | Moderate                                         | Strong                          | Moderate to strong     | Strong             | Strong                   | 8/10              |
| Mattock et al., (2020)           | Moderate to strong                  | Moderate to strong               | Moderate                 | Weak to moderate              | Moderate                 | Weak to moderate                                 | Weak to moderate                | Weak to moderate       | Moderate           | Moderate                 | 5/10              |
| Truesdale-Kennedy et al., (2010) | Strong                              | Moderate to strong               | Moderate to strong       | Moderate                      | Moderate to strong       | Weak to moderate                                 | Moderate to strong              | Moderate               | Moderate to strong | Moderate to strong       | 6.5/ 10           |

## Appendix B

### Example of the Process of Interpreting Second-Order Constructs

| Study                            | First-Order Constructs (Participants' own concepts)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Second-Order Constructs (Author interpretations)                                                                                                                                                                                                                                                                                                                      | Interpretive Process (How constructs were translated)                                                                                                                                                                                                                      | Contribution to Third-Order Construct                                                                                                                                                                                                       |
|----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Truesdale-Kennedy et al., (2010) | Participant described wanting more person-centred information and explanation of the procedure as it would make the process easier for them: <i>“If they explained it more to you for women with learning difficulties it wouldn’t be so bad because you go in there and they say they are going to help you and not to be feared and you go in there and they take your date of birth but they don’t explain anything about it...I have a mild learning difficulty and I need encouragement to get to the doctor and nurses.”</i> (FG3) | <p>These concepts were organised by the researchers under the themes: <i>“Perceived barriers to attendance”</i> and <i>“Perceived solutions to barriers”</i></p> <p>Researchers interpreted these barriers to access as a lack of understanding, which was found to increase participants’ distress prior to and during the procedure. This lack of knowledge was</p> | Poor communication or information access experienced both as a barrier and a potential factor for increased distress, as participants’ lack of understanding could make procedures more frightening and uncertain. Person-centred, tailored and adaptive communication was | <b>Barriers to Access:</b> Communication barriers, both in terms of information access and adaptive interaction, represent a central and recurring element of the Barriers to Access theme across the included studies. The lack of person- |

| Study | First-Order Constructs (Participants' own concepts)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Second-Order Constructs (Author interpretations)                                                                                                                                                                                                                                                                                                                                                                                                               | Interpretive Process (How constructs were translated)                                                                                                                                                     | Contribution to Third-Order Construct                                                                                                                                                                                                                                     |
|-------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|       | <p>Participants suggested more learning disability friendly and tailored information sources to make it more accessible: <i>“A wee story or pages to give....people like us would give people that weren’t able or worried or scared to go.”</i> (FG2)</p> <p>Participants wanting more individual support, staff to take the time to explain the procedure and for someone to be there with them: <i>“Talk to them, try to explain to the ones who can understand that its for their own health reasons and its not as scary or if some of their carers or whoever explained what it was going to be. And for someone to be with them and that the news maybe wouldn’t be as bad as they think.”</i> (FG3)</p> | <p>interpreted as the main barriers for women with learning disabilities and were underpinned by a fear of the outcome of the procedure and embarrassment around the procedure, e.g. needing to take their clothes off.</p> <p>Researchers also understood this limitation in knowledge as a sign of the lack of accessible means of health promotion and communication, that consider the varied cognitive functioning or limitations and specific needs.</p> | <p>also identified as a potential solution to the barrier of access, suggesting that the problem is located not in participants’ capacity but in the design and delivery of healthcare communication.</p> | <p>centred, accessible communication emerged not simply as a practical obstacle but as a structural feature of healthcare that systematically disadvantages people with learning disabilities, contributing to the pattern of inaccessibility captured in this theme.</p> |

## Appendix C

### Translation of Second-Order Constructs into Third-Order Constructs

| Study                                                  | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                                   | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                        | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                                                                                                                        |
|--------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>Third-Order Construct 1: Foundations for Coping</i> |                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                                                                            |
| Baxter et al. (2023)                                   | Researchers organised the subtheme "External coping strategies" to highlight the importance of other people to cope with the wait for services, interpreted as benefitting them with both practical and emotional support. Researcher interpreted the experiences of positive and helpful staff support in the subtheme "Received helpful support" | <i>"Loads of support [from support worker]. They [support worker] take me all over. If I want to go out, I go out." [SU2] "My helper [support worker] when she's here, the voices calm down, I don't hear as much." [SU4] "[Nurse] helps me through meetings or if I need to let something out I can talk to her." [SU7]</i> | The researchers' interpretation of external coping strategies was translated into the third-order construct by recognising that relational support, both practical and emotional, represents a foundational resource enabling people with learning disabilities to navigate healthcare systems. This contribution highlights the role of others in compensating for systemic inadequacies. |
| Boyden et al. (2013)                                   | Researchers described the importance placed on positive staff interactions to support a positive                                                                                                                                                                                                                                                   | <i>". . . I told her my name and [asked] what's her name and then this made me</i>                                                                                                                                                                                                                                           | The emphasis placed on rapport and positive staff interactions was translated by recognising that the                                                                                                                                                                                                                                                                                      |

| Study                     | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                                                                                                    | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                         | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                                         |
|---------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                           | experience of the service, and organised it in the subtheme "Rapport with the service"                                                                                                                                                                                                                                                                                                                              | <i>feel ok." "Talking about my interests. Things I am interested in. I talked about things I liked doing. That's important isn't it?"</i>                                                                                                                                                     | quality of relational encounters, rather than the service itself, was central to participants' sense of safety and wellbeing. This underscores the importance of interpersonal connection as a coping resource.                                                                                             |
| Cooper-Moss et al. (2024) | Researchers noted that participants relied on family members or support workers to help them access care, described in theme "Disconnection with a changing world". Researchers also noted that participants valued support from family networks and self-advocacy groups but that services sensitive to their ethnic identities were not always available, highlighted in the theme "Community and family network" | <i>"Family help me but everybody's busy now." (P3) "My support worker helps me the most...because I don't see my mum all the time... I meet people in another group for people with learning disabilities. Yes, I have met a lot of people going to this." (P2)</i>                           | The reliance on family and community networks was translated by recognising that social support is a primary coping mechanism but one that is unevenly distributed and not always adequately provided by services themselves. Cultural specificity and availability emerge as important moderating factors. |
| Drozd et al. (2021)       | Researchers interpreted the importance of carer support in the themes "Carer involvement" and "Family and carers". They described how carers helped both with communication and access to support, but also with practical things like personal hygiene.                                                                                                                                                            | <i>"... what they used to do is say ... in the morning was have a wash, get ready ... but I was scared to ask um to help me ... so I just waited for my Mom to come ... it was about how busy they are ..." (Kay, line 278–281) "... we asked the nurse that we first saw, didn't we? But</i> | The interpretation of carer involvement as central to both communication and practical support was translated by recognising that carers function as a necessary bridge between participants and healthcare systems, compensating for gaps in accessible care.                                              |

| Study                | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                            | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                                                                                  | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                   |
|----------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                      |                                                                                                                                                                                                                                                                                                             | <i>she didn't really know what we were talking about ..."</i> (Nat, line 85–86)                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                       |
| Hall (2024)          | Researchers found that participants coped using help from others and keeping busy while waiting for therapy, and highlighted it in the theme "Ways of coping".                                                                                                                                              | <i>"My support workers helped me go out"</i> (Participant 2) <i>"My mum helped me with my emotions and to manage how I was feeling"</i> (Participant 6) <i>"Talked to family and people at church"</i> (Participant 5)                                                                                                                                                                 | The researchers' identification of help from others and keeping busy as coping strategies during waiting periods was translated by recognising that relational support, even in the absence of formal services, is critical to sustaining wellbeing.                  |
| Malouf et al. (2017) | "Make sure you've got...very good support around you" Researchers stated that this theme considers how the mothers were aware that to succeed as parents, they needed to have good support from both family and professionals, and how several of the mothers who had been well supported were flourishing. | <i>"Make sure basically you've got a good team of people around you and very good support around you."</i> (Morgan) <i>"At the time I pushed my family away because I fell out with them... Which was a mistake I made and regret."</i> (Ellie) <i>"She's calm... She don't just take in what she wants to hear and then don't do nothing about it, she actually listens."</i> (Sasha) | The recognition that mothers who were well supported were more likely to flourish was translated by identifying the presence or absence of a robust support network as a key determinant of outcomes, reinforcing the centrality of relational foundations to coping. |



| Study                                       | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                                                                                    | First-Order Construct Examples (Participant accounts)                                                                                                                                                          | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                              |
|---------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Mattock et al. (2020)                       | In the subtheme "support within the focus group" researchers suggested that throughout the focus group the participants felt connected with each other, safe and comfortable to share personal experiences, which was not usually their experience. This was extended to professional support in the subtheme "being listened to", highlighting that being heard was important to the participants. | <i>"I've got the same, or similar problems that they have, but mine are slightly different" (P2) "I didn't think people had similar problems to me". (P1) "My mum don't listen" (P1) "They don't ask" (P3)</i> | The sense of connection and safety experienced within the focus group, and the importance of being listened to, was translated by recognising that peer and professional relational support provides a containing and empowering experience rarely replicated in everyday healthcare encounters. |
| Truesdale-Kennedy et al. (2010)             | In the subtheme "support from carers and nurses" researchers describing the impact positive staff relations had on the experience of the procedure, which helped to alleviate some of their initial fears and anxieties. Researchers reported that the presence of a carer, staff member or familiar person during the screening may make the process easier.                                       | <i>No direct data available: several noting the friendliness of the staff at the breast screening unit describing them as 'chirpy' and 'friendly' and 'kind'</i>                                               | The positive impact of friendly and familiar staff and carer presence on participants' experience of a potentially distressing procedure was translated by recognising that relational reassurance functions as a critical coping resource in clinical encounters.                               |
| Third-Order Construct 2: Barriers to Access |                                                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                  |

| Study                | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                   | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                                                                      | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                              |
|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Baxter et al. (2023) | Researchers described the perceived importance of transparency in team set-up and availability of the team for participants in the theme "Awareness of how to contact the team".                                                                                                                                                   | <i>"I have rung them [learning disability service] up before a few times and there's been someone... If I speak to someone it helps sometimes. But sometimes it doesn't." [SU6] "I've got the phone number somewhere, but I may have lost it so you may need to send it out to me so that if I need owt [anything], I can phone them and talk to somebody there" [SU3]</i> | The difficulty participants experienced in knowing how to contact services was translated by recognising that inaccessible systems of communication and navigation represent a structural barrier that places the burden of access disproportionately on individuals with learning disabilities. |
| Boyden et al. (2013) | Researcher described the perceived importance of flexibility and adaptive approaches to support service engagement in the subtheme "Practicalities of meeting with the service". They further explored the importance of communication, therapeutically, and value of creatively adapting approaches, in the theme "Communication" | <i>"I prefer my house. . . because it's quiet, I don't like a lot of noise." "The conversations with them have been good."</i>                                                                                                                                                                                                                                             | The importance of flexibility and adaptive approaches to service engagement was translated by recognising that the absence of such adaptations constitutes a barrier, and that rigid service structures fail to accommodate the diverse needs of this population.                                |

| Study                     | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                                                 | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                                             | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                |
|---------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cooper-Moss et al. (2024) | Following covid, an additional barrier to services was the reliance on digital platforms to access appointments etc which researcher interpreted in the theme "Digital Exclusion"                                                                                                                                                                                | <i>"Why can't people do some homework. To find out what is out there for people, to understand they might need a language interpreter, they might use Makaton instead of British Sign Language, they might use Braille." (P7) "People with learning disability don't have competency with computers." (P5)</i>                                    | The emergence of digital exclusion as a post-pandemic barrier was translated by recognising that technological shifts in service delivery can create new and additional layers of inaccessibility for people with learning disabilities, compounding existing structural barriers. |
| Drozd et al. (2021)       | Researchers highlighted communication as a challenge for all the participants whilst receiving orthopaedic and trauma hospital care and interpreted them in the themes "Communication" and "Problems with communication". Poor communication with health care staff was further linked with increased fear, anxiety, non-compliance with treatment for patients. | <i>"... I found it hard to understand ... erm ... long words ..." (Kay, line 373) "... I'm 32 ... and I'm not a child, I'm an adult" (Kelly, line 291–293) "Some said things what made sense but sometimes they said things which were not true or (did) not make sense. I was not always aware what was happening" (Email from Ted, 13.6.16)</i> | Communication challenges experienced across all participants were translated by recognising that the inaccessibility of clinical language and the absence of adaptive communication strategies represent a pervasive and systemic barrier rather than an individual difficulty.    |

| Study                | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                    | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                        | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                   |
|----------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Hall (2024)          | Researchers found that the overarching theme "Accessibility of letters" illustrated that many participants did not recall receiving a screening outcome letter. Furthermore, some participants were unable to read. Highlighting a need for services to ensure clients have support accessing written information about their care. | <i>"What letter? I can't remember, I get a lot of letters" (Participant 2) "It's hard to remember if they are not on my phone" (Participant 8) "I struggle with letters; I get all het up" (Participant 7) "I couldn't read it, my boyfriend read it out for me, cos I struggle reading" (Participant 4)</i> | The widespread failure of participants to recall or access written communications about their care was translated by recognising that standard written communication represents a significant and often unacknowledged barrier for people with learning disabilities. |
| Howieson (2015)      | Researcher stated in the theme "Healthcare for all" the ways in which information is packaged and delivered, and the attitudes of staff need to change.                                                                                                                                                                             | <i>'I got a letter and I couldn't understand it.' "It was hard to explain the things to do." "Needs to be more communication between your doctor and the hospital." "Pictures and bigger writing."</i>                                                                                                       | The need for both attitudinal change and more accessible information packaging was translated by recognising that barriers to access are simultaneously structural and attitudinal, requiring change at both the systemic and individual professional level.          |
| Malouf et al. (2017) | Researchers interpreted the range of difficulties which the mothers described with understanding written and oral information about their maternity care and looking after a baby in the theme "I find it harder to understand than other people". The clarity of the                                                               | <i>"I went through the whole pregnancy not really knowing what to do because I wasn't getting information off the doctors or the midwives" (Lisa) "There's bits of it that were quite</i>                                                                                                                    | The inconsistency of accessible information and resources across participants' maternity care experiences was translated by recognising that the burden of inaccessible communication falls disproportionately on people with learning                                |

| Study                           | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                                                                                                                      | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                             | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                                |
|---------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                 | communication that had been provided and availability of resources was inconsistent amongst participants.                                                                                                                                                                                                                                                                                                                             | <i>confusing...I wasn't sure what I had to click onto" (Jo) "I said, 'I don't understand what you're talking about'. 'Oh, we haven't got the time for that, I'm just going to prod you and poke you and I'm going to go'" (Jo)</i>                | disabilities, with significant consequences for their understanding and experience of care.                                                                                                                                                                                                        |
| Mattock et al. (2020)           | In the sub-theme "understanding treatment" researchers highlighted that some of the participants had many thoughts about their medication yet, appeared to have little understanding or knowledge about it. Moreover, in the subtheme "passed around from pillar to post" researchers stated that it appeared that there were some situations where important decisions regarding the participants were made without consulting them. | <i>"No more taking stupid medication" (P1) "I wanna come off my [medication]" (P2) "[. . .]left on my own [in] a children's home, nursery, junior school umm and then a boarding school". (P5) "I don't want to [live there] any longer" (P3)</i> | The limited understanding participants had of their medication, and the experience of decisions being made without their involvement, was translated by recognising that exclusion from information and decision-making processes represents a fundamental barrier to equitable healthcare access. |
| Truesdale-Kennedy et al. (2010) | Researchers identified the barriers to accessing the service through two subthemes: "Perceived barriers to attendance" "Perceived solutions to barriers"                                                                                                                                                                                                                                                                              | <i>"If they explained it more to you for women with learning difficulties it wouldn't be so bad because you go in there and they say they are going to</i>                                                                                        | Poor communication or information access experienced both as a barrier and a potential perpetuating factor for increased distress, as participants' lack of understanding could make                                                                                                               |

| Study | Second-Order Construct (Author's interpretation) | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                                                                               | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                                          |
|-------|--------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|       |                                                  | <p><i>help you and not to be feared and you go in there and they take your date of birth but they don't explain anything about it...I have a mild learning difficulty and I need encouragement to get to the doctor and nurses." (FG3)</i></p> <p><i>"A wee story or pages to give....people like us would give people that weren't able or worried or scared to go." (FG2)</i></p> | <p>procedures more frightening and uncertain. Person-centred, tailored and adaptive communication was also identified as a potential solution to the barrier of access, suggesting that the problem is located not in participants' capacity but in the design and delivery of healthcare communication.</p> |

### *Third-Order Construct 3: The Experience of Being Cared For*

|                      |                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                      |
|----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Baxter et al. (2023) | The strain of the wait for support and not having anyone to talk to was interpreted as the subtheme: "No one to talk to about difficulties". Service users feeling like they have been forgotten about by the service interpreted in the subtheme: "Received no support" | <p><i>"It's been painful because I haven't been talking to anybody." (SU3)</i></p> <p><i>"Been hard [waiting for therapy]...Not talking to anybody. Isolating myself from people. Not having nobody there to support me." (SU7)</i></p> <p><i>"I've only got</i></p> | The experience of isolation and feeling forgotten by services was translated by recognising that the emotional impact of inadequate care extends beyond the clinical encounter, shaping participants' sense of worth and their relationship with services over time. |
|----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

| Study                     | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                                                                                                                                                                             | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                                       | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                                              |
|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | <i>[support worker's name]. [...] Not since this call today. I haven't heard nowt [nothing]." (SU3)</i>                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                  |
| Boyden et al. (2013)      | Researchers interpreted one challenge in "Difficulties encountered" as the wish for more support after ended sessions, showing positive interaction but disappointment at ending.                                                                                                                                                                                                                                                                                                            | <i>"I wanted to talk more about the problems I had."</i>                                                                                                                                                                                                                                                                                    | The wish for more support following ended sessions was translated by recognising that positive therapeutic relationships heighten awareness of their absence, and that the emotional impact of care endings is a significant and underacknowledged dimension of the experience of being cared for.               |
| Cooper-Moss et al. (2024) | Researchers described the challenges experienced by participants when being met by the service in the following themes: "Substandard and Unresponsive Care", "Discrimination", "Reduced access to services", "Barriers to vaccination". Researchers highlighted that for people with learning disabilities from ethnic minorities, communication barriers are especially pronounced, including a lack of interpreting and translation services. Racism and stigma further complicate access. | <i>"Why can't people do some homework. To find out what is out there for people, to understand they might need a language interpreter, they might use Makaton instead of British Sign Language, they might use Braille." (P7) "I don't like going to the doctors at all. Since COVID it is completely worse. It's worse trying to get a</i> | The experiences of substandard care, discrimination, and reduced access for participants from ethnic minority backgrounds were translated by recognising that the experience of being cared for is shaped by intersecting identities, and that racism and ableism compound one another in healthcare encounters. |

| Study              | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                          | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                                                                                      | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                                                                                              |
|--------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                    |                                                                                                                                                                                                                                                                                                                                           | <i>doctor's appointment and a prescription." P8</i>                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                  |
| Droz et al. (2021) | Researchers described the experiences participants had with healthcare in the following themes: "Lack of confidence in hospital care", "Lack of competence of staff", "Environmental challenges". Highlighting the lack of trust participants had in the support they would receive or describing disappointment in their past treatment. | <i>"... He was the only one who even thought, I will try ... I might not be walking now if he didn't try ..." (Ted, line 123–125) "... nurses and doctors are not trained to look after disabled people ... most people in hospital don't have a disabled problem ..." (Ted, line 261–264) "... it was really, really, noisy ... you know what hospitals are like ..." (Len, line 200)</i> | Participants' lack of confidence in the care they received, and their experiences of staff incompetence and environmental challenges, were translated by recognising that the experience of being cared for is profoundly shaped by trust, or its absence, and by the extent to which the physical and relational environment is adapted to participants' needs. |
| Hall (2024)        | Researcher interpreted the theme "impacts of wanting to be seen" as an indicated that participants recalled a long wait for therapy and struggled emotionally with this, particularly if they experienced a decline in their mental health.                                                                                               | <i>"very rough with my voices" (Participant 8) "I was getting more and more aggressive and anxious" (Participant 1) "it would have helped if someone had said how far on the list I was" (Participant 2)</i>                                                                                                                                                                               | The emotional deterioration experienced during long waits for therapy, and the distress caused by lack of information about waiting times, was translated by recognising that the experience of being cared for begins before any clinical encounter and is shaped by how services communicate and respond to those waiting for support.                         |



| Study                | Second-Order Construct (Author's interpretation)                                                                                                                                                                                                                                                                                                                                                                                            | First-Order Construct Examples (Participant accounts)                                                                                                                                                                                                                                                                                                                     | Interpretive Notes (How constructs were translated)                                                                                                                                                                                                                                                                                 |
|----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Howieson (2015)      | Researcher stated in the themes "Hidden in plain sight" and "Treat me right" that participants want hospitals to change so that they feel that they are being treated with dignity and respect, and feel more valued, which will reduce their feelings of anxiety and vulnerability when accessing acute hospital services.                                                                                                                 | <i>"It's difficult to understand why they don't come and talk to you." "I don't think that's fair, because they just throw everything at me and they must know by looking at my face that I don't understand." "I think they should come and speak to you." "I think sometimes the doctors don't believe me at all." "They just make a face, thinking 'she's at it'."</i> | The desire to be treated with dignity, respect, and to feel valued was translated by recognising that the experience of being cared for is fundamentally relational and ethical in nature, and that attitudinal deficits on the part of staff translate directly into experiences of invisibility and disrespect.                   |
| Malouf et al. (2017) | The researchers identified a shared longing for "normality" amongst participants, contrasting themselves with "normal parents" which was described in theme "I hate being treated differently". Researchers described a sense that almost all the mothers felt that becoming a mother had been overshadowed by the requirement to demonstrate to others their ability to be good-enough parents in the theme "We've had to prove ourselves" | <i>"We would have understood from the beginning if they told us the reasons why. And they didn't." (Morgan) "They were watching over my shoulder" (Rachel) "We weren't allowed to do anything unless the midwife was supervising us... I felt too nervous to enjoy it... like when you bottle-feed and you just have this odd</i>                                         | The experience of being watched, judged, and required to prove parental competence was translated by recognising that for people with learning disabilities the experience of being cared for is frequently distorted by surveillance and the implicit requirement to demonstrate normality, which undermines dignity and autonomy. |

| Study | Second-Order Construct (Author's interpretation) | First-Order Construct Examples<br>(Participant accounts)                                                                                                                         | Interpretive Notes (How constructs were translated) |
|-------|--------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------|
|       |                                                  | <i>glance at your husband... I just found I<br/> had to x my eyes on my son... I didn't<br/> feel I could look somewhere else in<br/> case I got marked down for it." (Lisa)</i> |                                                     |

## Appendix D

Overview of third-order construct across systematic synthesis data

| Third-order constructs            | Second-order construct    | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Total |
|-----------------------------------|---------------------------|---|---|---|---|---|---|---|---|---|-------|
| Foundations of coping             | The Role of Relationships | ✓ | ✓ | ✓ | ✓ |   |   |   | ✓ |   | 5/9   |
|                                   | Social Support            | ✓ |   | ✓ | ✓ | ✓ | ✓ | ✓ |   | ✓ | 7/9   |
| Barriers to access                | Communication             | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 9/9   |
|                                   | Adjustments               |   | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |   | ✓ | 7/9   |
|                                   | Systemic exclusion        |   | ✓ | ✓ |   |   | ✓ | ✓ | ✓ |   | 5/9   |
| The experience of being cared for | Power                     |   | ✓ |   | ✓ |   | ✓ | ✓ | ✓ |   | 5/9   |
|                                   | Attitudes                 |   | ✓ | ✓ |   |   | ✓ | ✓ | ✓ | ✓ | 6/9   |
|                                   | Emotional Impact          | ✓ |   |   |   | ✓ | ✓ | ✓ | ✓ | ✓ | 6/9   |

## Appendix E

### **Thesis Interview Topic Guide: People with LD's Understanding and Engagement with Climate Change**

#### **Introduction to the Interview**

##### **Welcome!**

- Hello. Thank you for joining me today. We are going to talk about climate change, which is an important topic that affects all of us.
- This is a friendly space where you can share your thoughts and feelings. There are no right or wrong answers; I just want to hear what you think.
- If at any time you feel uncomfortable or want to stop, you can end the interview or choose not to answer any questions.

#### **Brief explanation of Climate Change**

##### **What is Climate Change?**

- Climate change is when the Earth's weather changes over a long time.
- It can make things warmer, and sometimes it causes more storms, floods, or droughts (which is when there is not enough rain).
- It's important to learn about climate change because it affects nature, animals, and people's lives.
- People with disabilities may be more at risk during extreme weather events, for example not being able to get to hospital.
- Today I would like to hear your thoughts on climate change.

#### **1. Understanding/ thoughts about Climate Change**

##### **What is climate change?**

- Can you explain in your words what you think climate change is?

##### **Where do you normally hear about climate change?**

- Do you see it on TV, hear it on the radio, or read about it online?

##### **What do you think causes climate change?**

- What do you think makes climate change happen?

##### **How do you think climate change can affect people?**

- Do you think climate change can change how we live or the world we live in?

#### **2. Feelings About Climate Change**

##### **How do you feel about climate change?**

- Does it make you worried, confused, or maybe something else?

##### **Did you know that people with disabilities may be more at risk during extreme weather events?**

- How does this make you feel?

##### **Do you think it is important? Why?**

- Why do you think we should care about climate change?

### **3. Personal Experience and Engagement**

**Is there anything you can do to help to stop climate change?**

- Do you know of any things people can do to help climate change?

**Have you done anything to help with climate change?**

- Can you tell me about any small things you do to help with climate change? (prompt: like recycling or using less water?)

**What would you like to do to help with climate change?**

- If you could do something big or small to help, what would it be?

### **4. Learning and Sharing**

**How do you learn about climate change?**

- Do you talk to friends or family about it? Do you learn from school?

**Would you like to learn more about climate change?**

- What things would you like to know more about regarding climate change?
- Would you like to learn more about how you can help stop climate change?

**Can you think of a way that you might like to learn more about climate change?**

- Is there a way you prefer to learn about it?

### **5. Community Involvement**

**Do you know anyone in your community who is doing things to help with climate change?**

- Can you think of any groups or people who are trying to help the environment?

**If there was a group or event about climate change, would you be interested to join it?**

- What kind of events or activities would interest you?

### **Conclusion**

**Any final thoughts?**

- Is there anything else you want to say about climate change or helping the planet?

## Appendix F

### Focus Group Schedule

**Welcome and introductions** (*5 minutes*) Researcher introduces themselves and the purpose of the session. Participants introduce themselves. Ground rules agreed (confidentiality, no right or wrong answers, everyone's view is valued).

**Recap: Climate change** (*5 minutes*) Brief accessible reminder of what climate change is, supported by visual aids if needed.

**Discussion: Understanding climate change** (*10 minutes*) Findings shared around the spectrum of understanding. Participants invited to share their thoughts — does this reflect their experience? What do they know about climate change and where did they learn about it?

**Discussion: "It's on the news"** (*10 minutes*) Findings shared around how participants encountered climate change through media. Does this feel familiar? Where else might they expect to hear about it?

**Discussion: "Come tell me about it"** (*10 minutes*) Findings shared around wanting to be approached and included. Would participants like to know more? What would help them get involved?

**Closing** (*5 minutes*) Summarise key points raised. Thank participants. Reminder of what happens next with the research.

# Appendix G

## Interview notes example

P.10

### Thesis Interview Topic Guide: People with LD's Understanding and Engagement with Climate Change

#### Introduction to the Interview

**Welcome!**

- Hello. Thank you for joining me today. We are going to talk about climate change, which is an important topic that affects all of us.
- This is a friendly space where you can share your thoughts and feelings. There are no right or wrong answers; I just want to hear what you think.
- If at any time you feel uncomfortable or want to stop, you can end the interview or choose not to answer any questions.

#### Brief explanation of Climate Change

**What is Climate Change?**

- Climate change is when the Earth's weather changes over a long time.
- It can make things warmer, and sometimes it causes more storms, floods, or droughts (which is when there is not enough rain).
- It's important to learn about climate change because it affects nature, animals, and people's lives.
- People with disabilities may be more at risk during extreme weather events, for example not being able to get to hospital.
- Today I would like to hear your thoughts on climate change.

#### 1. Understanding/ thoughts about Climate Change

**What is climate change?** — Hot, cold  
not easy — Can you explain in your words what you think climate change is? — Pollen  
↳ how people feel, frightened of duster storms

**Where do you normally hear about climate change?**  
— Do you see it on TV, hear it on the radio, or read about it online?  
↳ normally on facebook (friend), news, housemates. — 'easy to understand'

**What do you think causes climate change?** — don't know. (long)  
— What do you think makes climate change happen?  
↳ people? people not talking about it

**How do you think climate change can affect people?** — 'hesitates'  
— Do you think climate change can change how we live or the world we live in?  
↳ ppl pregnant + old ppl = heat. not sure.

#### 2. Feelings About Climate Change

**How do you feel about climate change?** — not too bad. frightened of duster storms  
— Does it make you worried, confused, or maybe something else?  
↳ no. Talking about it is fine.

**Did you know that people with disabilities may be more at risk during extreme weather events?** yes.  
— How does this make you feel? anxious, worried.  
— normally have ways to manage stress.

**Do you think it is important? Why?**  
— Why do you think we should care about climate change?  
↳ yes. ↳ so people can be more careful, don't throw rubbish on the street.

### 3. Personal Experience and Engagement

Is there anything you can do to help to stop climate change?

- Do you know of any things people can do to help climate change?

↳ big or small

Have you done anything to help with climate change?

- Can you tell me about any small things you do to help with climate change? (prompt: like recycling or using less water?)

↳ do recycling.. people not littering.

What would you like to do to help with climate change?

- If you could do something big or small to help, what would it be?

↳ be part of campaigns or discussion

### 4. Learning and Sharing

How do you learn about climate change?

- Do you talk to friends or family about it? Do you learn from school?

↳ home, alone + talking to people

Would you like to learn more about climate change?

- What things would you like to know more about regarding climate change?
- Would you like to learn more about how you can help stop climate change?

↳ have enough info

Can you think of a way that you might like to learn more about climate change?

- Is there a way you prefer to learn about it?

↳ not really

### 5. Community Involvement

Do you know anyone in your community who is doing things to help with climate change?

- Can you think of any groups or people who are trying to help the environment?

If there was a group or event about climate change, would you be interested to join it?

- What kind of events or activities would interest you?

↳ yes.

### Conclusion

Any final thoughts?

- Is there anything else you want to say about climate change or helping the planet?

↳ anything.

↳ "Someone to come tell me about."



- . P2D : not included in conversations
  - don't know why.
- . Helpful.
- . Should be asked for rules ++

## Appendix H

### Transcript Example

Participant 3

Interview date: 22/07/25

Interview duration: 40.12 minutes

Transcript

Interviewer

And so the recording is just for me to listen to after we've spoken, so I can remember what you've said and when I've done that, I'll write it down. It'll all be anonymous. So no one will know that it's you. Yeah. And. And then when I've done that, I'll delete the recording. Yeah. Does that sound OK?

Participant 3

Yeah, yeah. What I would expect, yeah.

Interviewer

But no one else is going to see it, but just as part of that, I have what's called a consent form, which is to say that you you're OK to take part

Participant 3

Yeah, yeah.

Interviewer

It's very long. So what I've asked people to do is just to sign at the back if you wouldn't mind.

Participant 3

Yeah.

It takes a long time if you wouldn't mind just to say that you agree. So you can make a cross or a tick or whatever, and just just sign there.

Whatever (laughs)

Interviewer

Let's just do whatever.

Participant 3

Yeah.

Interviewer

So I'll just make a note for myself that this is #3. So that I remember later and just before we start. Where am I?... What are your initials?

Participant 3

(Redacted)

Interviewer

(Redacted) and how old are you?

Participant 3

25

Interviewer

25. Yeah, nice round Number. And I ticked female for your gender, is that right?

Participant 3

Yes, yes.

Interviewer

Great. (...) It's a lot of. It's a lot of paperwork that it involved in this. So just to say, if at any point you don't wanna talk anymore, you're very welcome to finish the interview.

Participant 3

Oh, yeah, yeah, yeah.

Interviewer

That's fine. I won't take that personally.

Are we ready to ready to go? OK. So you just let me know if you want to stop it.

Participant 3

Oh, yeah yeah.

Interviewer

Yeah. So I'm. I'm just going to give a brief explanation of climate change. So I've been giving to everyone so that everyone has sort of the same basic understanding. So climate change is when the Earth's weather changes over a long period of time, does that sound?

Participant 3

Yeah, I know about climate change (laughs)

Interviewer

You know, and it can make things warmer and sometimes it causes things like floods or storms or droughts. Yeah. Sound familiar?

Participant 3

Yeah.

Interviewer

It's important to learn about it because it affects nature and animals and people's lives. And and people with disabilities may be more at risk during extreme weather changes. So, for example, needing to get to the hospital or coming to push a button, things like that can be if there's a flood, it's quite hard to go to the hospital isn't it?

Participant 3

Or to go anywhere. Tornado you won't get anywhere.

Interviewer

And and so I would just like to learn your thoughts about that today. Yeah, that sounds OK. Yeah. OK. So a few questions. There's 2 pages, and I might take a few notes so that I can remember as well. Yeah, it's. You can tell I'm very forgetful. I need to take a lot of notes. So in your own words, what is climate change?

Participant 3

That's what we're doing to the earth.

Interviewer

It's what we're doing to the earth.

Participant 3

(Nods) What we have done.

Interviewer

Yeah. Would you be able to tell me a bit more?

Participant 3

The pollution we have caused. The harmful gases that we have released. That's affects the ozone layer that's caused a hole in it.

Interviewer

You really are very knowledgeable about this.

Participant 3

You've got a real animal lover here (points thumb to self).

Interviewer

You. Ohh yeah. (laughs) Same. So there's a big hole in the ozone layer... So I'm just going to recap, you mentioned that climate change is what we've done here is all the pollution. That we've caused with the gases. And then you mentioned the ozone layer. There's a hole in it. Anything else that you can think of?

Participant 3

(Pause)

Interviewer

This isn't a test.

Participant 3

It's not. No, no, it's not. (laughs)

Interviewer

Sometimes it feels a bit like it, but it's not a test testing knowledge.

Participant 3

The pollution that we've caused into our seas. Destroying the animals.

Interviewer

Yeah.

Participant 3

The landfills as well from our litter. For some isn't biodegradable.

Interviewer

No, a lot of it is. You know, you know a great. I'm very impressed. You know, a great deal.

Where do you normally heard about hear about climate change?

Participant 3

Lot's of places, but I haven't thought about it.

Interviewer

Would you be able to name a few?

Participant 3

I have got Facebook. Yeah, and my own research.

Interviewer

You've done your own research, yes. Where did you do your research.

Participant 3

Internet. Books. It's a bit of an old-fashioned way. (laughs) ... News.

Interviewer

OK. Yeah. It's a lot on the news.

Participant 3

It's a lot on the news and then you have a family conversation about it. More of a debate sometimes, right? (nods to researcher)

Interviewer

So sometimes you you have a debate with your family about it.

Participant 3

(Nods and smiles)

Interviewer

Yeah.

So, it sounds like it's a little bit everywhere. Yeah.

Participant 3

Yeah, it's. Sort of. It's not organised at all.

Interviewer

No, it's not organised and that you've had to do your own research.

Participant 3

Yeah, it's not... Everybody saying different things about it. Yeah, it's no one set.

Interviewer

It's hard to know what's true and what. Yeah, right. And you, it sounds like you've had to do quite a lot. Of that yourself? Yeah. Wow. That's a lot of work. And and you've already mentioned it a little bit, but what do you think causes climate change?

Participant 3

People. Us. That's what we're doing. (gestures outwards with arms)

Interviewer

The people, us, what we're doing...

And how do you think climate change can affect people?

Participant 3

By us no longer being here. Not good. Because you would have the smog and the litter.

And people with asthma wouldn't be able to breathe. And the older generation.

Interviewer

Yeah, so people who've already got difficulty breathing



Participant 3

And underlying health conditions.

Interviewer

Yeah, it could be really hard for them. Anything else?

Participant 3

The animals get tangled up in the rest and they'll just die and that will ruin the ecosystems.

Interviewer

The animals dying. There's the ecosystem.

Participant 3

Yeah, and if you kill all the animals completely. The predators that eat off the animals, they would also die and then... (trails off)

Interviewer

And then I guess that impacts what we can eat or how we can survive.

Participant 3

Yeah and if you (brief pause) but if you killed off all the bees you killed off all the pollinators, we wouldn't have any food. And in the end we will just die out.

Interviewer

It sounds like really the thing that could happen is that there won't be people.

Participant 3

Or any animals and the earth will turn into a big, massive volcano with tornadoes.

Interviewer

Hmmm, yeah, luckily, that's that's a long time in the future.

Participant 3

Yeah, yeah, yeah. But it's still a possibility for next generation, like if you've got kids they have kids, you go... Got to think about what the next generation is gonna be like.

Interviewer

Yeah, that's really true. So for the next generation, it might be even scarier.

Participant 3

Or what's it going to be like when we get older.

Interviewer

Exactly. If, if we get breathing problems. Yeah, that's going to be hard for us that's really true.

Participant 3

If the weather conditions get worse well.

Interviewer

Yeah. Yeah, what could happen then?

Participant 3

Then a lot more people would die, and there'd be a lot more people poor in this world. Because they can't have water because of the droughts. You can always see it now, yeah.

Interviewer

So this is the difference. There's so many different effects of it. Yeah, that like you said, people could get really poorer than they are now and.

Participant 3

Yeah, and if the sea rises.

Interviewer

I guess so, yeah, If the sea rises, yeah.

Participant 3

Yeah. If the sea rises. There'll be (brief pause) the endangered animals. They won't be here anymore.

Interviewer

The endangered animals won't be here anymore. that's true.

Participant 3

Could be caught up in the rubbish or yeah. (nods)

Interviewer

And and how? How do you feel about climate change. How does climate change make you feel?

Participant 3

Passionate about doing something about it to stop it.

Interviewer

It, yeah, passionate about stopping it.

Anything else?

Participant 3

It's not really stop it, but you can slow it down.

Interviewer

You can slow it down. And I guess there's...

Participant 3

Stopping it would need everyone.

Interviewer

Yeah, everyone would have to...

Participant 3

(Overlapping) You will need everyone to be on the same page.

Interviewer

Yeah, that's really difficult, isn't it? Yeah. So we can slow it down and I guess sometimes people talk about alternatives that we get and that we just maybe live a bit differently.

Participant 3

Yeah, because they live in the past like that. What's wrong with having plast (stops and rethinks) What's wrong with having paper bags instead of using plastic? What's wrong with that? People just live in the past.

Interviewer

So having paper bags now it's not any different?

Participant 3

(Nods)

Interviewer

No, exactly. So making changes. Does it make you feel anything else when you think about climate change?

Participant 3

Upset by it all and what we've done to it.

Interviewer

OK. Yeah, so quite upset. About what we've done to it. We're talking so much I'm running out of space (laughs) So did you know that people with disabilities could be more at risk during extreme weather?

Participant 3

Yeah. So some people with wheelchairs will not be able to get up and run. Yeah. And like with the earthquake, they want to get to the safe place because they won't be able to get lower under the ground because they won't be able to do steps.

Interviewer

So you already you already knew about that. It would be harder people with disabilities.

Participant 3

Yeah, yeah, it might be a lot harder, yeah.

Interviewer

And how does it make you feel?

Participant 3

And if a hospital got hit. Well, they won't be able to get out.

Interviewer

And how does it make you feel that people with disabilities are more at risk, or maybe more at risk?

Participant 3

Disappointed that we have caused it. We can slow it down, but you can't (pauses) you can't really fix it.

Interviewer

Yeah, it sounds disappointing cause I guess people with disabilities aren't the ones causing damage

Participant 3

(shakes head in agreement)

Interviewer

It's a bit unfair, isn't it?

Participant 3

(nods head in agreement)

Interviewer

Yeah.

Participant 3

Yes. And it's not like this one person caused the damage. It's lots of people.

Interviewer

Is a bit unfair that some people yeah struggle more.

Participant 3

Yeah, it shouldn't be like that. Everyone should have the chance. There was so many people dying in this world now.

Interviewer

It is. It's a difficult time at the moment.

Participant 3

Yeah (nods)

Interviewer

But I feel quite I feel quite happy that I've met someone like you who knows a lot about it. It's nice to talk to someone who feels the same.

Participant 3

Hmm, yeah. Yeah it is actually.

Interviewer

And you know that you're not alone and that loads of other people who are also thinking about and worrying about and trying to be (overlapping)

Participant 3

Yeah, because sometimes you do feel quite alone. You know when you're the only one and you try to debate with your friends and they're not interested.

Interviewer

Yeah, exactly. That can be really difficult.

Do you think it's? I mean, you probably have already answered this question, but do you think it's important for people to know about climate change?

Participant 3

Yeah, yeah. If they don't know, there's nothing they can do about it.

Interviewer

And do you think information about climate change is easily accessible for people?

Participant 3

Not as easy what it should be. You might see it in leaflets and might see it in photos yeah. There's good more could be done. It could be taught like here at (references community centre). There could be a class about, yeah.

Interviewer

So there could be a class about it or something.

Participant 3

Because some people can't read. So having a book (pause) yeah, wouldn't be any good?

Interviewer

And do you think it's accessible for people with disabilities or learning disabilities?

Participant 3

A bit more difficult because there's certain disabilities that makes it harder. Like Someone Like who only know sign language. (brief pause) Yeah you don't see a lot of sign language work around it at all? No, not at all. (shakes head) No, I've never seen a sign-language version.

Interviewer

That's a really good point. I hadn't thought about that. I've never seen that.

And is there anything that you can do to help to stop climate or any small things?

Participant 3

Be patient. You can make sure your rubbish is actually put away properly. That's that's the easy one that people can start doing straight away.

Interviewer

So people can recycle, yeah.

Participant 3

Nice easy one.

Interviewer

It's a very nice easy one.



Participant 3

Definitely (nods)

Interviewer

I mean that's I think that's often the first one that people think of as well.

Participant 3

Yeah, yeah that is the first one. Yeah. Then there is the harder ones. Yeah. And you got things like solar panels. And (pause) Yeah, the winds one. Collect rainwater.

Yeah. To like water the garden.

Interviewer

Yeah, that's true. To save the water.

Participant 3

Yeah, because that's also important. If you didn't have water. What are we gonna drink?

Interviewer

Collect rain water (pauses while writes) Anything else that you can think of?

Participant 3

Don't use lots of plastic

Interviewer

Trying not so use lots of plastic items. Ohh not a lot of plastic items. Yeah, reducing plastic.

Participant 3

(Nods) Re-use. Re-use what you can.

Interviewer

Yeah. So we need to reuse what we have and.

Participant 3

But if you had a toy that you would love, then you can give it to someone else. Re-use clothes or something. Nice little clothes and you like them.

Interviewer

So we can reuse things like toys like you said, if you (overlapping speech)

Participant 3

Clothes. Furniture. Whatever. (pause) As long as it's safe to do so.

Interviewer

Some some, I mean some clothes and furniture are too well loved.

Participant 3

(Nods)

Interviewer

Yeah, they can't be given away, can they?

Participant 3

(Shakes head)

Interviewer

But then there's loads (overlapping speech)

Participant 3

You can break them down.

Interviewer

Yeah, you can break them down. And some people are really good at, I guess making new things out of their stuff.

Participant 3

Yeah.

Interviewer

So is there anything that you've done to I guess reduce your impact on the climate?

Participant 3

Well, of course, take my litter home... Always.

Interviewer

You always take your litter home?

Participant 3

Recycle. Re-use and recycle as much as possible, yeah.

Interviewer

Reuse and recycle anything else that you've done or that you do?

Participant 3

LED bulbs.

Interviewer

I don't think many people think about that one, but that's true. That helps with electricity (overlapping speech)

Participant 3

Save the rainwater to water the plants. Better than water that comes out of the sink.

Yeah, it's better than (pause) rainwater is the same thing, yeah.

Interviewer

Anything else that you can think of?

Participant 3

Be careful how much you use with like showers and that. Try not just let the water run everywhere. Turn off the tap when you're brushing your teeth, don't just let it run, that's really waste. Wasting a lot of water.

Interviewer

It does. (Pause)

How are we doing? We're still doing good.

Participant 3

(Nods and gives thumbs up)

Interviewer

What would you like to do to help with climate change? If possible? Anything possible?

Participant 3

Anything possible? I know if I could convince my auntie to have electric car and get rid of her petrol car.

Interviewer

Have you convinced her?

Participant 3

Nearly. Nearly trying to.

Interviewer

Trying to convince your auntie.

Participant 3

I said, "you're not getting that other new car that's petrol". We got the car. You don't need to (trails off)

Interviewer

That's a really good one. So it sounds like you're not just trying to do things for yourself, you're trying to help the people around you to do things as well.

Participant 3

(Nods)

Interviewer

OK, is there anything else that you would like to do to help with climate?

Participant 3

Speak to more people about it.

Interviewer

Do you think people (brief pause) People with learning disabilities or disabilities are included in conversations about climate change.

Participant 3

(Brief pause)

Not really. Cause some people think they don't understand.

(pause)

Interviewer

It's really difficult... It's difficult to be part of a change when you're not included in the.

Participant 3

No, cause some people think its above them. People think "Oh they won't know anything about climate change".

Interviewer

So they... they assume that people won't know, so they don't know ask?

Participant 3

(Nods)

Interviewer

OK.

If someone was to. I don't know be making rules or making any preparations for climate change. Do you think it would be helpful for people with learning disabilities to be asked about it?

Participant 3

Yeah. Yeah, cause some people with learning disabilities don't just wanna put themselves forward sometimes. It's harder to put themselves forward as they want to be asked.

Interviewer

Yeah.

So if they're asked, they might feel like they can say "Ok"?

Participant 3

(Nods) OK.

Interviewer

That's really helpful to know. This sounds like someone like you would have a lot to share.

Participant 3

(Nods)

Interviewer

Yeah, but it might be hard to know where to share?

Participant 3

(Nods) Or when.

Interviewer

And do you talk to, you know, friends and family about climate change.

Participant 3

Oh yes. (brief pause) Some of them have completely different views to you.

Interviewer

Yeah, that happens.

Participant 3

They might go “What are you on about?”

Interviewer

Do you have to educate people sometimes?

Participant 3

Yeah they are like “What are you on about?”. Or they are saying it's boring and don't bother. (long exhale) Ohh that's yeah, that's does something to me. The “What are you on about? Not this. Not that thing again. Not about that thing again” (trails off)

Interviewer

Always on that thing we're always talking about it.

Participant 3

(Nods and laughs) “Talking about the animals again, aren't you?”

Interviewer

Well someone must talk about the animals. That's important.

Participant 3

(Nods) Little ones, yeah.

Interviewer

How do you learn about climate change?

Participant 3

(Pause)

Interviewer

So how did you learn about that? You mentioned it a bit that you've done your own research, but (overlapping speech)

Participant 3

You do a lot of your research, yeah. See it on Facebook sometimes if you're lucky.

Interviewer

If you're lucky.

Participant 3

Well if you're involved in that sort of group then.

Interviewer

So you already have to be engaging with that stuff.

Participant 3

Yeah, you'd have to engage with it or you don't hear about it. You see it on the news quite a lot.

Interviewer

Yeah. So then the news, isn't it?

Participant 3



(Nods) Yeah. But not a lot of people are now watching this.

Interviewer

No, that's true. Just on the news, did you learn about it in school?

Participant 3

Yeah. Yeah. So I did. Did I? (Pause) Yeah, I did learning at school.

Interviewer

So you learned about the school. Is that where you first heard about that?

Participant 3

(Nods)

Interviewer

OK.

Participant 3

Well, I was at school. First, like to play it when I was little. I was watching TV.

Starting on there.

Interviewer

So really the first time was on TV.

Participant 3

Yes, because there was a turtle that was stuck in the fishing net. Yeah. And then as I got older from like beer cans, the little circle things. I know you see animals getting caught up in different things, yeah and having to rescue them. Yeah. You've got to be putting stuff in the bin, when you see that stuff.

Interviewer

So it sounds like you first learned about it watching TV.

Participant 3

(nods)

Interviewer

Yeah. And then maybe it was a bit confusing?

Participant 3

Yeah it was. And then as you get older and watch it on news, it becomes less confusing.

Interviewer

Yeah, it becomes less confused. Yeah, and it sounds like you also school need to engage a lot with it to understand it better.

Participant 3

Yeah

Interviewer

I mean, would you like to learn more about climate change?

Participant 3

Yeah.

Interviewer

So that's something that you are interested in and it sounds like you are very interested.

Participant 3

(Nods)

Interviewer

What kind of things would you like to know about?

Participant 3

Everything! (Laughs)

Interviewer

Easy answer. Is one of those things, learning how to help sort of prevent it or slow it down so it you know.

Participant 3

Yeah, that would be. (Pause) And I remember when was younger and the tree that was nearby us was being cut down, I cried my eyes out because of those (Brief pause) there was a big pair of birds that was living there.

Interviewer

Yeah.

Participant 3

And you got this nest. I was about 10. Because there's a nest in there as well, and they cut it down while the nest was in there. They couldn't wait. They wouldn't wait. Yeah. They wouldn't wait until they left.

Interviewer

So you were really upset when they cut the tree. Yeah.

Participant 3

Yeah. (Pause) Well, it's to give us oxygen. It's very important. Couldn't just wait until the birds left? That would have been nice.

Interviewer

That would have been really nice. Yeah. I would also be upset by that.

Participant 3

Yeah, you won't listen, no.

Interviewer

No, I can imagine

Participant 3

And I went and knocked on the door. I went “What are you doing?” “don’t cut it down”, they didn’t listen. They wanted the new drive they put in. “I think you could wait till the birds left” (trails off)

Interviewer

No, they couldn't wait.

Participant 3

(Shakes head)

Interviewer

Hmm. No, that's really upsetting. So that was when you were ten. Yeah, that's really brave of you to go to your neighbour.

Participant 3

(Nods)

Interviewer

Can you think of a way that you might like to learn more about it? As is there a preferred way that you would want to learn about that. Yeah, yeah.

Participant 3

Not really. Well, as long as it's not by e-mail. (Laughs)

Interviewer

Not by e-mail.

Participant 3

I get lots of emails online not losing, not answer that.

Interviewer

No, I get that. So not by e-mail.

Participant 3

Usually junk e-mail. Of them. Yeah. So I had one time delete over a hundred emails in one go so (trails off)

Interviewer

That's a lot of junk email.

Participant 3

Some of them were more important. Some of them were, but not about 10. No, no.

Interviewer

And is there a way that you think would be, that would make it easier for people to learn about climate change that they can.

Participant 3

So you actually need to have something there for them to learn.

Interviewer

How do you think it would be easiest for them? (pause)

Do you think it would be easiest through talking to people to and watching a programme about, to hearing about it.

Participant 3

It all depends what disabilities they have. Like, I like figures and facts, but then there's someone that doesn't like to face the facts. What if someone uses sign-language, there

might be someone who's can't see and can hear. Yeah, well, it all depends on what their disabilities are.

Interviewer

So it would need to be multiple different ways that people can engage with it.

Participant 3

Yeah and that's the problem at the moment. Using only a couple of ways to engage with it.

Interviewer

That's really true. It's really not very easy for, you know, to learn about it.

Participant 3

And sometimes the way they say it, it's hard for people to understand. Yeah, which they use all that scientific words. And that can be hard for other people to actually understand what they mean.

Interviewer

So because the word that people words typically use

Participant 3

(Nods)

Interviewer

Yes, it's very difficult.

Participant 3

Yeah it's really hard to engage with it, yeah. They might listen to it. And think "What are they on about?"

Interviewer

They might say (pauses trying to remember) what did you say? You said they might think “What are they on about?”

Participant 3

Yeah, that's the only thing.

The news is only showing it in a (brief pause) So we see nature in the bad (pause) in a bad way. You (brief pause) honestly it was something bad happened and you don't know anything about it before. And every time you see it its always in a bad light.

Interviewer

Light. That's really true. The only time you see it, it's only in the bad light.

Participant 3

Yeah, you don't see it when it's (Pause) After someone's done something good. You don't really see that side of it.

Interviewer

So that's also makes it difficult for people to engage with.

Participant 3

They think “Ohh if it's bad, it's going to happen anyway. What difference can I make?”, (pause) “What's the point?”

Interviewer

Yeah. “What's the point?” I'm sure that some people think that. Especially if all you ever hear is the negative.

Participant 3

Yeah, because don't really hear the positive side of it.

Interviewer

Because I guess there are good things, and people doing good things all the time, but we never hear about it.

Participant 3

No you never hear it. It's just about (pause) Well for some people, it can be scary, yeah.

Interviewer

Why do you think it can be scary?

Participant 3

Because the Earth's gonna end in so long. It causes them to feel anxious and panic. Gonna have to start them off slowly so they don't end up being completely off the side again. Call it hysterical. Yeah, Being well half of the time. Yeah, you gotta (brief pause) you better go off slowly. You don't hear this other side of it very often.

Interviewer

No. And how do you think you know? Is there a way that we could Include people with learning disabilities in a way that doesn't feel scary for them.

Participant 3

Slowly. Probably start quite slowly.

Interviewer

OK.

Do you have any ideas of how we could do that or? What might be helpful?

Participant 3



Can't think in this present moment. Cannot be too over the top. Because we know we all get passionate it and we get over passionate about it. Yeah, otherwise it might cause an argument because you're so passionate about it.

Interviewer

I guess we also don't want people to think that sometimes when you're too passionate (pause) we're not very good at listening to people.

Participant 3

(Nods) Yeah. (Pause) Answer their questions, yeah. Focus will form. Be patient. And empathise with them.

Interviewer

You're saying so many lovely things I've had to add another page. (Both laugh)  
And do you know anyone in your community who's doing things to help with climate change?

Participant 3

Probably. Eeh (Pause) Half of them were bored by it. Yeah, half of them are like what we do, we do recycle a lot. We do kind of recycle a lot and the next-door neighbours too. (Pause)

My auntie used to do reusable coals, but they're not collecting them anymore, so try to do reusable coals where you put them in the bags back. But they're not collecting them anymore.

Interviewer

Ohh that's annoying.

Participant 3

That was very annoying. They're not collecting anymore. I don't know why.

Interviewer

Do you know of any like groups or anything that do you any anything to help with climate change?

Participant 3

Only the one on Facebook. Yeah, the one on Facebook, but no proper groups in the community.

Interviewer

If there was one, would you be interested in joining it?

Participant 3

Yeah, yeah. A lot.

Interviewer

What kind of activities would you be interested in in taking part in? Is there any that you can think of?

Participant 3

Would be nice to talk to people to learn.

Interviewer

Anything else? Any other activities you would like to take part in?

Participant 3

Don't know actually.

Interviewer

Do you think it would be easier to hear about any of those kinds of groups?

Participant 3

(Nods)

Interviewer

Yeah, yeah, no. And that was my last question. Do you have any other thoughts or anything that I didn't?

Participant 3

No.

Interviewer

OK, well, great. Thank you so much.

Participant 3

You're welcome. You got a lot of writing on there. (Laughs)

Interviewer

Yeah. No, it was. I got so many, so many things. This is wonderful.

Thank you.

## Appendix I

Example of coding from interview with Participant 1

| Transcript                                                                                  | Codes                  |
|---------------------------------------------------------------------------------------------|------------------------|
| Interviewer                                                                                 |                        |
| So we're just going to think a bit about it. OK.                                            |                        |
| So my first question is, can you explain in your words what you think climate change is?    |                        |
| Participant 1                                                                               |                        |
|                                                                                             | Weather, temperature,  |
| Like. When the weather changes are and it's... that hot, cold weather, floods, earthquakes. | extreme weather events |
| Interviewer                                                                                 |                        |
| Yeah. So hot, cold weather. Yeah. Tornadoes. Earthquakes.                                   |                        |
| Yeah. Yeah.                                                                                 |                        |
| Participant 1                                                                               |                        |
|                                                                                             | Extreme weather        |
| Same thing. You know. Tsunamis. Yeah, yeah.                                                 | events                 |
| Interviewer                                                                                 |                        |
| So weather changes?                                                                         |                        |
| Where do you normally hear about climate change?                                            |                        |
| Participant 1                                                                               |                        |
| On the news. Yeah.                                                                          | News                   |

Interviewer

So mostly on the news is that on TV and radio?

Participant 1

(Nodding) Both of them. Yeah. TV and radio, yeah.

TV, Radio

Interviewer

What about? Do you ever, like, read about it online? Or do you hear about it, when you're online.

Participant 1

Online, difficult to

You can read about it online, yet nothing

access information?

Interviewer

Yeah. Are there any particular sources that you found on?

Participant 1

Facebook, own

Facebook mainly, yeah.

research?

Interviewer

Facebook.

So people, you know?

Participant 1

Yeah.

Friends, family?

Interviewer

Might be talking about it and it comes up.

Participant 1

Yeah.

Interviewer

OK. And what do you think causes climate change?

Participant 1

Ehm. Heat. Yeah

Heat, temperature

Interviewer

What about heat?

Participant 1

Ah uhm.. Hmm Maybe something that, like you, you can. The

world can get warmer and it can get□ things can change yeah□  
the world can change, yeah.

Heat, temperature,  
global warming(?)

Interviewer

So because of the heat, yeah, that then changes all the other  
things?

Participant 1

That□s it and things can get warmer.

Temperature, heat

Interviewer

Yeah. And I think there's□ have you heard about that because  
of how the sort of thing that's around the earth, the atmosphere.  
Yeah, it keeps the heat in.

Participant 1

Yeah.

Interviewer

So that's one of the things that can do it. And I guess when it's really hot, it makes things melt, yes, which then makes more water.

Participant 1

Yeah, that's true.

Interviewer

And how do you think climate change can affect people? Or do you think it can affect people?

Participant 1

Ehm□ So□ Uh□ (pause)

Interviewer

That's OK. Take your time.

Participant 1

Thank you. (pause)

They can be hard to get one from place to another.

Travelling impacted,  
impact mobility

---

## Appendix J

### Ethics application approval

**From:** ERAMS erams@essex.ac.uk  
**Subject:** Decision - Ethics ETH2324-1938: Miss Maria Nordset  
**Date:** 14 January 2025 at 17:15  
**To:** Maria Nordset [REDACTED]

E

## University of Essex ERAMS

14/01/2025

Miss Maria Nordset

Health and Social Care

University of Essex

Dear Maria,

### **Ethics Committee Decision**

Application: ETH2324-1938

I am pleased to inform you that the research proposal entitled "Including people with learning disabilities in conversations about the climate crisis" has been reviewed on behalf of the Ethics Sub Committee 1, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

### **Extensions and Amendments:**

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

### **Covid-19:**

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance Team

**Ethics ETH2324-1938: Miss Maria Nordset**



# Appendix K

## Ethics amendment application approval

**From:** erams@essex.ac.uk  
**Subject:** Decision - Ethics ETH2526-0166: Miss Maria Barker-Nordset  
**Date:** 21 November 2025 at 14:52  
**To:** [REDACTED]

E

### University of Essex ERAMS

21/11/2025

Miss Maria Barker-Nordset

Health and Social Care

University of Essex

Dear Maria,

#### **Ethics Committee Decision**

Application: ETH2526-0166

I am pleased to inform you that the research proposal entitled "Including people with learning disabilities in conversations about the climate crisis" has been reviewed on behalf of the Ethics Sub Committee 1, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

#### **Extensions and Amendments:**

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

#### **Covid-19:**

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance team

**Ethics ETH2526-0166: Miss Maria Barker-Nordset**

This email was sent by the [University of Essex Ethics Review Application and Management System \(ERAMS\)](#).

# Appendix L

## Community centre governing body research approval

**From:** [REDACTED]   
**Subject:** Research  
**Date:** 30 March 2025 at 18:06  
**To:** [REDACTED]  
**Cc:** [REDACTED]



**CAUTION:** This email originated from outside our organisation. Do not click links or open attachments unless you recognise the sender and know the content is safe. If you are not sure it is safe, please contact the IT Helpdesk.

Afternoon Maria,

I have been forwarded your email regarding research for your Doctorate from [REDACTED].

[REDACTED] would be happy to support you with your research and if you contact [REDACTED] she will facilitate and work with you in [REDACTED].

Regards

[REDACTED]

[REDACTED]  
[REDACTED] and [REDACTED]  
[REDACTED] & [REDACTED]  
[REDACTED]

**M:** [REDACTED]  
**P:** [REDACTED]  
**E:** [REDACTED]

[REDACTED]

[REDACTED]

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**Consider the environment. Please don't print this e-mail unless you really need to.**

## Appendix M

### Easy-Read Participant Information Sheet



University of Essex

#### **Taking part in a research project**

Introducing the Researcher and Information  
about the Research Project (Study  
Information Sheet)



Adapted from forms developed by:

Amy Colla, Trainee Clinical Psychologist, Doctorate of  
Clinical Psychology, 2017 Cohort, University of Essex

Bennett, D., Flood, S., Howarth, J., Melsome, M., Northway,  
R. (2013). *Looking into Abuse: Research by People with  
Learning disabilities*. Wales: University of Glamorgan and  
People First and New Pathways.

## Introducing the Researcher



This is Maria Nordset

She is a Trainee Clinical Psychologist.

She is in her second year of training.



She learns at the University of Essex 2 days a week.

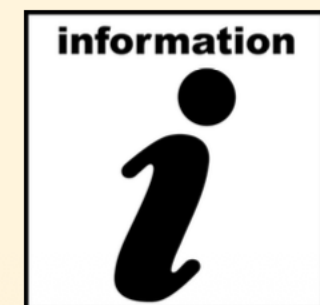


She works in the NHS on Wednesdays, Thursdays, and Fridays.



She will do a research project for her course.

Research is when we ask people questions to find out new information



She would like to ask if you want to take part in her research project.

This form will tell you information about her research project to help you decide if you want to take part.

Including people with learning disabilities in conversations about climate crisis

## Information about the Research Project



Our planet is getting a lot warmer.

This is called climate change.



Climate change can affect:

- weather
- temperature
- air pollution
- water
- people's health
- how people feel



Many people think about climate change and try to help stop it by making small changes, like recycling or planting trees.

People with learning disabilities have not yet been asked about their views and this is important because people with learning disabilities can be at risk if there are big changes to the weather.



Information about climate change is often not easy to understand.

This research will ask people with learning disabilities questions about their thoughts, feelings and opinions about climate change.

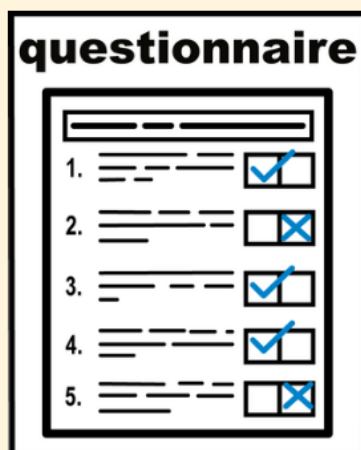
Including people with learning disabilities in conversations about climate crisis



If you want to share your thoughts and feelings about climate change then Maria will arrange to meet with you in person.

You can have a support person with you.

### What will happen in the interview?:



You will complete a form that asks for information about you, for example your age and ethnicity.



You will do an interview with Maria that she will record.

This will take 45 to 60 minutes/1 hour.

Maria will delete the recording once she has written down what was said.





Climate change is a subject that can make some people feel anxious. If you become upset or anxious, Maria and the staff at Project49 team can help you, or help you find someone to talk to.



Maria will keep anything you tell her safe and private. However, if you tell Maria that you or someone else is being hurt, Maria will talk with you about who she needs to tell.

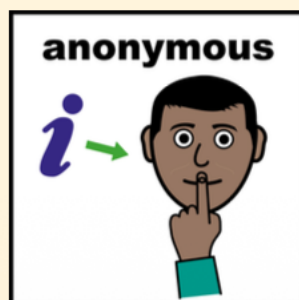


Alison and Joseph, who are teachers at the University of Essex, will help Maria with her project. Only Maria, Joseph and Alison will see or hear what you told Maria.



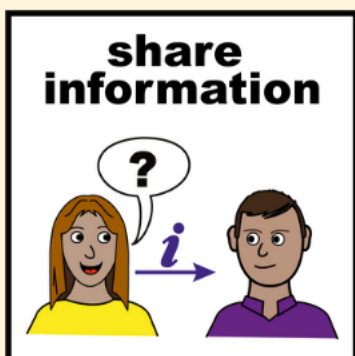
Maria will do a report on what she finds out.

Maria will use what you have said in the report.



Maria will not use your name in the report. This means no one will know that you said anything.

Including people with learning disabilities in conversations about climate crisis



If you decide to take part in the project, Maria will tell you what she finds out. Maria will also tell other people with learning disabilities, carers and professionals what she finds out. She will use journals and conferences.



A group of people with learning disabilities will help Maria with her project.



You can stop doing the research at anytime. You do not have to give a reason. This is ok.

It will not change the care you receive from Project49.



Once the study has finished, the information you gave will be stored safely at the University of Essex for 5 years, in case the research team need to check it.

If you want to know more about this, you can ask Maria any questions.

Including people with learning disabilities in conversations about climate crisis





University of Essex



If you take part in the project, you will get a £5 gift card after the interview as a thank you for your time.

Thank you for your time

Maria Nordset, Alison Spencer and Joseph Rehling

Including people with learning disabilities in conversations about climate crisis



## Information about the Research Project Reporting Concerns and Complaints



If you have any concerns or complaints about the study you or someone who supports should follow these steps.



**1.** If you have any concerns about any part of the study or you have a complaint about the study, the first person to contact is the researcher, Maria Nordset by email: [mbjorka@essex.ac.uk](mailto:mbjorka@essex.ac.uk)



**2.** If you are still concerned, you think your complaint has not been dealt with or you feel that you cannot speak to Maria, please contact Maria's supervisors, Dr Joseph Rehling or Dr Alison Spencer, by email.

Joseph's email: [jr18520@essex.ac.uk](mailto:jr18520@essex.ac.uk)

Alison's email: [as16018@essex.ac.uk](mailto:as16018@essex.ac.uk)



**3.** If you are still not happy, please contact the University's Research Governance Team by email. Please include the project number in your email: ETH2324-1938

The team's email: [reo-governance@essex.ac.uk](mailto:reo-governance@essex.ac.uk)



**4.** You can also contact the University's Research Integrity Manager, Dr Mantalena Sotiriadou

Mantalena's email : [ms21994@essex.ac.uk](mailto:ms21994@essex.ac.uk) ),

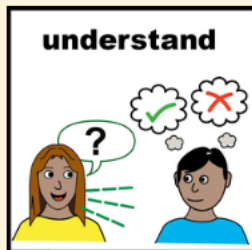
Including people with learning disabilities in conversations about climate crisis



## Information about the Research Project

Name.....

Date.....



I understand what the project is about.



Yes



No

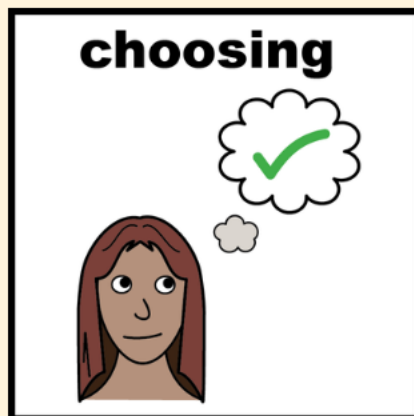


Not sure

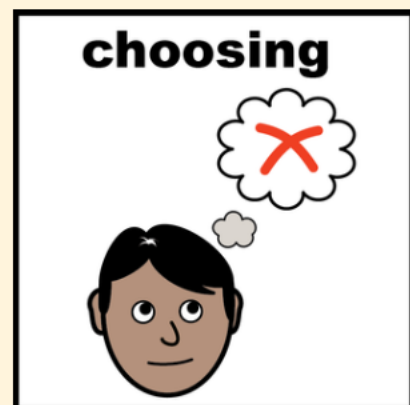
You will receive a copy of this form

# Visual cards for Yes, No, Not sure questions

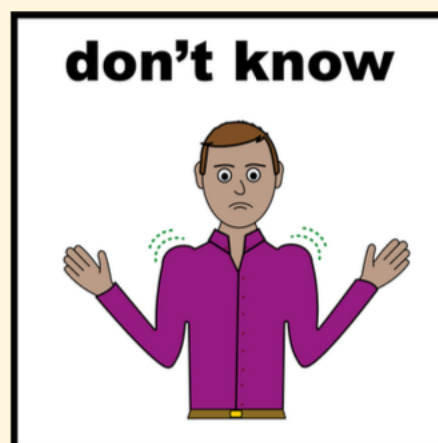
**Yes**



**No**



**Not sure**



Including people with learning disabilities in conversations about climate crisis

## Appendix N

### Easy-Read Consent Form



#### **Taking part in a research project**

- Consent to contact form
- Consent to take part in the research form
- Consent for respondent validation



Adapted from forms developed by:  
Amy Colla, Trainee Clinical Psychologist, Doctorate of  
Clinical Psychology, 2017 Cohort, University of Essex

Bennett, D., Flood, S., Howarth, J., Melsome, M., Northway,  
R. (2013). *Looking into Abuse: Research by People with  
Learning disabilities*. Wales: University of Glamorgan and  
People First and New Pathways.

The pictures have also been taken from various online  
sources.

## Consent to contact form

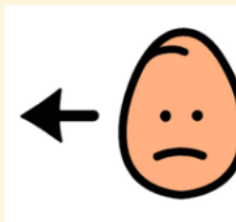
Name:.....

Date:.....



### Important

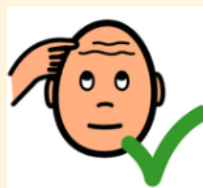
This form asks for your permission for some things



You do not have to say yes.  
**It is OK to say no.**



It is OK to say you are not sure.



It is OK to ask for time to think about it.

**Project 49**

Your service will be the same if you say yes or no.



I understand this information.



Yes



No



Not sure

Including people with learning disabilities in conversations about climate crisis

## Consent to contact form

Name:.....

Date:.....



If you would like to take part in the project, Maria will phone you or speak with you at Project49 to ask you if you want to do the interview.



You and Maria will pick a day you can do the interview. You can have a support person with you.



Maria will tell the team you are taking part in the study.



I understand this information.



Yes



No



Not sure



I am interested in finding out more about the project.



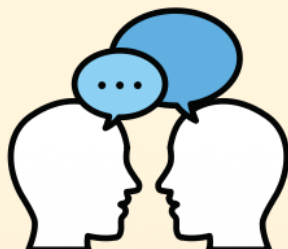
Yes



No



Not sure



I agree for Maria to speak with me to ask me if I want to do the interview.



Yes



No



Not sure

Including people with learning disabilities in conversations about climate crisis

**Consent to contact form****Name:.....****Date:.....**

Name:.....

My phone number:.....

Maria will call you on this phone number

Sign:.....

Date:.....

You will receive a copy of this form

Including people with learning disabilities in conversations about climate crisis



## Consent to take part form

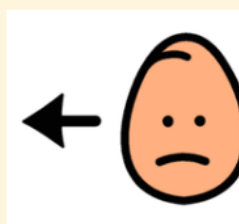
Name:.....

Date:.....

### Important



This form asks for your permission for some things



You do not have to say yes.  
**It is OK to say no.**



It is OK to say you are not sure.



It is OK to ask for time to think about it.

### Project 49

Your service will be the same if you say yes or no.



I understand this information



Yes



No



Not sure

Including people with learning disabilities in conversations about climate crisis

## Consent to take part form

Name:.....

Date:.....



I understand what the project is about.



Yes



No



Not sure



I agree to be interviewed by Maria.



Yes



No



Not sure



I agree for the interview to be recorded



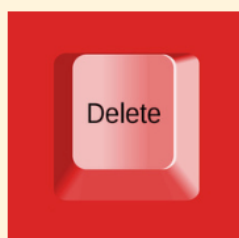
Yes



No



Not sure



Maria will listen to recording again and write down all the information from it. Maria will then delete the recording.

If we do a video call, Maria will also delete the video.

**Consent to take part form****Name:**.....**Date:**.....

I understand that all the information I give will be kept safe and private. Maria, Joseph and Alison will not share it with anyone else.



Yes



No



Not sure

**MY NAME**

I agree that anything I say can be used in the report. My name will not be used.



Yes



No



Not sure



Maria will use a secret name for me. This means no one will know I said anything. It is like wearing a disguise. I can pick my own secret name.

**My secret name is:**

Not sure



Maria can choose

## Consent to Respondent Validation

Name:.....

Date:.....



When Maria is writing her report she will look at all the information that people who took part in the study told her.

She will work out what information is important and interesting to tell other people about. Maria would like to check with some of the people who took part in her study that they think this is important and interesting information too.



If you want to do this with Maria, she will send you the information in the post or by email, then invite you to a meeting to share the information.

Maria will tell the team she has contacted you.

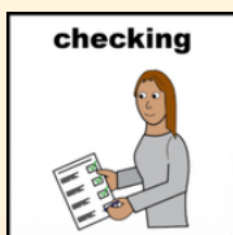


I understand this information.

☐ Yes

☐ No

☐ Not sure



I am interested in checking the information with Maria

☐ Yes

☐ No

☐ Not sure

Including people with learning disabilities in conversations about climate crisis



## Consent to Respondent Validation

Name:.....

Date:.....



I agree for Maria to phone me to arrange a time to check the information with me, after the interview.



Yes



No



Not sure

Sign:.....

Date.....

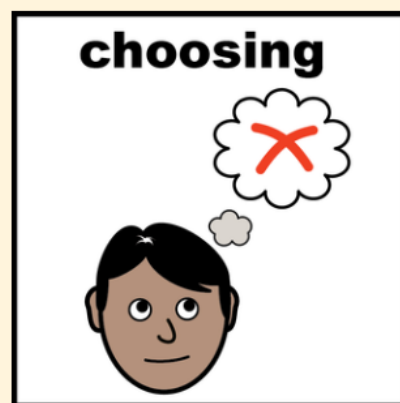
You will receive a copy of this form

# Visual cards for Yes, No, Not sure questions

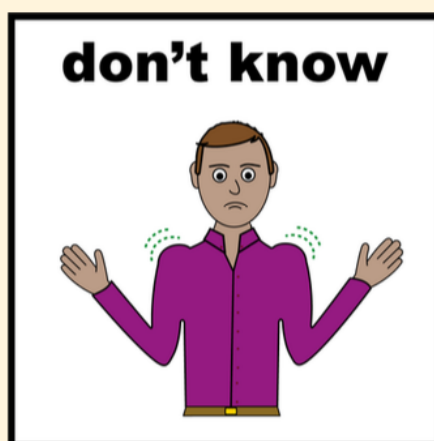
Yes



No



Not sure



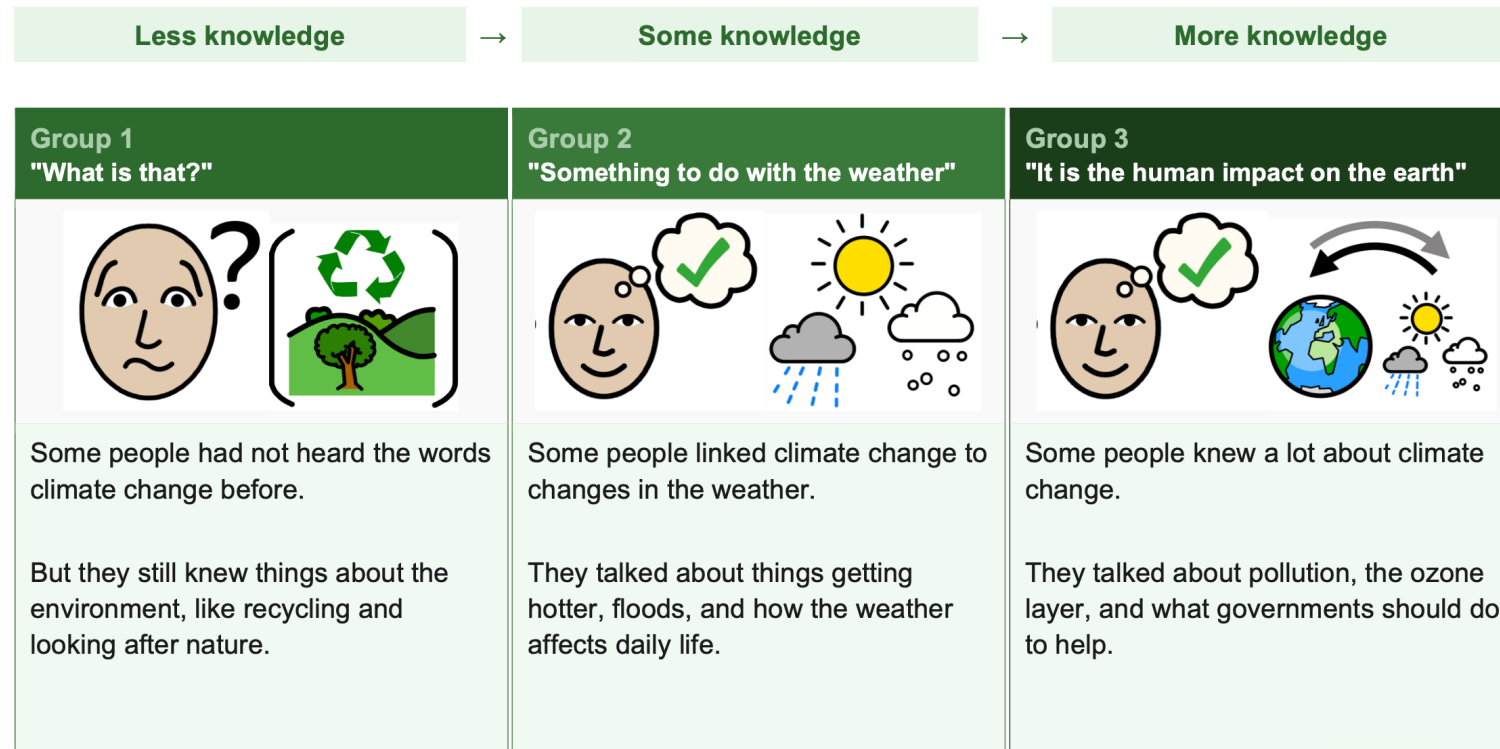
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## Appendix O

Easy-read version of Figure 2

### Theme 1: Understanding Climate Change

People with learning disabilities understand climate change in different ways.



**What does this mean?** People with learning disabilities understand climate change in lots of different ways. This is not because of what they can or cannot do. It is because they have not always had the chance to learn about it.

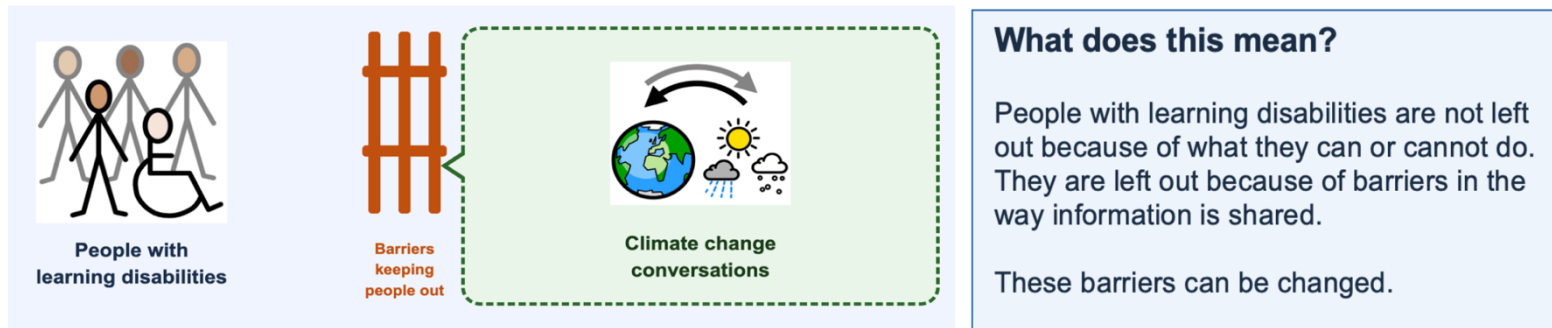


## Appendix P

Easy-read version of Figure 3

### Theme 2: Inaccessible Climate Change

People with learning disabilities are often left out of conversations about climate change.



There are three main barriers why this happens:

#### Reason 1

##### Not understanding

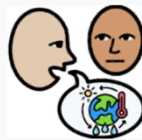


Most people find out about climate change from the television or the news. But the news is not always easy to understand.

There is very little climate change information made especially for people with learning disabilities.

#### Reason 2

##### Not being told



People with learning disabilities want to learn about climate change. But no one comes to tell them about it in an accessible way.

Information needs to come to them. People should not have to find it on their own.

#### Reason 3

##### Not being included



Some people think that people with learning disabilities do not understand climate change.

But this is not true. People with learning disabilities do understand. They just need information in an accessible way.



## Appendix Q

Easy-Read Research Summary for Participant

### About this research

---



#### Who did this research?

My name is Maria. I am a psychologist.  
I did this research as part of my studies.

---



#### What was this research about?

This research was about climate change.

Climate change means the weather and  
the world around us is changing.



This is mostly because of changes in the  
way we live, like using cars and factories  
to make energy.

---

#### I wanted to find out:

- What do people with learning disabilities know about climate change?
- How do they feel about it?
- Would they like to be part of conversations about climate change?



### **Who took part?**

14 people with learning disabilities took part. They all attended a day centre in East England.

Each person had a one to one conversation with me about climate change.

9 people also came to a group meeting where I shared what I had found.

---



### **What did we find out?**

People with learning disabilities know lots of things about climate change.

Some people knew a little bit, like that it is connected to the weather getting hotter or colder.

Some people knew a lot, like that people and governments need to do more to protect the planet.

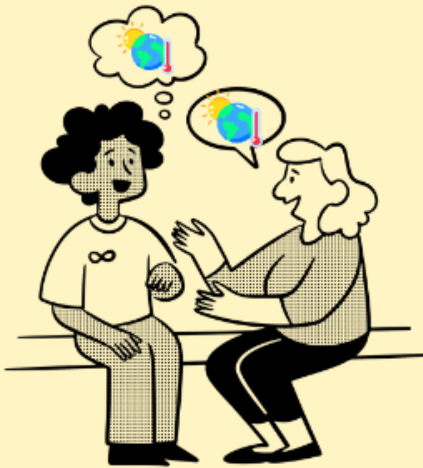


Everyone had something important to say.



## What did we find out?

People said they would like to know more about climate change.



They said it would help if someone came to talk to them about it, rather than expecting them to find out by themselves.



People also said they felt left out of conversations about climate change. They felt that other people thought they would not understand.



This is not fair. People with learning disabilities have the right to be included in these important conversations.

### **What does this mean?**



The problem is not that people with learning disabilities cannot engage with climate change.

The problem is that information about climate change is not made accessible enough, and people with learning disabilities are not always included or asked for their views.

This needs to change.

---

### **What happens next?**



The plan is to share the findings of this research by writing a paper and going to a conference. This will help others to understand that people with learning disabilities should be included in conversations about climate change

---

# **THANK YOU**

### **Thank you**

Thank you to everyone who took part. Your time and your thoughts were very valuable.

This research would not have been possible without you