A Carer's Journey

What are the Needs and Experiences of South Asian Informal Parent-Carers for Individuals over aged 18 with a Learning Disability?

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

Introduction

The prevalence of learning disabilities amongst the South Asian community is high. South Asian people with a learning disability are considered to be one of the most neglected groups in the UK and can experience double discrimination due to their learning disability and ethnicity (NHS Race and Health Observatory; NHS-RHO, 2023b; pg. 11). Within the South Asian community, there is stigma around learning disabilities and many South Asian informal carers are unaware of what a learning disability is. Overtime, South Asian informal carers learn to adjust to their child having a learning disability whilst supporting their physical, emotional and medical needs with reduced support. Little is known about their experiences and their needs across the lifespan through significant phases, including childhood, the transition phase (aged 16-18) and adulthood/the present day. This research seeks to understand and build on this.

Method

Semi-structured interviews were completed with six female South Asian informal-carers who were a parent to their adult-aged son/daughter who had a learning disability. Data was analysed using Interpretative Phenomenological Analysis (IPA).

Results

The findings highlighted the individual and shared experiences of all six participants. Shared experiences included a lack of support, feeling disempowered, hidden experiences and feeling abandoned as a South Asian informal carer.

Discussion

The findings are discussed in relation to the current literature. The role of an informal carer was found to be physically and emotionally demanding and is often completed with little support or preparedness. This research has highlighted a need for more support to guide South Asian informal-carers and people with learning disabilities through the lifespan to ensure they are supported. The strengths and limitations of the research have been considered, alongside implications and suggestions for future research.

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Introduction

The experiences of informal carers supporting children with Learning Disabilities (LD) can often involve significant emotional, physical, and social demands. A learning disability (LD) is a lifelong condition characterised by reduced cognitive and intellectual functioning, typically identified during childhood. Individuals with an LD often experience challenges across social, academic, personal, and emotional domains (Russak & Hellwing, 2019). Individuals with LD often require varying levels of support across the lifespan, placing ongoing demands on those who care for them.

An informal carer (IC) is defined as an individual of any age who provides unpaid care and support to a family member, friend, or neighbour with a disability, illness, long-term condition, or age-related needs (Carers UK, n.d.). ICs play a crucial role in meeting these needs, with the prevalence of informal caregiving increasing alongside rising life expectancy (Löckenhoff et al., 2011). While existing research has explored caregiving broadly, there remains limited understanding of carer experiences within the UK South Asian community.

In the UK, the term South Asian is commonly used to describe individuals originating from the Indian subcontinent (Minority Rights Group, 2022). This includes diverse groups such as Indian, Pakistani, Bangladeshi, and Sri Lankan communities, as well as individuals of mixed Asian heritage (Heer et al., 2012; Minority Rights Group, 2022). South Asia is recognised as one of the most diverse regions globally, encompassing a wide range of identities, religions, cultures, and languages (Dokuru et al., 2024).

Many South Asian ICs encounter additional challenges linked to stigma and potential inequalities within health and social care systems. Some carers and their children may experience a “double discrimination” (NHS-RHO, 2023b, pg. 11) due to their LD and ethnicity. Despite this, individuals from South Asian backgrounds are likely to be underrepresented in research (Quay et al., 2017) which results in limited understanding of carer experiences within the UK South Asian community when supporting a child with an LD.

This research therefore aimed to explore the needs and experiences of South Asian informal carers when supporting their child with a Learning Disability (LD) across the lifespan.

This thesis was structured as follows: chapter one introduced the research context and relevant literature; chapter two outlined the methodological approach; chapter three presented the findings; chapter four discussed these findings in relation to existing theory and research.

Chapter One: Literature Review

The following literature review aimed to identify the existing research literature on the experiences and perspectives of South Asian carers who provide care to a person with an LD.

The key concepts identified initially as search terms were, LD, Carer, and South Asian. Further search terms included: intellectual disabilities, Asian, British-Asian, Bangladeshi, Bangladesh, Indian, India, Sri Lankan, Sri Lanka, Pakistani, Pakistan, caregivers, family members, relatives and informal carers. This accounted for variation in terminology across the literature and to ensure closely related terms and synonyms were also included in the literature search. Relevant publications were retrieved from databases including, British Education Index, Cochrane Library, Medline, PsycINFO and Web of Science. Databases were searched from January 2001 to January 2026.

The retrieval results adhered to inclusion and exclusion criteria. Inclusion criteria for the literature review consisted of: (i) South Asian population as outlined above; (ii) people with learning disabilities (PWLD), caring for / carers of someone with an LD; (iii) any methodological approach; (iv) perspectives, needs and experiences of PWLD and / or carers; (v) quantitative and qualitative studies, including relevant systematic reviews. In addition, articles had to be written in English and accessible via peer-reviewed journals. Whilst searching for these terms, crossovers were also identified and included within the literature review, such as experiences of caring for people with LD, the views of LD from the perspective of individuals identifying as South Asian, and South Asian carer needs and experiences. Exclusion criteria for the review consisted of articles which did not include the initial key concepts and articles unrelated to the needs and experiences of people with LD, South Asians and/or carers. Studies which did not provide full text access were omitted from the literature review.

It is important to note that most research within this area that adheres to the inclusion criteria has largely been qualitative.

Learning Disability

A learning disability (LD) is a lifelong reduced cognitive and intellectual ability usually identified within childhood. Individuals with an LD often experience difficulties from a social, academic, personal and emotional perspective (Russak & Hellwing, 2019). Approximately 1.5 million people in the United Kingdom (UK) (1.3 million in England) have a diagnosed LD, including over 950,000 adults aged 18 and over (Office for Health Improvement and Disabilities, 2025). LD's can have a genetic cause or can develop following an accident or illness in utero. Alternatively, a child can develop an LD through illness and/or trauma after birth (Mencap, 2024).

An Intellectual Disability is "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains." (The Diagnostic and Statistical Manual for Mental Disorders: Fifth Edition: Text Revision; DSM-V-TR, 2022, pg. 37). The term 'Intellectual Disabilities' is becoming more common (NICE, 2025). Countries such as Canada, Australia and the USA have adopted this term to replace 'LD' and historical terms such as "mental retardation" (Cluley, 2018, pg. 24). However, in the UK, 'Intellectual Disabilities' is becoming increasingly used in replacement of or interchangeably with LD (Cluley, 2018).

Learning difficulties, such as dyslexia and dysgraphia may be mistaken for an LD. This is when an individual mainly has difficulties with learning information within an academic environment (Khoo et al., 2025). Neurodevelopmental conditions, such as attention-deficit/hyperactivity disorder (ADHD) can also be mistaken for an LD. Neurodevelopmental conditions are categorised as a disruption in brain development (Thapar et al., 2017). This can impact our communication, learning, social skills and behaviour, however the ability to learn and process information within academia may not be directly impacted (Thapar et al., 2017).

Both learning difficulties and neurodevelopmental conditions are lifelong and have an impact on development (Gaddes, 2013). However, what distinguishes an LD from a learning difficulty and a neurodevelopmental condition is the presence of a global developmental delay. A global developmental delay is when an individual is impaired within two or more areas of development, such as communication, motor skills, cognitive abilities, social skills and emotional skills (Riou et al., 2009). However, it is important to note that a person with an LD can also have a learning difficulty and/or a neurological condition (Mencap, 2024).

For the purpose of this research, the term "learning disability" (LD) will be used, as this is more well-known in the UK and has been used for a significant amount of time by professionals, lay people and people with LD (Cluley, 2018).

Diagnosing a Learning Disability

The Diagnostic and Statistical Manual for Mental Disorders is a standard diagnostic tool used by many health professionals to categorise various mental health conditions. The term 'Intellectual Disabilities' was used to replace all references of 'mental retardation' (DSM-V-TR, 2022) and many professionals use the DSM-V-TR (2022) criteria for 'Intellectual Disabilities' to diagnose an LD due to their close association (Cluley, 2018).

The DSM-V-TR (2022) criteria for 'Intellectual Disabilities' states individuals must have an "onset of intellectual and adaptive deficits during the developmental period" (DSM-V-TR, 2022, pg. 37). The British Psychological Society (2015) also state that onset of an Intellectual

Disability is before adulthood. Individuals are likely to have deficits in adaptive functioning which limit one or more activities of daily living, such as independent living, school, work community and/or social participation (DSM-V-TR, 2022). The DSM-V-TR (2022) criteria also state individuals must have deficits in intellectual functions which have been confirmed through a clinical assessment and standardised intelligence testing (DSM-V-TR, 2022).

To diagnose an LD, an initial assessment interview is completed to determine previous and current difficulties as relevant evidence of an LD. This can include obtaining information on the individual's developmental and medical history, cognitive difficulties, impact on activities of daily living, family history and family interpretations (British Psychological Society, 2015). Standardised assessments may also be used alongside assessment interviews to support a diagnosis of LD. These can include the Wechsler Adult Intelligence Scale, Fifth Edition (WAIS-V; Wechsler, 2024), the Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V; Wechsler, 2014) and the Adaptive Behaviour Assessment System-third edition (ABAS-III; Harrison & Oakland, 2015) (British Psychological Society, 2015).

An LD can range from mild to profound (World Health Organisation; WHO, 2022). The International Classification of Diseases-Eleventh Revision (ICD-11; WHO, 2022) states an individual with an LD will have an IQ score below 70. An individual with mild LD will have an IQ range of 50-69. They may have some difficulties within academia but are able to manage basic self-care needs. Individuals with a mild LD are also likely to work and live independently but may require some support. An individual with a moderate LD will have an IQ range of 35-49. They are likely to have some difficulties in academia but may need more consistent support to live an independent lifestyle. An individual with a severe LD will have an IQ range of 20-34. Their language and academic skills are likely to be more impacted and there may be evidence of motor impairments. Individuals with a severe LD are also likely to require daily support for activities of daily living, but there may be some scope for individuals to develop skills in completing basic-self-care routines with adequate support and training. An individual with a profound LD will have an IQ below 20. Their communication and motor skills are likely to be very limited and sensory impairments may also be present. Individuals with profound LD are likely to require daily support for activities of daily living which they cannot complete themselves.

People with Learning Disabilities in Society

Historically, LD was poorly understood in society and many people with LD (PWLD) were labelled negatively (Jarrett, & Tilley, 2022). Although having a diagnosis of LD can be beneficial in getting children and adults appropriate support during their education and employment, some viewed PWLD as different and a threat to learning and adapting within society (Vidyadharan, &

Tharayil, 2019; Jarrett, & Tilley, 2022). There was a belief that the cause of an LD was related to a family curse or punishment and some communities developed religious or medical procedures to cure PWLD (Roth, Sarawgi, & Fodstad, 2019). Other communities and families put PWLD into institutionalised care to support their needs (Walmsley, 2005). However, some PWLD reported experiencing poor living conditions, neglect and abuse within institutionalised care (Roth, et al., 2019).

In the late 20th century, there was a push to de-institutionalise PWLD in the UK. Many institutions were closed, and community-based services were implemented (Glasby, et al., 2025). Community-based services aim to take on the responsibility of caring for adults and children presenting with a range of different needs within the community and reduce inpatient care (Pickard, & Glendinning, 2002; NICE, 2018). Strategies included: providing professionals who can advocate for PWLD, delivering short-term and long-term interventions to support PWLD and providing information, advice and guidance for families and carers (NICE, 2018). Overall, there was a need to support PWLD to live in the community and have equal opportunities to those without an LD (Bibby, 2013; Jarrett, & Tilley, 2022).

Experiences of people with Learning Disabilities

This section will outline experiences of people with LD from various ethnic backgrounds. Labelling theory suggests humans manage the world around them by assigning labels to themselves and other individuals and groups, which can shape identity and behaviour (Becker, 1963 & Lemert, 1951). Labelling somebody with an LD can bring positive and negative responses (Otunyo, 2023). Having a label of LD may help health professionals to understand individual difficulties, so tailored support can be put in place and access to resources and opportunities can be provided (Otunyo, 2023). Labels can also help families and individuals to understand themselves, the LD and how their needs can be supported (Otunyo, 2023). However, labelling theory fails to account for the labels becoming stigmatising and negatively influencing the individual's self-identity and behaviour (Otunyo, 2023). In the context of LD, some may hold stereotypes towards PWLD. There may be assumptions that individuals with LD are less capable of completing certain activities than those without LD, particularly within education (Festus et al., 2010). Whilst the label of LD can provide a sense of community and belonging, attaching such a label, also holds the risk of depersonalising the individuality of the person (Otunyo, 2023).

Lalvani (2015) aimed to understand the complexities, nuances, similarities and conflicts in the interpretations of parents and teachers when educating and raising children with disabilities, including LD, Autism, Down Syndrome, speech impairment and hearing

impairment. Lalvani (2015) conducted semi-structured interviews with 32 parents (2 fathers and 30 mothers) and 30 teachers (20 general education teachers and 10 special education teachers; four males and 26 females) in the USA. Parents were from a range of ethnic and socioeconomic backgrounds and their children were aged between 4-14. Teaching experience ranged between 4-30 years. Using inductive analysis, a technique derived from grounded theory, two themes of the meaning of disability, and beliefs about families of children with disabilities were identified.

The researchers found parents viewed disability labels as stigmatising and feared health professionals and teachers would hold lower expectations of their child. Teachers felt the labels were helpful with supporting the needs of children with LD. Teachers were also found to have positive perceptions about parents of children with disabilities, whilst acknowledging parents may also feel stressed, burdened and experience feelings of grief over the loss of having a "normal child" (Lalvani, 2015, pg. 386). However, parents rejected these views and described themselves as having normal lives. Parents identified stress as stemming from societal attitudes around LD and having to educate others, protecting their child from rejection and ensuring their child was not stigmatised.

Parents also felt the environment was not suited to their child's needs (Lalvani, 2015) which aligns with the Social Model of Disability (The Union of the Physically Impaired Against Segregation and Disability Alliance 1976). This identified that PWLD were not disadvantaged by their impairments but through societal attitudes. The model suggests elements of society may not be equipped to support PWLD and they can be disadvantaged socially, economically and environmentally (Oliver, 2013). This included not having adequate access to buildings and toilets and reduced employment opportunities which can impact finances (Mencap, 2024).

As the sample included a range of disabilities, the research does not allow for direct understanding around the impact of being labelled with an LD. Limited demographic information around socioeconomic background and ethnicity restricts insight to how parents may have viewed the label of disability. Varied teaching experience also restricts understanding around whether those who were newly qualified had different opinions to those teaching for longer periods, especially as views of LD and how PWLD are supported have changed over the years. Despite this, the research has highlighted the positive and negative impact of labelling somebody with a disability and demonstrated how perceptions of disabilities can vary amongst parents and teachers. This emphasises a need for collaborative approaches to support the needs of PWLD at home and in the community.

Kenyon et al. (2014) conducted semi-structured interviews with 8 White-British PWLD (seven males and one female) aged 25-63, all living in England. Three themes of participants developing awareness of their differences and comparing this to those without an LD, the impact of having an LD label, and how participants lived and managed with an LD were identified using Interpretative phenomenological analysis (IPA).

Participants noticed differences with handling money, managing challenging behaviours, regulating emotions and completing academic work. Having practical support, e.g. housing, finances, access to community activities and easy-read information, promoted independence and positive well-being. However, many participants felt the label of LD limited opportunities for them in society and overlooked the positive outcomes, social experiences and talents associated with their identity. For example, having sexual relationships and getting married are common within the LD population, however many are restricted from this (Kenyon et al., 2014).

The researchers acknowledged the gender bias within the sample and that attempts were made to address this. Recruiting more females may have helped to distinguish whether the experience of an LD differs between males and females. All participants did not have their IQ level assessment. They were assumed to "likely" (Kenyon et al., 2014, pg. 258) fall in the mild range of an LD, though the researchers did not disclose how they reached this decision. Inclusion criteria was limited to having an LD diagnosis and exclusion criteria was not presented. There was also a lack of diversity in the study, with only White-British participants being interviewed. This limits how much we can generalise these results to other ethnic populations with LD.

However, Kenyon et al. (2014) also identified that participants felt their outlook on LD was different to how society portrayed them. Being labelled as having an LD provided a sense of group identity amongst participants where they could talk openly about any stigma they faced and work together to bring social change around how LD is viewed. This lends some support to labelling theory as it demonstrates the label of LD provided a sense of group identity.

The research also lends support to social identity theory (Tajfel & Turner, 1979). This explains how group membership can help shape an individual's sense of self (McLeod, 2023). The theory suggests that individuals are likely to have enhanced self-worth, purpose and feeling of belonging when they are part of groups which match aspects of their identity, such as nationality, race, and gender. These are known as in-groups (McLeod, 2023). The theory also discusses the term out-groups, which are social groups that individuals do not identify with (McLeod, 2023). Kenyon et al. (2014) identified an in-group amongst participants regarding their

LD. The label of LD created a sense of cohesion amongst participants where they shared a goal of wanting to bring social change to how LD was viewed and work together to achieve this. In this scenario, the participants' out-group may have been those in society who did not understand their needs and experiences of having an LD. Whilst social identity theory can help us to understand how we choose our social groups based on common aspects of identity, the theory does not give explanation to how ingroups may manage potential conflict (McLeod, 2023). In addition, by categorising individuals into groups, there is a risk of potential stereotyping and prejudice towards out-groups (McLeod, 2023).

In line with social identity theory, 'community' can be understood as a form of belonging and supports a sense of safety and wellbeing (Wiseman and Watson, 2022). Wiseman and Watson (2022) explored the role of belonging with twelve PWLD over aged 18 in Scotland. They also conducted two focus groups with ten adults with LD. Four themes of community violence, impact on wellbeing, devalued and belonging were identified through a thematic analysis.

Most participants experienced bullying, harassment, and victimisation from an early age with some female participants reporting sexual violence in school, on public transport and care settings. It resulted in some participants fearing to leave their homes. Acts of violence were often witnessed by the public and participants felt devalued and ignored as nobody helped them, including feeling dismissed by the police and other professionals. This negatively affected their mental health, contributing to feelings of anxiety and low mood, self-harming behaviours, suicidal thoughts, and/or suicidal attempts. This excluded many participants from the community, diminishing their sense of belonging and having a negative impact on their long-term health and wellbeing. However, participants expressed when they were included within communities, it increased their sense of belonging and self-worth.

This study has contributed to our understanding of the negative experiences faced by some PWLD, highlighting how communities can play a crucial role in creating a space for PWLD to integrate into society and how the absence of this can impact negatively on their sense of belonging. This lends some support to social identity theory (Tajfel & Turner, 1979). When participants were part of a community it promoted a sense of safety and belonging, contributing to a positive impact on individual wellbeing. Wiseman and Watson (2022) also lend support to Sarason (1974) who introduced the concept of "psychological sense of community". This emphasises that people who feel they belong within a community can feel a sense of interdependence and mutual commitment. This feeling encourages community members to want to do more for their community and show their commitment (Sarason, 1974).

However, the study lacks clarity around some of the demographics of participants, such as ethnicity, race and social class, limiting the ability to generalise the findings to other populations. It is unclear whether these may have impacted their experiences of being in the community and their sense of belonging, particularly as previous literature has identified that experiences of LD can vary across ethnic groups.

Experiences of People from Ethnic Backgrounds with a Learning Disability

Pestana (2011) conducted four semi-structured interviews with adults (two females and two males) diagnosed with a mild LD from a range of ethnic backgrounds, including South Asian (Pakistani and Indian) and European (Serbian and Irish) heritage. All participants were receiving support from an independent living project in London. They aimed to explore life experiences of having an LD. Following IPA analysis, four themes were identified of abuse, social isolation, support at work and unmet cultural needs.

These findings have offered some insight into the experiences of PWLD from a South Asian and European heritage. Participants described a lack of social support and limited contact with family and friends, whereas those who were employed in part-time roles reported positive and supportive relationships in the workplace. This highlights the beneficial impact of having a supportive community and how the absence of this may have contributed to the difficult experiences of participants, including bullying in school and community settings. This links to Wiseman and Watson, (2022) who identified many PWLD experience bullying, harassment, and victimisation within community settings which had a negative impact on their emotional wellbeing. When exploring aspects of their culture, participants disclosed they felt unsupported with their cultural needs. Some participants felt their traditions were not supported or understood and there was a lack of culturally meaningful activities to engage with. These findings have demonstrated the need for the wider cultural and environmental context of PWLD to be considered to support their safety, support and integration within society.

Pestana (2011) lends support to social identity theory and the positive impact of in-groups as when participants felt supported, they were satisfied, felt safe and it provided a sense of belonging and achievement. However, this research had a small sample size which impacts how far the findings can be generalised to other populations.

In the USA, Rosetti and Henderson (2013) conducted interviews with participants aged 14-18 (three male and one female) on their experiences of having an LD. Participants identified as Caucasian, Chinese American, Native-American and Latino. Following IPA analysis, three themes of social support, school experiences and understanding of LD were identified. The study found families were key to supporting PWLD and they created a safe home environment.

School was difficult for some participants because their learning levels were different to their peers, which participants felt made them more vulnerable to name calling and bullying. Classrooms were not tailored for PWLD which caused some participants to feel uncomfortable with attending school. Most participants had better experiences in high school as by then they had developed understanding and strategies to support them academically and emotionally, which increased their confidence in their abilities.

The researchers captured the experiences of adolescents with LD, although with a small sample size (n=4). As the study was conducted in the USA, there are problems with generalising the results to a UK population. However similar experiences around exclusion were identified here, and from Wiseman and Watson (2022). Although there was some diversity within the sample regarding race, further research is needed with other racial groups to conclude generalisability. The researchers suggested that PWLD may be more likely to have negative experiences when they lack support to manage the diagnosis and associated difficulties.

This section has summarised literature in relation to the experiences of PWLD, highlighting that many PWLD can face difficulties with adjustment when they are diagnosed with an LD. As they integrate into the community, PWLD can experience a variety of social and emotional difficulties, belonging and support being key to helping them adapt and thrive. This can positively impact mental health, wellbeing, personal growth and achievements. The following section will consider literature in relation to the health needs of PWLD.

Health

PWLD have been found to have poorer mental and physical health needs and comorbidities compared to the rest of the UK population (Michael & Richardson, 2008; Cooper et al., 2015). Comorbidities are when an individual has more than one chronic health condition (Valderas et al., 2009; Truesdale & Brown, 2017). The Learning from Lives and Deaths report for PWLD and Autism in 2022 (White et al., 2023) also found PWLD have a much lower age of death (age 63) compared to the general UK population which was 83 for males and 87 for females. The report highlighted there was possible under-reporting of deaths, however, it was acknowledged that PWLD have a younger average age of death in comparison to the UK population. The common causes for death amongst PWLD included life-long health difficulties, Cancer, flu, pneumonia and cardiovascular difficulties (White et al., 2023). Out of approximately 3648 PWLD who passed away, around half were avoidable deaths (White et al., 2023). PWLD who did not receive adequate care and treatment and/or those from Black, Asian or Mixed backgrounds were also more likely to die younger (White et al., 2023). This supports a previous report from the Independent Inquiry into Access to Healthcare for PWLD in 2008. It was found that many

PWLD had an avoidable death, and the likely cause was a lack of appropriate and efficient treatment (Local Government Ombudsman, 2008).

Access to mainstream healthcare is essential for PWLD to support their needs (Elliott et al., 2003). Approximately £6 billion of UK Government funding supported PWLD and their health needs in 2019-2020. Government initiatives such as introducing annual health checks for PWLD aimed to identify and treat underlying illnesses and minimise the risk of early mortality and ensure they can live a healthy lifestyle (Elliott et al., 2003; NHS Digital 2019; NICE, 2021; NICE, 2024). In 2017-2018, only 55% of PWLD attended their annual health check, (NHS Digital, 2019). Most PWLD were found to be missing from the LD register (NHS Race and Health Observatory; NHS-RHO, 2023a; Lodge et al., 2011). The LD register identifies all individuals with an LD so health professionals make reasonable adjustments, such as providing easy-read information, allowing carers to attend appointments, offering longer appointments and offering quieter spaces (NHS England, 2025). This issue appeared to impact the South Asian community as some parents of PWLD reported their General Practitioner (GP) was unaware of an annual health check or that an LD register existed in the UK, suggesting there may be some underrepresentation of South Asian PWLD (NHS-RHO, 2023a; NHS-RHO, 2023b).

Whilst Government initiatives appear supportive, recent proposed cuts of £5 billion of disability payments, such as universal credit in the UK, may impact the ability to afford additional costs associated with living and health, e.g. accessible transport, heating and specialist food required to support the needs of PWLD (Stacey et al., 2025; Mencap, 2025). The proposed Government cuts are also likely to impact PWLD as their ability to work may be compromised by their fluctuating or progressive health needs (Ryan, 2025).

COVID-19

The COVID-19 pandemic highlighted inequalities for PWLD. Between 2020-2022, there was a reported 134% increase in mortality despite government guidance for PWLD to isolate in their homes due to their high susceptibility to catching COVID-19 (NHS-RHO 2023a). Scherer et al. (2023) explored the experiences of 24 PWLD (aged 18-65; 13 females and 11 males) in England and Scotland during the pandemic using semi-structured interviews. A thematic analysis identified four themes of feeling ignored, invisible and neglected by the UK Government, reduced care and support, disrupted routines and delayed vaccine prioritisation.

Participants reported feeling unprioritized during the COVID-19 pandemic despite their high vulnerability. Many felt disappointed about the lack of easy-read information which excluded them from knowing the status of the pandemic. Reduced care packages resulted in many PWLD not receiving the care they needed and many felt this was not compensated for by

the Government, leaving many feeling unsupported and isolated, increasing distress. Routines were disrupted and many participants felt they lost independence and became more reliant on family members.

The research suggests that the Government responses during the COVID-19 pandemic resulted in many PWLD feeling disadvantaged, and appeared to exacerbate their risk and vulnerability, negatively impacting their physical and mental health. Limited demographic information around ethnicity, social class and severity of LD has reduced our understanding of how these factors may have impacted their experiences, particularly as Patel et al. (2020) highlighted more Ethnic Minority individuals, such as those from the Black and South-Asian communities, were disproportionately impacted by the COVID-19 pandemic. Pre-existing health conditions, material deprivation and lower socioeconomic positions were common amongst Ethnic Minority households and likely contributed to early mortality (Patel et al., 2020). From the literature, we are aware that PWLD also face similar disadvantages so it may have been helpful to have further understanding on whether additional social factors potentially further disadvantaged PWLD and created a different experience during COVID-19.

Cavanagh et al. (2025) aimed to explore carers experiences of supporting family members with profound and multiple intellectual disabilities during the COVID-19 pandemic. Six family members, all White-British (3 mothers, 2 fathers and 1 sibling) took part in two interviews, the first being an opportunity to share experiences of caring for a family member with intellectual disabilities during the pandemic, and the second exploring in-depth, the topics that arose during the first interview. All data was analysed using thematic analysis and produced four themes: deepening exclusion and inequality, feeling exhausted by the pandemic, trauma and feeling the future was scary.

Participants felt the pandemic exacerbated existing health and social inequalities, making them feel overlooked and invisible. The removal of support services and visiting restrictions imposed by the Government resulted in families feeling abandoned, exhausted and more pressured and stressed. The circumstances around the pandemic also raised further concerns for families around whether loved ones could potentially be excluded from lifesaving treatment should they have fallen ill with COVID-19. Disrupted routines, activities and relationships removed participants' sense of security and structure and deepened psychological trauma for some. However, others reported positive outcomes following the disruption, such as finding new activities for their family member to engage in. The relationships between participants and their family members were also varied. Some participants reported strained relationships, others felt unsupported to have regular contact with their family

member who was in residential care and felt they were being deliberately prevented from seeing and communicating with their loved ones. Finally, participants expressed fears about the future of their family member's care and worried about institutionalisation. This promoted many families to plan for the future to ensure their family member was safe and looked after.

Cavanagh et al. (2025) provided insight to the experiences of family members looking after somebody with an LD, particularly during the COVID-19 pandemic. Despite the small sample size, the findings have indicated that family members can experience psychological trauma related to their caring experiences and this can have a long-term impact on emotional wellbeing. As challenges within health and social care services continue following the pandemic, this can increase the vulnerability of people with LD especially as they are at increased risk of multiple and complex health conditions which require ongoing management (Cavanagh et al., 2025), placing further strain on carers. The following section considers literature in relation to carers.

Carers

An informal carer (IC) is "a person of any age who provides unpaid care and support to a family member, friend or neighbour who is disabled, has an illness or long-term condition, or who needs extra help as they grow older" (Carers UK, n.d., para. 1).

ICs have become increasingly common as life expectancy lengthens (Löckenhoff et al., 2011). The 2021 Census (Office for National Statistics; ONS, 2023) states there are 5 million ICs in England and Wales. Carers Week (2022) have estimated there are 10.8 million ICs in the UK. They are not employed professionally, nor is this completed through a voluntary organisation (Department of Health and Social Care; DHSC, 2016; ONS, 2023). The 2021 Census (ONS, 2023) identified approximately 4.4% of England and Wales residents aged 5 years and over are providing up to 19 hours of unpaid care per week. Alongside this, approximately 2.5 million IC in England and Wales, are balancing caring responsibilities alongside full-time employment (Carers UK., n.d.). Unpaid care provided by ICs has been found to contribute £162 billion per year to the UK economy; a figure that exceeds the National Health Service (NHS) budget in England alone, which was £156 billion in 2020-2021 (Petrillo and Bennett, 2023).

The Role of a Carer

The specific tasks completed by ICs are vary depending on the needs of the individual being cared for (Ike et al., 2024). This can range from covert monitoring of a cared-for individual to 24-hour care of a highly dependent individual (Payne & Ellis-Hill, 2001), including supporting the person with activities of daily living such as bathing, toileting, feeding and dressing, as well as supporting medical needs (Knowles et al., 2016). Tasks can include attending appointments,

regularly monitoring the health status of the individual and undertaking nursing tasks such as giving medication/injections, changing catheters, and tending to wounds Such tasks can place a physical demand on ICs and reduce their opportunities for socialisation and employment due to the time constraints they may bring (Payne & Ellis-Hill, 2001).

The demands of providing care to a family member can impact the carers physical and psychological health resulting in a greater propensity to stress, depression and anxiety, as well as physical health conditions such as arthritis, high blood pressure and limited physical activities (Grey et al., 2018). Jorgensen et al. (2010) aimed to identify the characteristics and demographics of carers (n=300, 242 females and 58 males) in New Zealand and their unmet support needs using a mixed methods design. Quantitative data was collected via the Centre for Epidemiologic Studies Short Depression Scale (CES-D 10; Radloff, 1977) and the Caregivers Reaction Assessment (CRA; Given, 1992). Qualitative data was also collected via telephone interviews. Most carers (n=180) were aged 30-59 and care recipients included partners, parents and children with Dementia, neurological conditions and developmental conditions.

The researchers found 85% of carers showed signs of moderate-severe stress on the CRA (Given, 1992) The highest levels of stress were found in carers aged 30-59. Scores from the CES-D 10 (Radloff, 1977) showed 89% of carers reported depression, with the highest levels of depression found in carers aged 30-39.

Qualitative data was analysed using a General Inductive approach and produced two themes: 'support needs for themselves' and 'the impact of caring on their lives'. To summarise, participants felt they needed more information when they first became a carer, particularly to help access services and support to assist them in their caring role. Participants reported a need for financial support due to the person's specific needs and being unable to remain in paid employment due to inflexible working arrangements. Many participants expressed they had little free time for their own activities reducing social interactions and increasing isolation.

Jorgensen et al. (2010) has provided a richer understanding of the unmet needs of carers. Although causality cannot be predicted, the use of qualitative and quantitative methods can help us understand what may be contributing to the stress, burden and depression faced by carers that they report. However, despite its large sample size, notably all participants were from New Zealand. The authors did not highlight diversity in the sample which means we cannot extrapolate whether differences in the needs of carers are apparent across these domains. In addition, the researchers have not distinguished whether different health conditions place different needs for carers. It may have been helpful for the researchers to distinguish between

health conditions to help illustrate whether different health conditions potentially create more or less psychological impact.

Alternatively, many carers are also found to be nurturers and feel a sense of obligation, commitment, altruism and self-sacrifice to care for a dependant family member (Sharma et al., 2016; Ike et al., 2024). Seligman (2011) introduced PERMA, a positive psychology model, which states five components (positive emotion, engagement, relationships, meaning and accomplishments) that individuals pursue, as they contribute to positive wellbeing.

Positive emotions are an indicator of flourishing and include hope, compassion, gratitude and love. When these emotions are integrated into daily life, it promotes resilience and positive wellbeing reducing the impact of negative emotions. To achieve this, individuals are encouraged to spend time with people they care about, do activities that interest them and focus on the things that are going well in their lives. Engagement is focussed on flow and living within the moment. Individuals are encouraged to focus on the task presented in front of them and spend time doing the activities they enjoy, whilst watching, listening and observing the things around them to identify their strengths. Positive relationships refer to feeling loved, supported and valued by others including partners, family members, friends, work colleagues and their community. To build positive relationships, individuals are encouraged to join social groups to create friendships and connections. Meaning refers to having a purpose which helps individuals to focus on what is important for them when facing significant challenges. To build a sense of purpose, individuals are encouraged to find activities and people they connect with and use their values and passions to guide them. Accomplishments include perseverance and having the passion to achieve a goal (Seligman, 2011).

Mishra et al. (2023) used the PERMA model (Seligman, 2011) with an aim to understand the nature of positive caregiving and what factors contributed to this among 100 family carers (74 females and 26 males) of older adults in India. Participants were daughters, daughters-in-law and sons, aged 30-50. Semi structured interviews with questions devised around the PERMA model (Seligman, 2011) were analysed using a thematic analysis. To understand the nature of positive caregiving, four themes were identified: caregivers attitude, care and compassion, roles and responsibilities and beliefs and values. To understand what factors contributed to positive caregiving, four themes of meaningfulness in life, sense of belonging, personal growth and empathetic understanding were identified.

Caring brought meaning to participants' lives and was viewed as respectful and showing gratitude for their family member looking after them when they were younger. It was a way for participants to uplift their family member whilst giving them fulfilment, purpose and

satisfaction. This made their family bond stronger as they developed closer relationships amongst themselves which contributed to their spiritual development and family welfare. The caring role was seen to help to bring good deeds and good karma to the family and support carers to be more disciplined, organised and self-regulated. Participants recognised that although the role was difficult, they could learn how to be patient, regulate their emotions and manage their time between their caring role and their own work and families. They developed a greater empathetic understanding towards their family member, enhancing their ability to meet their physical and emotional needs.

The researchers have provided insight to the positive aspects of caring for family members. However, using purposive sampling from four cities in India and a sample predominantly consisting of adult-aged children caring for older relatives limits generalisability to other countries and other types of carers, such as children. The research has not acknowledged the needs of the care recipients to understand the responsibilities of the participants and whether this may have affected their attitudes to the caregiver role. Despite this, using the PERMA model (Seligman, 2011) appears to have help identify that caregiving can promote positive attitudes and emotions, meaningful engagement and positive wellbeing. It can also strengthen the family bond and provide an overall sense of valued accomplishment.

Professionals Engagement with Carers

Some ICs may adapt to the role of a carer with readiness, whereas others may struggle to manage the increase sense of responsibility (Payne & Ellis-Hill, 2001). Many are likely to liaise with health and social care professionals to support them in their role. Twigg and Atkin (1994) highlight the different patterns ICs may have when engaging with health and social care professionals. These are: carers are resources, carers as co-workers and carers as co-clients (Twigg and Atkin, 1994).

Carers as a resource suggests health and social care professionals automatically assume relatives and spouses will be available for the dependant individual when statutory provision is unavailable (Manthorpe et al., 2003). However, this framework has received criticism for suggesting there is an expectation for family members to adopt a caring role without considering the needs of the IC and potentially taking them for granted (Manthorpe et al., 2003).

Carers as co-workers is when the carer and health and social care professional work alongside each other to benefit the dependant individual (Payne & Ellis-Hill, 2001). To achieve this, there was a recognition for ICs to be involved in treatment planning and being educated about sources of support and specificities such as medication and managing behaviours

(Manthorpe et al., 2003). However, the ideas around this framework can minimise the ICs identity as a relative and change the dynamic of the relationship between the IC and the cared-for individual (Manthorpe et al., 2003).

Carers as co-clients is when carers needs and wellbeing are supported by health and social care services to enable them to carry out their role (Manthorpe et al., 2003). Occasionally, this can be in the form of respite care and financial benefits which are put in place to alleviate some of the responsibilities and burden on carers so they can continue their caring role (Manthorpe et al., 2003). However, this is not a legal requirement, and it has resulted in some ICs being declined additional support (DHSC, 2016).

Nolan et al., (1995), proposed an additional pattern of ICs which was, carers as expert. They suggested that ICs build their knowledge overtime of the dependant individuals needs and therefore are considered an expert within their care. However, Payne and Ellis-Hill, (2001) recognised that power and differences in knowledge can be detrimental to this pattern as ICs may be less inclined to challenge health and social care professionals.

Carer Entitlements

The NHS and Community Care Act (1990) was introduced to provide local councils with more responsibility over social care services (UK Government, 1990). Social care services are part of voluntary and statutory sectors. Their responsibility includes reducing the risk of poor care outcomes and ensuring relevant and necessary support is provided to those who required this at an early stage, including IC (Poon et al., 2022).

To identify the needs of ICs and support them in their role, carers assessments were introduced. Local authorities assess the circumstances of the IC to determine if they are eligible for support based on specific criteria. If the IC is eligible, a support plan is put in place which outlines how the needs of the carer will be met and is likely to involve the use of social care services (Carers UK, 2023a).

However, to qualify for a needs assessment, ICs must be providing “a substantial amount of care on a regular basis” (DHSC, 2016, “what does the care act do; assessments” section). In 2022, only 25% of unpaid carers qualified for a carers assessment (Carers UK, 2022a). Greenwood et al. (2015) also highlighted that many ICs felt social services were more likely to respond in a crisis, as opposed to an IC generally asking for support. The Care Act (2014) also states that carers have a right to an assessment but are not legally entitled to receive support as this is done at the discretion of the local authorities (DHSC, 2016). In addition, some ICs face long waiting times for a carers assessment (Carers UK, 2022a). In 2022, 34% of IC in the UK had been waiting over one year for a carers assessment.

The Joseph Rowntree Foundation (Evidence and Impact Team, 2022) found 44% of working-age adults proving 35+ hours of care per week are in poverty. Carers Allowance is the main source of UK Government funding for carers and as of 2022, 977,506 IC were receiving this (Carers UK, n.d.). Unfortunately, not all carers are entitled to receive carers allowance, and 2.2 million IC reported financial worries around how they can support themselves and the care recipient when they are not entitled to further Government funding (Carers Week, 2022). As a result, many ICs have been forced to cut-back on spending money for essentials such as food and heating, and hobbies outside of work have limited. This has become more common due to the current cost of living crisis in the UK (Carers UK, 2022).

Carers Needs and experiences

As more cared-for individuals are receiving support in the community, ICs have been identified as requiring more support with fulfilling their role as a carer (Chan et al., 2021). This section will explore the literature in relation to carers needs and experiences when supporting a cared-for individual.

Plöthner et al. (2019) completed a systematic review of 40 studies. All articles included in the systematic review directly explored the needs and preferences of ICs for a familial elderly care recipient, with qualitative research being the most prevalent methodology used. Specific needs identified by ICs included organisational needs, informational needs, support needs, and societal recognition.

Organisational needs centred on ICs wanting a work-life balance, so they were able to carry out their carer-related tasks whilst being employed in their usual working role (Plöthner et al., 2019). For some ICs, this was achieved through flexibility at work, where they were able to communicate with their employers about their caring role and receive support, such as carers leave (Plöthner et al., 2019). Respite also supported some ICs with creating a work-life balance (Plöthner et al., 2019). This is a period of rest for caregivers and can allow time for self-care (Mastel-Smith & Stanley-Hermanns, 2012). Previous research has identified that ICs felt weekly, or bi-weekly periods of respite were sufficient to help them rejuvenate and minimise burnout (Mackenzie & Holroyd, 1996). Respite can be organised through third sector organisations, such as a day centre. However, poor quality services and reduced trust and confidence with respite providers were barriers to accessing respite services (Plöthner et al., 2019). Alternatively, care responsibilities can be shared with family members which can alleviate some carer burden (Plöthner et al., 2019). Many family members expressed wanting to take on the caring-role particularly as financial limitations can limit access to community care and institutionalised care (Plöthner et al., 2019).

Informational needs were split into three subcategories: informational needs (related to community services and support), information sharing (related to involvement in care-coordination with professionals) and educational needs (e.g. about safety and symptom management) (Plöthner et al., 2019). When the educational needs of carers' are met, it can give them a better understanding of how to support the needs of the cared-for individual which can help them cope better within their caring role (Gilbert et al., 2021; Poon et al., 2022).

Informational needs were also found to be a need of carers via research conducted Hirakawa et al. (2011). They aimed to explore the priority information needs and sources of family carers of home elderly patients and the difference in information needs according to the severity of their family member's dementia in Japan. Participants (n=475) average age was 65, with 75% being female. Using questionnaires, it was identified that participants required more information on dementia, first aid, available long-term care insurance services, food and nutrition to help support them in their role. Whilst this helps us to understand the specific need of some carers, the researchers have not disclosed content of the questionnaire or whether it was standardised. Therefore, the reliability and validity of the research is uncertain, and the conclusions may be misleading and/or biased.

Plöthner et al. (2019) also identified that carers have multiple needs including financial, medical, social and emotional. Participants highlighted a need for financial information and support to be available to them, support in managing medication and symptoms, frequent contact from health professionals and practical support with transport, physical aids and adaptations. Emotional support around the physical and psychological distress of caring was also required due to caregiving potentially inducing stress, depression and anxiety, impacting the carers ability to remain positive within their situation (Gilbert et al., 2021; Poon, et al., 2022). Social support from other carers was found to help alleviate depression (Cannuscio et al., 2004) and stress (Gleeson et al., 2016) and enhance confidence (Kelley et al., 2017) whilst minimising the risk of relationship breakdowns and disengagement from social interactions (Poon et al., 2022).

The Care Act (2014) outlines the responsibilities of local authorities in improving the quality of life for carers and care recipients by providing services, facilities and resources that promote independence and delay deterioration (DHSC, 2016). Carers hold the responsibility of supporting another individual but there was a need for societal recognition in relation to carers wanting more respect, support, encouragement and understanding from society for the role they are doing (Plöthner et al., 2019).

Plöthner et al. (2019) have provided a good overview of the individual and systemic needs of ICs. There is an acknowledgement that many ICs are balancing their caring role alongside employment, which has been reflected in recent statistics (Carers UK, n.d.). Additional research completed following the systematic review has also clarified some of the needs of ICs. The researchers concluded their systemic review by highlighting a need for a structure where families and friends are respected and supported in their caring-role through formal and informal care services whilst ensuring the needs of the dependant individual are met.

However, the majority of studies from the systemic review were focussed on the needs of carers with an elderly care recipient. It may have been useful to include research investigating the needs of carers for care recipients across the lifespan to understand whether carer needs vary depending on the age of the care recipient. Plöthner et al. (2019) also discounted studies where carers were supporting the needs of someone with a disability. As discussed, some PWLD may have additional needs and it may have been helpful to ascertain whether carers for PWLD had more needs given their additional difficulties, compared to carers for elderly recipients. The researchers also did not compare the needs of male and female carers. This may have been useful to understand, particularly following research identifying that white and Asian women are more likely to spend more time doing unpaid care work than males which can increase levels of psychological distress (Xue & McMunn, 2021). In addition, the studies included in the systematic review were from a total of seventeen countries, however the specific ethnicities of the participants were unclear to determine if the needs of carers may be different across ethnicities.

Van Houtven et al. (2010) explored the need, feasibility and content of carer programmes to support informal carers of veterans in the USA through a survey. Participants (n=17) were asked about any training received and what more they needed. The results found approximately 50% carers received training around clinical care tasks, including wound care, blood sugar readings and catheter care. However, participants expressed they would like more training around supporting their self-care and coping with the carer role. 12% of participants reported they were not confident they could take care of the veterans physical needs, and 41% they could not take care of the veterans emotional needs.

The researchers provided some understanding of the need, feasibility and content of carer programmes for carers of veterans but the survey questions are unclear. The small sample size also indicated these results may not be representative of other carers of veterans or carers with family members who potentially have different needs, such as carers of PWLD, thereby

limiting the reliability, validity and generalisability of their findings. Participants were also recruited via veterans who responded to a questionnaire and were willing to provide their carers details, which poses a risk of sampling bias. Using a mixed methods approach may have supported Van Houtven et al. (2010) to gain a richer understanding on the impact of carer programmes on carers and how these could be tailored to fit the needs of carers.

Barbabella et al. (2016) aimed to evaluate the impact of a web-based psychosocial intervention on family carers (n=94) in Italy (n=42), Sweden (n=36) and Germany (n=16) of older adults. 68% of participants were women with a median age of 58 years, most of whom were looking after their parents. The programme included information around coping strategies, available support, general information on diseases and coping via individual and group online support. Pre and post quantitative data included the World Health Organization Well-being Index (WHO-5; Topp et al., 2015), the Carers of Older People in Europe (COPE; McKee et al., 2003) and the Multidimensional Scale of Perceived Social Support (MSPSS, Zimet et al., 1988). Results showed participants reported lower levels of positive feelings and social support following the group, and levels of subjective burden and psychological well-being did not change.

A focus group in each country was also organised to discuss the appropriateness and usefulness of the intervention and participants' experience of using the programme. A content analysis identified five themes: online social support, role awareness, caregiving activities, psychological wellbeing and technical concerns. Participants benefitted from social inclusion and receiving advice from other carers which helped them to feel less burdened and stressed. Their understanding of the caregiver role and condition of the care recipient also increased. However, some participants also noted technical difficulties around accessing some aspects of the programme.

The researchers have shown training programmes can be beneficial for some carers to develop improved self-efficacy, role awareness and social recognition. However, participants' tasks and the health conditions of care recipients were not disclosed, and these may have impacted their needs and experiences. Despite information and social support being provided, the programme did not appear to improve emotional wellbeing, suggesting that carers' emotional needs remained unmet following the intervention. To enhance the research, focus groups could have explored the emotional needs of carers and how the programme can be developed to accommodate this.

Chan et al. (2021) conducted semi-structured interviews with thirty-seven ICs (twenty-eight females and nine males), aiming to explore experiences when accessing social support

from family and community organisations. Age range was from under 18-years-old to over aged 75, with most participants aged 45-74. 22% of carers were from Black and minority ethnic groups and 70% of participants were born in the UK. Cared-for persons were partners, parents, sons and daughters.

The study found 76% of participants sought support from immediate and extended family members which helped to alleviate some stress for the main carer. However, stigmatisation around certain difficulties, such as mental health and alcoholism, meant some carers felt reluctant to seek support from family. This impacted ethnic minority families more than white families. Community organisations, such as local charities, were utilised by many carers who reported positive experiences when accessing. However, the study highlights organisations for Black and ethnic minority populations were more impacted by UK budget cuts which limited their resources to support their communities.

Chan et al. (2021) highlights the importance of social support from families and community organisations for carers. They also highlight the impact of stigmatisation around certain difficulties on the carers ability to seek support. They interviewed a variety of different carers which can help us understand some of the difficulties all carers can face. However, it is unclear which region in the UK all participants were recruited from. There was also no mention of whether additional support was provided to the Black and Ethnic Minority groups who may be struggling with reduced access to community support services, particularly if they also experienced difficulties seeking support from family due to stigmatisation around the difficulties of the individual they are caring for.

Carers of PWLD

Dudley-Hicks, James and Morgan (2025) aimed to explore parental experiences of caring for their child with an LD using the Power Threat Meaning Framework (PTMF; Johnstone and Boyle, 2018). The PTMF offers an alternative view of diagnosis by focussing on five domains (power, threat, meaning, response and strengths) to understand emotional distress (Johnstone and Boyle, 2018). Seven White-British parents (6 mothers and 1 father) watched a video on the PTMF and reflected on their experiences of supporting their child during their transition to post-school services. Data was analysed using a template analysis, with the themes based on the PTMF domains.

Participants experienced power imbalances in various aspects of life. They felt relationships with friends and family were lost which limited their social network. They also described feeling powerless in protecting their child from bullying, marginalisation and distress and when supporting their child with their physical health needs. Participants felt their

children's limitations held more focus and their ability to meet their children's needs were impacted through government laws and policies.

With threat, Johnstone and Boyle (2018) encourage individuals to discuss how power impacted them. Participants experienced threats to themselves and their child, including the loss of relationships with friends and family, threats to employment and financial security and feeling devalued and marginalised in society.

From the perspective of meaning, participants were encouraged to make sense of the threat. The researchers found participants felt powerless and ignored by educational institutions and health and social care services. Despite being responsible for their child, participants expressed having limited influence.

As a response, participants felt the need to advocate for their child to ensure their needs were met. This included challenging professionals and inequalities they may have faced in society. Plöthner et al. (2019) also highlighted that carers have organisational, informational, medical, social and emotional needs. When these are achieved, as identified by Van Houtven et al. (2010) and Barbabella et al. (2016), it provides a sense of empowerment for carers. Creating new narratives about their child's experience was also helpful for participants to manage with the demands of being a carer. Participants felt more compassionate towards themselves and others when focussing on the joy their child had brought. Willmot (2023) discusses how the PTMF can be applied to ethnic minorities to understand their response to power, therefore it may have been helpful for our understanding to see how ethnic minorities can use the PTMF to explore their experiences of caring for their child with an LD.

This was also highlighted within the double ABCX model of family stress. The double ABCX model of family stress (McCubbin & Patterson, 1983) explains how families respond to crises. Component A represents the stressors, strains and demands arising from individual family members, the family system and/or the community. Component B represents the family's resources for meeting the demands and needs, such as social support, religious involvement, skills development and reallocating roles and responsibilities to involve extended family members. This can also include the ability to nurture, which is shaped through the experiences we have in our early interactions with our families (Bowlby, 1969; McCubbin & Patterson, 1983). Here, we learn how to be cared for, and how to be caring towards others (Payne & Ellis-Hill, 2001). Component C relates to the family's definition and meaning to the situation which can provide a new meaning for a crisis, such as an opportunity for growth or viewing the situation as a testament to God. Combining A, B and C produce X, the family's ability to adapt and manage the crisis and restore stability. The overall model suggests there are

multiple paths to recovery and these are determined by the family's resources, coping strategies and meaning towards the crisis.

Dudley-Hicks et al. (2025) has provided insight to how the experiences of parents of children with LD can be mapped onto the PTMF. However, these were limited to the transition to post-school services and did not include experiences from childhood to the present day. In addition, there was a lack of cultural variety within the sample as all participants identified as White-British.

South Asian Carers

Approximately 5.5 million people in the England and Wales combined identify as Asian (Bangladeshi, Chinese, Indian, or Pakistani); this is the most common Ethnic group after White (ONS, 2022). "In the UK the term South Asian usually refers to people from the Indian subcontinent" (Minority Rights Group, 2022; pg. 1). South Asian minority groups include Indians, Pakistanis, Bangladeshis, Sri Lankans, and Asians of mixed percentage (Heer et al., 2012; Minority Rights Group, 2022). South-Asia is one of the most diverse continents in the world as it encompasses an array of identities, religious beliefs, cultures and languages (Dokuru et al., 2024). South Asians hold substantial populations across the world due to migration that has occurred over the last 60,000 years (Dokuru et al., 2024). Outside of South-Asia, Canada and the UK hold the largest prevalence of South Asians (Dokuru et al., 2024).

The "State of Caring" survey 2025 (Carers UK, 2025) was a large UK-based survey examining the experiences of ICs. Out of 11,064 respondents, 81% were female, most carers were aged 18-64 and 3% of respondents were also from an ethnic minority group. Tending to the needs of an individual who need care and support is considered culturally normal within many South Asian communities (Victor et al., 2012). However, many South Asian carers may not realise they are a carer and considered as hidden. This is a group of individuals who do not recognise themselves as carers and are therefore less likely to access health and social care services and complete surveys such as the "State of Caring" (Knowles et al., 2016; Carers UK, 2025).

The South Asian community can face higher levels of inequalities and therefore require greater care and support (Victor et al., 2012). The next section will outline the literature examining the needs and experiences of South Asian carers.

South Asian Carers' Needs and Experiences

Merrell et al. (2005) conducted interviews with twenty Bangladeshi carers (sixteen females and four males) from Wales, aiming to identify their health and social care needs. Participants were aged between 16-62, with most participants aged 41-61. Care recipients had

medical needs including Diabetes, Cancer, respiratory conditions, and cardiac problems. Relationships between the informal carer and care recipient were all familial.

The study found most South Asian parents and children cared for each other because it was part of their ethnic identity, and it was a duty to help those in need. Utilising respite services was considered as abandonment and evoked disapproval within the family and community. The commitments of the carer depended on the needs of the care recipient. The researchers also found within some South Asian communities, older children may support the main carer with transportation to appointments, translating information from professionals and running errands, such as buying the weekly shopping (Merrell et al., 2005). Young children are likely to have a role in translating information and emotionally supporting the care recipient (Merrell et al., 2005). For many participants, caring provided a sense of strength, fulfilment, and honour. It was also found that although many carers were supported by family members, some reported their family members did not live nearby and could not lend their support.

Furthermore, caring roles mostly fall onto the females within South Asian families but as many South Asian women continue to have children into later ages, they can hold simultaneous caring responsibilities such as caring for children, spouses and older adults, such as parents and in-laws. To manage, some participants reported making sacrifices around their education and employment, so they had more time to fulfil caring responsibilities (Merrell et al., 2005).

A lack of support from family and health and social care services can also increase the risk of burnout (Merrell et al., 2005). Merrell et al. (2005) found thirteen participants were unaware of the health and social care support services available for them and fourteen participants were unaware of specific financial support. This can be detrimental as many marginalised groups, such as South Asian families, may reside in socioeconomically deprived areas which can increase their susceptibility to having poorer physical and psychological health outcomes (Jaspal & Lopes, 2021). Within socioeconomically deprived areas, access to health and social care services may be limited, potentially reducing access to support (Hepworth, 2005).

Despite this, carers expressed their reluctance to access support services for various reasons. These included feelings around support services having reduced cultural knowledge and not tending to their cultural and religious needs (Merrell et al., 2005). Minimal education on different cultures is evident within the British educational curriculum, with more focus on White-British traditions, culture, and historical figures in comparison to other cultural backgrounds (Commission on Race and Ethnic Disparities; CRED 2021a).

Many carers expressed a need for more professionals from South Asian backgrounds to be recruited into health and social care services (Merrell et al., 2005). Within the organisational structures of most health and social care services, there are fewer professionals from South Asian backgrounds, particularly in senior level positions where changes are determined and implemented (CRED 2021a). This may increase the risk of cultural and religious needs being unconsidered and many South Asian carers may feel obliged to fit within the "white norm" (Merrell et al., 2005; pg. 554). Having more South Asian representation, may encourage this community to access health and social care services, as they may see someone who can understand their cultural and religious needs (CRED, 2021b).

However, all health and social care professionals have a legal and moral obligation to provide a duty of care to treat and support the community, regardless of protected characteristics including race, religion, and belief (DHSC, 2023). Lack of cultural and religious awareness can limit the care and support offered by some services, which contradicts the main aim of the NHS Constitution for England, "the NHS belongs to the people" (DHSC, 2023). Therefore, the responsibility of providing culturally sensitive care lies within all such professionals, regardless of hierarchy and ethnicity (Merrell et al., 2005).

Overall, Merrell et al. (2005) has provided insight into the needs of South Asian carers, specifically Bangladeshi, supporting different family members with varying physical health difficulties. Although their study was conducted twenty years ago, their use of a thematic analysis has highlighted the shared experiences amongst all the participants and showed how the carer role can have similar experiences despite the care recipient's specific needs. However, it may have been helpful to understand if there were any differences amongst the participants' experiences of caring. Using a data analysis method such as Interpretative Phenomenological Analysis (IPA), may have provided this insight as it focuses on the individual stories of each participant as well as the shared experiences.

Hubert (2006) aimed to examine the services which 30 families (24 mothers, 5 fathers and 1 sister) from Black and ethnic minority groups accessed, how appropriate these were and whether they experienced any social, cultural and/or communication barriers when accessing and gaining information. Each family had an adult with LD being cared for at home, with degree of LD varying amongst all participants.

Using grounded theory, the study identified some health and social care professionals may assume that South Asian families will have familial support, so additional need, such as a Social Worker, was not required. Social Workers can support families to access community services and can coordinate between support services. Without a Social Worker, some South

Asian ICs may be unaware of their entitlements. For most participants, including those with large families, they often felt isolated which was further exacerbated by the lack of social networks around them.

The study identified some of the difficulties faced by black and ethnic minority families, supporting Merrell et al. (2005) in regard to many carers not having family support. The large sample size incorporated a mixture of carers who were identified from a local register for PWLD. As previously discussed, more recent research identified that many South Asian PWLD from ethnic minority groups are missing from the LD register (NHS RHO 2023b) therefore, some families may have missed out on an opportunity to partake in the research at the time. All families lived in South-London, with many originating from the Caribbean and India, so their experiences may have differed to those in other regions of the UK or those who were born in the UK.

This section has outlined research in relation to South Asian carers and their needs and experiences, highlighting that they may not always receive support from their family. This, alongside reduced support from health and social care services, has the potential to increase the risk of burnout. For some carers, there was a reluctance to access support from services due to professionals' reported lack of cultural knowledge and attention to religious needs.

LD within South Asian Culture

South Asian countries, such as India, Pakistan and Bangladesh hold various policies and laws to ensure PWLD are supported and protected (Kalyanwala et al., 2019).

In India, disability legislation began with the Persons with Disability Act (1995), later replaced by the Rights of Persons with Disability Act (2016). This legislation defines PWLD as individuals with long-term physical, mental, intellectual or sensory impairment requiring high levels of support (Narayan & John, 2017; Kalyanwala et al., 2019). In Pakistan, they introduced the Disabled Persons (Employment and Rehabilitation) Ordinance (1981), later updated to the National Policy on Disability (2002) to include mental and intellectual disabilities (Chauhdry, 2022). This also highlighted a responsibility of the State to provide medical care, education, training, employment and rehabilitation to people with physical and mental disabilities (Kalyanwala et al., 2019). The legislation defines a person with disability as someone who is visually/hearing impaired and/or mentally or physically disabled (Ahmed et al., 2011). In Bangladesh, they introduced the Bangladesh Persons with Disability Welfare Act (2001), later replaced by the Rights and Protection of Persons with Disabilities Act (2013) (Nuri et al., 2022). This was to reflect a shift in Bangladesh from a medical model to a right-based model which emphasised a need from the Government to ensure all individuals considered to have a

disability will continue to have equal rights to individuals without disabilities (Kalyanwala et al., 2019; Nuri et al., 2022).

Stigma and discrimination towards PWLD can be pervasive across South-Asia (Kalyanwala et al., 2019). In India people with intellectual and developmental disabilities are likely to face more discrimination in the form of being verbally abused, discouraged to continue further education, and being avoided in social interactions (Kalyanwala et al., 2019). Parents of PWLD in India often go through a process of coming to terms with their son/daughter's disability and may blame themselves and experience feelings such as guilt, helplessness and anger (John et al., 2017).

In India, families living in socioeconomically deprived areas are known to be "doubly disadvantaged" (Kalyanwala et al., 2019, pg. 42) as they have reduced access to support services and getting government assistance. Kalyanwala et al highlight that in Pakistan, people with intellectual and developmental disabilities tend to be hidden from society as they are viewed to bring shame to the family and threaten the social status. These families were also likely to feel stigmatised and isolated within their extended families and the wider community creating barriers to their children getting employment. In Bangladesh, parents of children with intellectual and development disabilities are likely to face discrimination due to the stigma attached to their child's disability, and encounter a lack of educational opportunities for their children (Kalyanwala et al., 2019).

This section has summarised the historical and cultural context of LD within south Asian communities. It highlights that policies and laws are in place to protect the needs of PWLD, however, stigma and discrimination towards the LD community continue across South-Asia and the UK. Although the literature around the current context for carers in the UK and the needs and experiences of South Asian ICs is sparse, it highlights a need for further exploration into whether the needs of South Asian ICs have changed or remained the same within an evolving society. The following section reviews literature in relation to South Asian Families, IC's and PWLD in the UK.

South Asian families, informal carers and people with LD in the UK

The prevalence of LD amongst the South Asian community is thought to be three times higher than other communities in the UK (Heer et al., 2012). This has been attributed to potential social and material disadvantages, poorer uptake of maternity services and high genetic risk factors associated with consanguineous marriages amongst the South Asian community (Heer et al., 2012). The Equality Act (2010) states individuals with protected characteristics, for example disability, race, ethnicity and age, should be free from

discrimination and victimisation in services, work, and education (UK Government, 2015). Disadvantages should be removed or minimised for individuals to have the freedom to participate in all areas of life (UK Government, 2015). However, intersectionality highlights that certain protected characteristics influence an individual's position in society (Atewologun & Sealy, 2014).

South Asian PWLD are also considered to one of the most neglected groups in the UK and can experience "double discrimination" due to their LD and their ethnicity (NHS Race and Health Observatory; NHS-RHO, 2023b, pg. 11). South Asian PWLD are considered to have less power in society in comparison to White, middle-class/upper-class, cis-gender, able-bodied males, who are considered to have the most power in society (Mahn, 2020). This suggests White, middle/upper class groups are more likely to have advantages within the social structure. For example, better education to obtain senior level employment positions, and residency in less deprived areas with better access to health and social care services (Mahn, 2020). Thus, South Asian ICs for PWLD may be more likely to be disadvantaged in relation to accessing formal support services. The following section discusses potential barriers for South Asian ICs of PWLD (Mahn, 2020).

Barriers faced by South Asian ICs of PWLD in the UK

Greenwood et al. (2015) defines a barrier as a difficulty which permits and/or limits an individual from accessing a service or need. Much literature has highlighted the various barriers faced by many South Asian ICs of PWLD when accessing support and the community.

One barrier identified for many South Asian ICs is access to high quality services. Many South Asian families reside in socioeconomically deprived areas (Jaspal & Lopes, 2021). Areas such as these are more likely to be of poorer quality due to underfunding which may deter some South Asian families from utilising these health and social care services for support (Greenwood et al., 2015). Underfunded health and social care services may face greater risk of closure which can result in many South Asian families feeling unsupported and at greater risk of unmet needs (Poon et al., 2022).

Another barrier faced by many South Asian families are language barriers (Greenwood et al., 2015). Many South Asian PWLD have reported being excluded from obtaining necessary information due to assumptions around low levels of intellect and ability to speak English (NHS-RHO, 2023a). Many South Asian families may communicate using their native language, for example, Punjabi, Arabic, Urdu. In the UK, English is the predominant language and many South Asian families may not understand English, creating difficulties communicating their needs. Some South Asian families have also reported that translating information into their preferred

language was not sufficient at times due to the use of jargon, and the information not being presented in a culturally sensitive format (Greenwood et al., 2015; NHS-RHO 2023b).

Many South Asian families have expressed differences in understanding between themselves and some professionals. For instance, in the UK PWLD are encouraged to be independent within the community. However, many South Asian PWLD' can face increased racism and discrimination within society; South Asian families feel a need to protect their loved ones, particularly if they have increased vulnerabilities (Kenyon et al., 2014). Some professionals perceive this as parents being overprotective and preventing PWLD from fulfilling an independent life (Bibby, 2013). This highlights that some professionals may have reduced understanding of the additional difficulties experienced by South Asian PWLD and how there may be a conflict of values between how South Asian families and Western society support (Bibby, 2013, & Durling et al., 2018).

Differences in understanding between South Asian families and some health and social care professionals have also been found in the context of utilising respite services. Respite Care can be a sensitive and emotive issue for some South Asian families. For some families, utilising respite services may be viewed as going against the religious duties of looking after family members and can prompt a sense of failure and abandonment (Merrell et al., 2005; Durling et al., 2018). In addition, many parents of PWLD were more likely than parents to a family member without an LD to have their parental rights terminated when caring for their child with an LD (McGaw et al., 2010). Thus, the idea that children do not come back home once they go to respite, could also initiate fear about utilising such services (Hubert 2006).

The historical and current anxieties held by many South Asian ICs for PWLD may also be linked with feelings of grief. Kubler-Ross and Kessler (2005) developed the grief cycle which consists of various stages a person may go through when experiencing grief. These include anger, depression, denial, bargaining and acceptance. The grief cycle is not considered to be a linear process as individuals can move back and forth between the stages during their grieving (Kubler-Ross & Kessler, 2005). In addition, not all individuals will go through the same emotions that are on the cycle (Kubler-Ross & Kessler, 2005).

Some parents of children with LD may experience a process of adjusting to the child they expected and how they may not be considered a "normal family" (Dobson et al., 2001, pg. 26; Fernández-Ávalos et al., 2021). Using semi-structured interviews Fernández-Ávalos et al. (2021) aimed to understand the process of grief and loss of parental carers of children with LD (n=16). Using grounded theory, the researchers identified an LD diagnosis triggered guilt, anger, sadness, fear and search for meaning. Parents self-blamed for their child's LD and felt angry

towards professionals when they felt physically and emotionally unsupported. They reported uncertainties about the future and questioned how the LD will impact their chid. There was a need to understand what happened and seek solutions for their child's LD.

The researchers showed that parents of children with LD can experience grief and loss but a lack of information on ethnicity and severity of their child's LD have limited how these factors may shape their experiences and emotional reactions. Despite this, the findings show grief and loss can be experienced from parents of children with LD. They also align with Summers and Jones (2004) who identified that South Asian families experience feelings of grief at the loss of a "normal child" (pg.688). However, many South Asian families can face barriers alongside processing their grief, which may not be experienced by White families. Thus, it could be suggested that intersectionality can make South Asian families' experience more complex as they navigate their grief and access to services.

Support groups may be offered to bring together South Asian ICs as a community (Parveen et al., 2018). This may also be beneficial for immigrant South Asian ICs who may have reduced social connections (Chan et al., 2021). Culturally tailored support groups can allow South Asian ICs of PWLD to fulfil their practical needs via sharing information and resources and signposting other South Asian ICs to health and social care services available to them (Kramer-Roy, 2012). The emotional needs of ICs may also be met by building their own supportive community, particularly if they are feeling stigmatised (Parveen et al., 2018). However, whilst carer support groups may reduce the risk of isolation and carer breakdown, not all South Asian carers may have access or time to attend (Parveen et al., 2018).

Experiences of South Asian ICs for PWLD in the UK

Devapriam et al. (2008) aimed to compare stress levels in South Asian (n=277) and White (n=465) carers of adults with LD who were identified via the Leicestershire LD register. Most family members were female parental carers under age 65 and LD severity ranged from mild-profound. All participants completed the Disability Assessment Schedule (Holmes et al., 1982) which has items relating to carer stress. Participants were found to support their children with their practical needs, personal care, completing paperwork and accessing the community. South Asian carers reported greater unmet needs than White carers, including long-term moral support, home adaptations, support at home, access to a social worker and GP advice. South Asian carers reported a lesser need for respite care but experience higher physical and psychological stress overall compared to White carers.

The researchers highlighted a need for professionals to be aware of carer stress amongst South Asian families who felt a greater sense of responsibility to support their family

member. Limited cultural understanding meant many South Asian families were reluctant to access support services. However, as all participants were below age 65, it is difficult to consider carer stress and levels of unmet needs across the lifespan.

Durling et al. (2018) aimed to explore how cultural values and practices impacted the experiences of Bangladeshi parental carers (3 mothers and 1 father) of children with LD. Participants were aged 21-50, each receiving at least one form of financial benefits as they were not in paid employment. All participants resided in a London borough which, at the time of the study, was ranked the sixth most deprived borough in the UK.

Using a thematic analysis, the researchers found participants described LD as an "alien concept" (Durling et al., 2018, pg. 1136) and was absent from the Sylheti or Bengali languages. Instead, impairments are spoken about and understood differently, whereas LD was more well-known for professionals. This highlights a need for culturally appropriate ways to educate the Bangladeshi community about LD. Participants described creating a "circle of life" (Durling et al., 2018, pg. 1137) and felt it was their Islamic duty to support a family member in need whilst focussing on the care recipient's strengths. This aligns with the double ABCX model of family stress (McCubbin & Patterson, 1983) which suggests that finding a new meaning for a crisis can give them the ability to cope. Families prioritised seeking spouses who shared cultural values and beliefs around duty to care so family members with LD would always be looked after following parental death. This was partly due to the stigma around LD amongst South Asian communities where some members believe that having an LD or mental illness lowers their status. There was a need for South Asian families to protect family members with LD from possible negative encounters by the community (Gilbert et al., 2021, & Poon et al., 2022). However, this risked further isolation and disrupted family connections (Greenwood et al., 2015, & Gilbert et al., 2021).

The researchers provided insight to the experiences of Bangladeshi parental carers but the limitations in sample size, geographical location and socioeconomic status limits generalisability of the findings. The influence of systemic factors on participant experiences also appears overlooked by the researchers. Despite this, the research identifies a need for professionals to have awareness of how LD is viewed amongst South Asian carers and work collaboratively to develop a shared understanding and guide them to appropriate services.

Heer et al. (2012) aimed to explore the cultural context of caring within the South Asian community and proposed an experiential-contextual framework to understand the experiences of South Asian family carers of children with LD. They suggested that some South Asian parents were more likely to view LD as spiritual and a "test from God" (Heer et al., 2012; pg. 180), which

can influence whether they seek support services. The researchers acknowledged that South Asians are a heterogenous group with diverse languages, religions, education, migration history and financial situations and this may also influence how they view LD and what support they may or may not access. This aligns with Dokuru et al. (2024) who also acknowledged that South-Asia is one of the most diverse continents in the world, with a wide variety of languages, beliefs and cultures. Heer et al. (2012) highlighted the influence of socioeconomic factors on how caregiving is provided by parents and how support is sought. They suggest that carers residing in socioeconomically deprived areas consisting of poverty, poor housing, reduced benefits and unemployment likely face greater stress and burden, which aligns with recent literature. Jaspal and Lopes (2021) identified marginalised groups such as South Asian families may reside in such areas in the UK. Kalyanwala et al. (2019) identified families living in socioeconomically deprived areas are "doubly disadvantaged" (pg. 42) due to limited access to support services and government assistance.

To examine their framework, Heer et al. (2012) conducted two focus groups to explore South Asian parental experiences of caring for a child aged 8-19 with an LD. One group identified themselves as Sikh (two fathers and two mothers) and one group identified themselves as Muslim (two fathers and three mothers). All Sikh parents were born in India and all Muslim parents were born in Pakistan. They had been in the UK for 12-28 years. Interpretative phenomenological analysis (IPA) identified three themes: making sense of their child's LD, feeling let down by services and looking into the future/hopes for their children.

Within the first theme, most mothers reported religion developed their resilience in response to the demands of being an IC because their situation was a test from God. Many parents also felt they needed to adjust to the difficulties their child was experiencing, such as increased medical needs and difficulties with speech. Many parents had also struggled to get an LD diagnosis and reported doctors minimised their concerns about their child's developmental delays, often reassuring parents that these delays were a normal part of their development. Many parents also felt their child's LD was a result of medical negligence, particularly insufficient attention during the pregnancy and birth, and problems with medication.

The second theme focussed on parents feeling let down by services. Many parents felt angry towards their GP as they felt more could have been done to support them and their child. Many participants felt a referral to specialist services relied on the willingness of the GP. Some participants also felt they were not listened to by their GP and there was an over-reliance on prescribing medication as opposed to supporting a referral to specialist services. Many parents

also reported feeling blamed by health and social care professionals for their child's LD and told this was caused by their genetics.

The final theme focussed on parents looking into the future and their hopes for their children. Many participants expressed concerns over the future care of their child and how their child would manage without them. Many parents felt a need to prepare for the future and provide means of security to ensure their child was safe and protected. Some parents also reported a need for services to provide appropriate care to meet the needs of PWLD which may instil confidence in how their child will be supported in the future.

The researchers used focus groups and whilst this is considered cost efficient, some participants may not have felt comfortable talking about their experiences in front of others (Croucher & Cronn-Mills, 2021). They also highlight the experiences of South Asian ICs for PWLD age 8-19 but it is unclear what their experiences were as their children settled into adulthood. Their research was also conducted approximately thirteen years ago, and it is unclear whether participants' experiences remain the same today. However, Heer et al. (2012) provided an insight around how South Asian family carers of children with LD can make sense of their experiences.

Summary of the Literature

The literature review has explored the needs and experiences of PWLD and ICs, including South Asian ICs whilst also considering the literature around South Asian ICs for PWLD. Within this, there are key theoretical frameworks that can be utilised to deepen our understanding such as Becker (1963) and Lemert (1951) labelling theory, social identity theory (Tajfel & Turner, 1979), PERMA (Seligman, 2011), the power threat meaning framework (Johnstone and Boyle, 2018) and the grief cycle (Kubler-Ross & Kessler, 2005).

Overall, it is highlighted that many PWLD can face discrimination and feelings of threat within mainstream society, leading to a sense of not belonging. ICs have various needs in relation to their caring role which can be left unmet, impacting on their ability to care for their loved one. There is a sense of feeling unsupported by family members and health and social care services. For South Asian ICs supporting PWLD, there appears to be a conflict of values, knowledge and opinions between South Asian families and Western health and social care services. This seems to have caused many South Asian ICs to feel reluctant to access support from such services, or they may face barriers when they do access support. When support is not available or not accessed, this may increase the risk of early mortality, which was particularly highlighted during the COVID-19 pandemic. South Asian ICs also appear to face

difficulties within their own community, such as isolation and stigma, which can increase the risk of carer breakdown.

Although legislation has been developed to meet the needs of and improve the experience of IC, this literature review has highlighted that many South Asian IC and PWLD are likely still struggling within their role, some of this struggle being hidden. However, there is a dearth of recent literature investigating their experiences and hearing their needs.

Rationale

Previous research within the context of LD, carers and South Asians has demonstrated that this group of individuals can often face discrimination, stigmatisation and isolation within their families and community. Devapriam et al. (2008) identified that South Asian carers for PWLD experience psychological and physical stress. However, this has not been operationalised to help understanding what may be contributing to carer stress. This was also identified using quantitative methods which do not allow for further exploration and depth with participants stories. Whilst Durling et al. (2018) did use qualitative methods, the use of a thematic analysis has ruled out the opportunity for individual stories to be shared, particularly from an ethnic minority group who are often underrepresented in research (Hammarberg et al., 2016, & Quay et al., 2017). Heer et al. (2012) also used qualitative methods and whilst their choice of IPA did allow for individual stories to be considered, using focus groups meant that the detail of individual stories was potentially lost and some participants may have felt unable to be fully open about their experiences.

Therefore, this study aimed to add to existing literature by building on the work of Devapriam et al. (2008), Durling et al. (2018) and Heer et al. (2012) to explore the needs and experiences of South Asian ICs for familial members aged 18 and over with an LD during pivotal moments across the lifespan. These included childhood, the transition phase (ages 16-18) and adulthood/the present day. Childhood was chosen as this is when children usually receive their diagnosis of an LD and parents are learning about their child's needs and beginning to access services for support. The transition phase was chosen as this is when the child is moving into adult services. Adulthood/the present day was chosen to get an understanding of how carers have managed to access adult services for support. Their experiences at these transition points provide an understanding around what may be contributing to any psychological and physical stress in relation to the carer role. This research also explored how LD is viewed within the South Asian community, particularly as the literature has found many South Asian carers can feel isolated within the South Asian community. In addition, this research looked into how the carer role feels for South Asian carers overall and what their specific support needs were. The

research builds on Heer et al (2012) specifically through 1-1 interviews and using IPA which allowed the individual stories to be shared as well as common group themes identified amongst all the participants.

Research aims and questions

This research aimed to explore the needs and experiences of South Asian ICs for familial members over age 18 with an LD. The research questions were:

- What are the experiences of South Asian ICs when looking after an adult family member with a learning disability across childhood, transition (age 16-18) and adulthood?
- What are the experiences of South Asian ICs when accessing health and social care services for additional support in childhood, the transition phase (age 16-18) and adulthood?
- How do South Asian ICs navigate their role?
- What are the care needs of South Asian ICs?

Chapter Two: Methodology

This chapter aimed to outline the design, the methodology, my ontological and epistemological stance and why Interpretative Phenomenological Analysis (IPA) was chosen for this research over other methodologies. I have outlined the procedure of the research which includes how participants were recruited, interviews completed and data analysed. I have also discussed ethical considerations and reflexivity.

Design

This study used a qualitative design with semi-structured interviews to explore the aims and research question. IPA was used to analyse individual transcripts and to identify themes for each participant, as well as themes across all participants' experiences.

A qualitative design was favoured for its ability to produce rich, descriptive data that would capture individual experiences in relation to the study aims and research question (Howitt & Cramer, 2010). To explore the research question and aims, it was important to understand participants' experiences and perspectives in their own words to inform knowledge, as opposed to producing factual data that may prove or disprove a hypothesis. Quantitative designs were not chosen as they may over-simplify participants' experiences (Hammarberg et al., 2016).

Whilst clinical research helps to inform practice so better outcomes are achieved for all service users, most clinical research is predominantly conducted with white populations (NIHR, 2022, & Dima et al., 2025). Qualitative approaches provide a space for groups of individuals, who are likely to be underrepresented in research, (Hammarberg et al., 2016, & Quay et al., 2017). Including underrepresented groups in research gives them an opportunity to voice their needs, which helps to inform practice.

To determine which qualitative methodology was more suitable to answer the research question, it was important to explore the ontological and epistemological positioning of different methodologies. It was also important to explore my own ontological and epistemological positioning to ensure my views and the assumptions of the chosen methodology aligned. The next section explores my ontological and epistemological positioning and my rationale for choosing a suitable qualitative methodology for this research.

Ontological Position

Ontology refers to the theories and beliefs we hold about our world and whether these beliefs only exist in our minds, or they are a reality (Al-Saadi, 2014). Realism and idealism are the main ontological schools of thought and sit on opposite ends within a continuum. Realism proposes that there is an external reality which we can all see and is independent of our minds

(Al-Saadi, 2014). Data collection from a realist perspective reflects this reality and is uncompromised by the researchers' values and ideas (Willig, 2013). Idealism proposes that reality is subjective. When constructing reality from an idealist perspective, this may be influenced by our values and beliefs (Willig, 2013; Al-Saadi, 2014).

Epistemological Position

Epistemology refers to how we obtain knowledge to understand our perceived reality (Al-Saadi, 2014). Epistemological positions are also set on a continuum, ranging from positivism to interpretivism (Giacomini et al., 2010). A positivist approach assumes that research data is a direct correspondence to reality and sits within a realist ontological stance (Giacomini et al., 2010). An interpretivist approach sits within an idealist ontological stance and assumes that research data reflects individual experiences. The meanings derived from this are based on our values and beliefs and is therefore subjective (Giacomini et al., 2010).

My Positioning

My ontological positioning stands towards an idealist perspective. This was influenced by my socio-cultural background where my own values and beliefs impacted how I viewed the world. I realised this was different to my peers who had a different view of reality, and this led me to believe that multiple realities can coexist. I do not believe our reality is fully concrete and instead, I see the social world as dynamic. I feel our society is constantly changing and evolving based on our ideas, values and beliefs.

My epistemological positioning leans towards an interpretivist stance. This has stemmed from my beliefs around behaviours being influenced by personal experiences. In the section "reflexivity statement" I have written in detail how my personal experiences have shaped me. Considering this, I do not believe that humans are objective. I feel their behaviours have a meaning behind them and we should seek to understand this to inform our own beliefs and ideas. This has drawn me to prefer methodologies that seek to explore and understand human experiences rather than trying to prove a theory.

Interpretative Phenomenological Analysis (IPA)

Ontological and epistemological positions influence the methodology we choose to acquire knowledge and understand reality. IPA is a qualitative method that focusses on how people make sense of their own life experiences (Smith et al., 2022). An experience is something that occurs and can have a significant impact on an individual's life. It felt appropriate to use this methodology for this research as it acknowledges the interpretation of lived experiences from individuals and the researcher (Smith et al., 2022). IPA has three theoretical foundations: phenomenology, hermeneutics and ideography.

Phenomenology

The first theoretical principle within IPA is Phenomenology and relates to the philosophical approach of the experience. This aims to explore individual experiences as they are perceived, and the meanings these experiences have in their lives (Smith et al., 2022). Viewing these events as objective would have gone against the focus of IPA and my own ontological and epistemological positioning (Husserl, 1997). Therefore, it was important to have the phenomenological aspect of IPA within the research to understand the meaning of their experiences in their world.

Hermeneutics

The next theoretical principle within IPA is Hermeneutics and relates to the interpretation of experiences (Heidegger 2005). Interpretation offers deeper meanings and new insights on individual experiences which helps to inform our own personal beliefs and ideas. However, whilst simultaneously trying to make sense of the participants' experiences and understand what is occurring for the participant, researchers can be influenced by their own values and beliefs from their own experiences (Smith et al., 2022). This creates a double hermeneutic. I was mindful that undertaking this research was going to touch on personal experiences for me. Therefore, it was important for me to recognise this and be reflexive, which I have discussed in further detail in sections "reflexivity" and "reflexivity statement".

Ideography

The final theoretical principle within IPA is Ideography. This aspect of IPA focuses on how life events are experienced and understood within the context of each participant (Smith et al., 2022). As individuals from a South Asian background are generally underrepresented in research, it was important to provide participants with a space where they could reflect on their experiences and phenomena from their perspective. IPA also favours smaller sample sizes which allowed me to spend more time with participants to reflect on their experiences with them. This facilitated an in-depth data collection and detailed data analysis.

Alternative Methods

Thematic Analysis (TA) was considered a potential methodology for this research based on its ability to identify and analyse themes within a data set (Braun & Clarke 2021). However, TA views all interviews as one data set and aims to develop group themes and codes. Whilst IPA also encourages the development of group themes, TA does not allow researchers to immerse themself within each individual experience to understand how participants make sense of their reality in the way IPA does. The development of themes through an IPA methodology felt more appropriate for this research as it allowed me to take the time to understand and acknowledge

the participants' experiences from their perspective and for me to immerse myself into the world of those participating.

Grounded Theory (GT) was also considered a potential methodology for this research. This was based on GT's ability to develop new theories and concepts to explain individual experiences using ideas generated from the data analysis (Glaser & Strauss, 2017). However, the aim of the research was to be more exploratory, as opposed to derive theory, therefore GT was not a suitable methodology for this research.

Having explored additional methodologies for this research, the use of IPA over TA (Braun & Clarke 2021) and GT (Glaser & Strauss, 2017) was deemed most appropriate for the purpose of the research question and overall aims. The next section will be discussing reflexivity and my influence on the research.

Reflexivity

Qualitative methods, such as IPA, ensure rigorous processes are followed so the participant's voice remains at the forefront of the conclusions drawn from the data (Engward & Goldspink, 2020). However, it can be difficult to fully separate this from the researchers' interpretations of the data as this is likely to be influenced by their own experiences, values and beliefs (Palaganas et al., 2017). Therefore, researchers have a responsibility to be reflexive when conducting qualitative research (Dodgson, 2019).

Reflexivity is a process of reflection and self-awareness in which researchers describe the influence they may have on the research. This can include contextual factors such as age, race and cultural background (Dodgson, 2019). Reflexivity in IPA is a dynamic process. Researchers are encouraged to immerse themselves with the data through each stage of IPA. This requires a high level of commitment as the process can be time consuming and become more complex than initially anticipated (Engward & Goldspink, 2020). Researchers using IPA are encouraged to use self-reflective journaling and regular supervision to support them with justifying their actions at each stage of IPA and to explore their interpretations in line with the research (Engward & Goldspink, 2020).

Reflexivity Statement

I identify as a thirty-three-year-old British-Asian (Indian) female, and I do not have a learning disability. I am in the final months of my training to become a Clinical Psychologist; a career I have strived for since aged 15. What started out as pure interest in understanding human behaviour, has turned into something more meaningful due to the experiences I have had.

I secured my first health and social care role as a support worker for adults with learning disabilities and mental health in 2014. My manager at that time educated me on the needs of people with learning disabilities but also the disadvantages they experience. When going into the community with clients, I could feel the looks they were getting, and the passing comments from people who did not know them and judged them based on their abilities and looks. This ignited my passion for advocating for others because it somewhat mirrored my personal experiences of being different. However, in my case, it was my ethnicity and race that made me different. I experienced vast amounts of racism, discrimination, and being stereotyped in school, employment and in the community. Experiencing the judgement of others, on different characteristics, without them knowing who I was as a person, is an awful feeling. I have experienced that being different has significant disadvantages within society. It can make one feel powerless because there are rarely any chances to voice this and how it makes one feel.

In addition to this, I am also a daughter of immigrant parents. My mother was born in Kenya and my father was born in India. They worked hard throughout their lives to ensure me and my brothers were kept safe and looked after. Unfortunately, my father passed away from Cancer in 2019, and my mother passed away from Pulmonary Fibrosis in 2022. I was the main carer for my parents. In the run-up to both their passings, I balanced caring responsibilities alongside full-time employment as an Assistant Psychologist in the NHS. It was a difficult time and often resulted in me prioritising my parents over my needs. However, I felt it was my duty to look after my parents, just like they looked after me. I was proud of this decision and everything I did to help them in their times of need.

Being a carer and having this experience changed my outlook as a professional. Not only was I tending to my patient's needs, but also checking-in with families and supporting them accordingly. As I got to know different families, their experiences of being carers mirrored my own. I became aware that the difficulties of being a carer were not only experienced by me, but for many others, regarding how disadvantaged and unsupported they are. It felt like I could empathise with what they were experiencing from a physical and emotional perspective.

When deciding my research topic, I initially thought about the power and position I have as a Trainee Clinical Psychologist, especially from an ethnic minority background. Immediately, I knew I wanted to represent carers, particularly from South Asian populations to provide an opportunity for them to share their stories. Conducting this research within a learning disability population was influenced by the notion that being from a South Asian population group and having a learning disability creates a "double discrimination" (NHS-RHO, 2023b, pg. 11) and therefore, more disadvantage and less of a voice in society.

I was motivated but also nervous about completing a research project on such a personal and emotive area. I was aware that participants' experiences may resonate with me and evoke emotional responses, which it did. There were many times where I was reminded of the physical and emotional toll of being a carer and it was upsetting. In these times, I was able to take myself away from the research and to seek support from my research supervisors. During the difficult times of this research, the words of encouragement from the expert by experience on the project and the participants kept me motivated. They reassured me by telling me how helpful and valuable this research is and showed a lot of appreciation for me doing this and representing them. I was also kept motivated by my beloved parents who always taught me to never give up.

I was mindful of my experiences and the influence this would have on my approach to the research. This facilitated conversations in supervision with my supervisors to consider alternative perspectives and interpretations to the participants experiences. Keeping a reflective journal was very helpful. It allowed me to write down my thoughts and emotions whilst ensuring I was still as objective as possible, especially when I knew I would be approaching the research with a particular lens. Overall, I feel this research has been difficult but rewarding. It highlights the needs of a highly marginalised group, and I feel proud that I have been able to use the influence of my experiences and my current positioning to provide individuals with a voice to evoke change.

Participatory Research

Participatory research involves working collaboratively with those whom the research area is focussed on, when planning different aspects of the research, such as the methodology and dissemination (Bergold & Thomas, 2012). Despite my personal experience, I was keen to have a participatory approach within the research to provide a different lens other than my own with the research. I had little experience of working with individuals with learning disabilities and their families and I felt working with an expert within this area was beneficial to aid my understanding and ensure the research was conducted sensitively.

An Expert by Experience (EBE) was recruited to the project via email correspondence with potential field supervisors. The EBE was Adam (pseudonym), a devout Muslim man who had experience of caring and working with families who have children with learning disabilities. Adam asked not to be paid for his role in the research. He felt this would have gone against his Islamic faith and wanted to support the project from his heart. He shared how much he valued the research because of the benefits it will bring in helping South Asian people with learning disabilities and their families. Adam's expertise was valuable in the research as he taught me

about the impact of learning disabilities within South Asian populations. He supported me with developing the methodology which included finding organisations who could support my data collection and provided advice and motivation throughout the project. Given Adam's own experiences, and the sensitive nature of this research, I frequently checked in with him for 1-1 meetings to reflect on the research and the impact of our experiences on the project.

Procedure

This section will outline the process for how participants were selected and recruited for the research, a rationale for choosing semi-structured interviews to collect data, the development of the interview guide and the process for completing a trial interview.

Sampling

This research aimed to recruit a total of 6-10 participants. This was based on Smith et al. (2022) advising that doctoral research projects incorporating IPA methodology should aim to recruit 6-10 participants. The smaller sample size allows researchers to place more emphasis on quality rather than quantity (Smith et al., 2022). In practice, researchers are encouraged to produce less but more detailed accounts of individual experiences, so more time can be spent on becoming immersed within the data. This contrasts with striving for multiple personal accounts on personal experiences where time constraints can limit the level of detail obtained (Smith et al., 2022).

Inclusion Criteria

For the purposes of this research, the term, "South Asian" was used to refer to participants who had ancestral roots in the Indian subcontinent. This classification allowed for shared experiences to be identified. However, it was acknowledged that this group is highly diverse and encompassed a variety of nationalities, cultures, languages and religions. Whilst every effort was made to recruit a more homogenous sample, it was recognised that this may have been challenging. The impact of the group recruited is discussed in the findings and discussion. Participants who met the following criteria were eligible to take part in the research.

- Participant identified as having South Asian heritage (e.g. Indian, Pakistani, Bangladeshi, Sri Lankan and Asians of mixed percentage).
- Participant was aged 18-65.
- The familial member being cared for was aged 18+.
- The familial member being cared for must be diagnosed with a learning disability.
- The participant was the main carer for the familial member with a learning disability.

If participants did not meet this criterion, they were not eligible to take part in the research. In developing the research, I also considered whether to recruit single and two-parent families. This would have provided insight to whether the needs and experiences of South Asian carers differed when the household was occupied by one or two parents. I also considered focussing my sample on the more deprived areas in South-West Yorkshire. This was to understand the impact of deprivation on the needs and experiences of South Asian carers. However, I felt having these additional criteria may have limited the pool of participants for the research.

Recruitment

Participants were recruited via purposive sampling as this is common within IPA methodologies (Smith, 2017). This allowed me to recruit participants who had certain experiences in line with the research aims and questions (Robinson, 2014). This facilitated a representative sample that improves rigour of the research (Campbell et al., 2020). Recruitment for the research consisted of two phases:

1) Eleven third sector organisations within South-West Yorkshire were identified with Adam. Each organisation supported carers and/or people with LD. Each organisation was contacted via email to ask, 1) permission from the organisation to advertise the research to their members and, 2) for their members to take part in the research. Seven organisations responded and agreed to share the research advertisement (see appendix A) with members and consented for their members to take part.
2) In the event of 6-10 participants not being recruited via phase one, various organisations were contacted via email to ask the same permissions from phase one. These included, two national carer charities that specifically supported South Asian communities, three faith sector organisations within the South-West Yorkshire region, and two service user and carer (SUC) involvement groups at the University of Leeds. From these, two SUC groups responded to my email. They agreed to share the research advertisement with members and consented for their members to take part.

Semi-Structured Interviews

Semi-structured interviews are recommended for research projects using IPA because of their ability to gain in-depth understanding of individual experiences (Smith, 2017). Researchers develop an interview schedule with open questions based on topics that reflect the research aims and questions. This format allows interviews to be more conversational (Balushi, 2016). This felt appropriate given the sensitive nature of the research because it allowed me to build a compassionate relationship with participants where they could be flexible

in what they wanted to share from their experiences. This format also allowed me to clarify their interpretations so I could ensure the participant's voice remained at the forefront of the data analysis.

Semi-structured interviews were offered face-to-face or online via video-call on Microsoft Teams, with both formats using the same interview schedule. Face-to-face semi-structured interviews have been regarded to have a slight advantage in that non-verbal body cues, such as body language and gestures, can be detected and this can promote researchers to respond accordingly (Balushi, 2016). However, online interviews have increased in popularity as they still allow participants to be involved in research without the need to travel (Balushi, 2016). Offering online interviews felt appropriate because it saved travel costs for myself and the participants. Using video-calls also ensured I could detect non-verbal body cues during the interview and respond to these.

Interview guide

With support from research supervisors, Adam and guidance from Smith et al. (2022), an interview guide (see appendix B) was developed which reflected the research aims and questions and current evidence-based literature within this area. The interview guide was split into three sections which covered childhood/first diagnosis, the transition phase (age 16-18) and adulthood/present day. This structure allowed me to explore different focal points within the carers journey to understand their needs and experiences during these different phases and develop a story of the carers journey.

Trial Interview

Balushi (2016) highlights the importance of practicing interviews to help researchers become conversant with the research topic. Practicing interviews are common in qualitative research to test the practicalities of the research, including the research procedure and testing out technology. Practice interviews also provide an opportunity to check interview questions are suitable for participants which was deemed important.

Arya (pseudonym) and I were introduced via a professional of one of the third-sector organisations I initially contacted. Arya was a carer looking after her child (age 17) who had an LD. I explained the purpose of the trial interview was to provide feedback on the interview guide and to evaluate my approach in the interview to ensure this was appropriate. Arya was happy to support the research and declined payment, citing she wanted to do all she could to help carers' voices be heard.

Following the trial interview, Arya highlighted that some participants may become emotional during the interview, particularly when talking about how they sought diagnosis for

their child. She also advised me to have explanations for some terms, such as “transition” and “double discrimination” as some participants may not know what these meant. Arya also encouraged me to ask more questions about whether carers feel their cultural needs are met when they access services and work with professionals, as these questions are often missed in research related to carer needs and experiences. She also encouraged me to use the interviews to ask what changes carers would like to see to help them and others. Following this, the interview guide was revised to reflect these changes.

I also shared my personal experiences with Arya. She felt this helped her to feel more open and settled in the interview because there was an empathetic understanding from me. She felt this made the interview more conversational.

Interviews

Third-sector organisations were contacted in August 2024 to establish interest for the research. I informed them I would reestablish contact once ethical approval was granted, and I had permission for the research advertisement to be circulated. Ethical approval (reference number: MREC 23-064) was granted by the University of Leeds in September 2024. The third-sector organisations were then emailed to circulate the research advertisement.

Participants contacted me via a University of Leeds email address that was provided on the study advertisement. During email exchanges I asked participants to confirm they matched the inclusion criteria for the research and gave them opportunities to ask any further questions. We arranged a date, time and preferred location (face-to-face or online via MS Teams) for the interview and I provided the consent form (see appendix C) and information sheet (see appendix D).

Five participants opted for an online interview and were emailed a link for a video-call for their preferred date and time. One participant opted for a face-to-face interview. A suitable date and time were arranged for the interview. I notified my research supervisors of the details and completed a risk assessment before the interview, notifying my research supervisors when I left the property to confirm safety.

All interviews began with rapport building to help participants feel safe. This consisted of briefly outlining the aim of the research and the different topics that I would be covering. Participants were given opportunities to ask questions and request clarity. When participants were happy to continue, I asked for consent to start the audio recording on MS Teams. I went through the consent form, obtained demographic information and then proceeded to the interview as per the interview guide.

Interviews were arranged to last approximately 45-90 minutes; however, some interviews were much longer due the breadth of experiences. When the 90-minute mark was reached, I frequently checked in with participants to ask if they were still happy to continue. Following interviews, I checked in with participants to ask how they were feeling given the sensitive nature of the topic. I thanked them for their participation and provided a debrief form (see appendix E) via email which also had contacts for further support via third-sector organisations. Participants were also provided with a £15 voucher for Gift Pay as an appreciation for their support.

Following each interview, I reflected on the process, the content and how I felt. It was important for me to acknowledge any emotions that surfaced for me given my personal experiences within this area. Each interview was transcribed onto a Microsoft word document and stored securely as per the University of Leeds data management plan. I chose to transcribe each interview myself to help with the process of immersing myself into the data. From this, I could attend to changes in tone of voice and body language and this helped with my interpretation of each participant's experience. All identifiable information was removed before proceeding with the data analysis, which is discussed in the next section.

Data Analysis

Data analysis in IPA consists of six steps which guided me with connecting to and understanding individual lived experiences (MacLeod, 2019). Smith et al. (2022) encourage researchers to draw on psychological theory to support their understanding and sense-making during this process. Below, I have outlined the six steps of IPA data analysis as recommended by Smith et al. (2022), which were followed for this data analysis. Each individual interview was analysed prior to moving onto developing group themes.

Step 1: Reading and Re-reading

The audio recording for each interview was listened to alongside the transcript many times. This was to check for accuracy in the transcript but to also help me immerse within the participant's story. I kept a reflective journal where I noted the most striking aspects of the interview and why I felt attached to this. I also kept reflections on my personal thoughts and emotions that rose during this process.

Step 2: Exploratory Noting

To become more familiar with the data, I analysed each line within the transcript in detail (see appendix F). As per advice from Smith et al. (2022), I created a space on each side of the transcript where I could write my exploratory notes next to each line. I underlined what I felt was important and wrote what came to mind. Exploratory notes were either:

- Descriptive – describing the content of what the participant has said.
- Linguistic – exploring the participant's use of language and how this contributes to my understanding of their experiences.
- Conceptual – noting further questions of the data to add depth within the analysis.

To ensure my personal experiences had minimal influence on my interpretation of the participants' experience, I continued to use my reflective journal and kept this separate from the transcripts. I often noted how the exploratory noting was making me feel and the times where I felt I needed to have a break from the analysis to compose myself. It was important for me to acknowledge my reflexivity but also make space for participants to share their stories and ensure this remained at the forefront of the analysis.

Step 3: Constructing Experiential Statements

Smith et al. (2022) encourage researchers to develop experiential statements following exploratory noting. These are short and concise summaries capturing the participants' experiences and my interpretation of this. When developing my experiential statements, I used a blank transcript to record these whilst having my original exploratory noting next to me (see appendix G). I was unable to record my experiential statements on the same transcript, as advised by Smith et al. (2022), due to reduced space. This process had taken multiple attempts to ensure the statements remained as close to the original transcripts as possible. Once I felt content that the exploratory statements captured the essence of the participant's experience, I began step 4.

Step 4: Searching for Connections Across Experiential Statements

Each experiential statement was typed onto a Microsoft word document and printed out. All statements were randomly placed onto a table. I began grouping different experiential statements which seemed to fit together within a cluster (see appendix H). This process took multiple attempts to ensure the final clusters of experiential statements reflected pivotal moments within the participants' experiences.

Step 5: Naming the Personal Experiential Themes (PETs)

Each cluster of statements were given a title that represented its primary focus. When all clusters were named, these became my sub-themes. After looking at my sub-themes, I began to group these in PETs that represented the participant's experience. At this stage, I used support from my research supervisors to finalise my PETs (see appendix H). These were put into a table with the sub-themes, experiential statements and corresponding line numbers from the original transcript.

Step 6: Working with PETs to Develop Group Experiential Themes (GETs)

Once PETs were completed for all six transcripts, I began the process of looking for similarity across all PETs to create GETs. GETs are used to highlight shared experiences found for all participants. My initial thoughts at this stage were around what I wanted to convey from participants and what was at the heart of the research. To begin, I typed all the individual PETs into an MS Word document. Whilst doing this, I cross-referenced these with the experiential statements, exploratory noting and the original transcripts. This was to ensure I did not lose the essence of the participants' experience. When I felt I had my PETs, I started to group them together whilst bearing in mind what I felt was at heart of a South Asian carers journey (see appendix I). I rearranged the PETs multiple times until I felt I had some GETs that could tell a story which resonated for all six participants. Once all GETs and sub-themes were carefully examined and I felt they reflected the participants' experiences, these were put into a separate table and became the final GETs (see "group analysis").

Quality Checks

Elliott et al. (1999), Yardley (2000) and Nizza et al. (2021) outline criteria to consider when conducting qualitative research and using IPA. Table 1 shows their recommendations and how I applied these to the current research.

Table 1: *Table of criteria for qualitative research and how I have applied these within the current research*

Criteria	Application to the current research
Owning one's perspective (Elliott et al., 1999)	Owning one's perspective relates to a researcher being able to recognise their influence on the research. I have highlighted my potential influence on the research in my reflexivity statement (see "reflexivity statement"). I also kept a reflective journal throughout the research as part of IPA guidelines (Smith et al., 2022) to record the impact the research had on me. I also had regular supervision throughout the project with my research supervisors to reflect on all aspects of the research.
Situating the sample (Elliott et al., 1999)	Situating the sample relates to the researcher describing the context of participants in the research. I have discussed the inclusion criteria of participants who were recruited for the research (see "inclusion criteria"). Table 2 outlines the

	demographic information of each participant and I have provided their individual accounts which detail their experiences as an IC (see "individual analysis").
Grounding in examples (Elliott et al., 1999)	Grounding in examples relates to a researcher providing examples of the data to conceptualise meaning and understanding. When discussing individual themes, GETs and group-level sub-themes, I have provided quotes from the participants as part of the evidence for these (see "individual analysis" and "group analysis").
Sensitivity to context (Yardley, 2000)	Sensitivity to context relates to the researcher being aware of the context of the participants. I have provided demographic information for all participants involved in the current research. Throughout the research, I have spent time reflecting with my research supervisors and expert by experience on the context of participants. Using IPA methodology allowed me to highlight the individual stories of each participant as well as shared experiences to produce a set of GETs that reflected the carers journey (see "individual analysis" and "group analysis").
Commitment and rigour (Yardley, 2000)	Commitment relates to engagement with the research and rigour relates to the completion of data collection and analysis. I have evidenced by commitment to the research by planning all aspects of the project alongside my research supervisors and expert by experience. I have demonstrated my rigour by adhering to the guidelines of IPA set out by Smith et al. (2022) to an in-depth data collection and analysis.
Transparency and coherence (Elliott et al., 1999; Yardley, 2000)	Transparency and coherence relate to providing details of the research. I have demonstrated transparency and coherence by outlining my position as a researcher and proving a detailed methodology of the research (see "my positioning" and "methodology")
Impact and importance (Yardley, 2000)	Impact and importance relate to developing research which can support the community. This research has set out to

	add to the current literature around the needs and experiences of ICs, but focussing on when their child with an LD reaches adulthood. To my knowledge, research within this area is limited. Providing individual accounts of the participants' experiences ensured their voice and their story was heard. Providing the shared experiences of participants highlighted that some of the needs and experiences of ICs were also common. I have included a section where I have discussed the implications of the research (see "clinical recommendations"). I hope this can contribute to changes within health and social care services and influence future research to continue highlighting the needs and experiences of South Asian ICs and supporting them within their role.
Constructing a compelling unfolding narrative (Nizza et al., 2021)	Constructing a compelling unfolding narrative relates to IPA research conveying a story and developing a narrative which is coherent to the analysis. This research has told the story of people with LD, carers and individuals identifying as South Asian to understand their needs and experiences. Six South Asian carers shared their stories of their needs and experiences when supporting the needs of their adult-aged children with an LD. These stories have been related to previous literature and psychological theory.
Developing a vigorous experiential and/or existential account (Nizza et al., 2021)	Developing a vigorous experiential and/or existential account relates to IPA research focussing on the meaning of participants' stories, giving depth to the analysis. This research has encouraged participants to reflect on their needs and experiences as a carer. Following this, an in-depth IPA analysis was conducted to make sense of their experiences which produce individual and group themes that reflect the most significant parts of their stories.
Close analytic reading of participants' words (Nizza et al., 2021)	Close analytic reading of participants' words relates to IPA researchers paying close attention to the participants' quotes to give meaning to the data and the experience they discuss. This research has followed the steps of IPA data

	analysis rigorously. This included conducting exploratory noting where each line in all transcripts was analysed in detail (see appendix F). Following this, exploratory statements were developed that captured the participants' experiences and my interpretation of this, whilst also ensuring the statements remained as close to the original transcripts as possible whilst capturing the essence of the participant's experience.
Attending to convergence and divergence (Nizza et al., 2021)	Attending to convergence and divergence relates to IPA research illustrating the similarities and differences to show the connections between the participants whilst highlighting their unique experiences. Divergent themes are highlighted through the individual IPA analysis for each participant. This is in the form of pen portraits to honour their individual experiences and highlight key themes from their story. This has showcased the differences in all participants' experience. The research has also presented group themes to highlight the similarities amongst all participants.

Ethical Considerations

Ethical approval for the research was granted in September 2024 by the University of Leeds school of Medicine Research Ethics Committee (reference number: MREC 23-064; see appendix J). The next section will discuss the ethical considerations accounted for within this research.

Confidentiality

All communication between myself and participants was via a University of Leeds email address. The research information sheet and consent form made participants aware of how their data would be stored and password protected, only accessible by myself. Participants were informed their interview would be audio recorded for the purposes of data analysis and report writing. All participants were asked to choose their own pseudonym which they would be referred to in the final report. Identifiable information, such as names, cities/towns and organisations were removed from the final transcripts to protect confidentiality. This was particularly important when using direct quotations. Participants were also informed I may need

to consult with an expert by experience (Adam) and research supervisors during the data analysis.

Informed Consent

All participants were provided with an information sheet, detailing the study and what was required of them. Prior to the interview, participants were invited to ask questions and clarify queries relating to the information sheet. Participants were also provided with a consent form to read prior to the interview, and this was also read out aloud before the interview commenced. All participants provided verbal consent to take part in the interview which was audio recorded and a copy sent via email following their interview.

Data Protection

Prior to the research starting, I completed a data management plan as per University of Leeds ethical considerations. All interviews were recorded on Microsoft teams, under an account that is registered with the University of Leeds and only accessed by me. All data for the research was kept in a separate file on the University of Leeds OneDrive which only I could access using duo authentication. This was also password protected and encrypted using Microsoft encryption settings. No signed consent forms were completed for this research as all consent was recorded audibly and this was made clear on each consent form. Only I had access to the audio recordings of the interviews, full transcripts, contact details and demographic data from participants. Only, when necessary, were these shared with my research supervisors, e.g. sharing a participant's home address with my supervisors as part of the University of Leeds lone working policy.

Withdrawal

Participants were informed in their information sheet and consent form they have the right to withdraw from the study, five days following their interview. Participants were asked to email me if they chose to withdraw, without needing to provide a reason. No participants who were eligible to take part in an interview withdrew themselves from the research.

Distress and Risk

Potential distress was acknowledged for this research given its sensitive nature. I was also made aware from my trial interview with Arya, that some participants may become emotive during the interview.

Prior to interviews, participants were made aware that I would be required to break confidentiality and consult with my research supervisors if I felt there was an element of risk. I had access to mental health crisis team contacts for participants should they have needed this, however, no issues regarding risk came up during the interviews.

As part of my role, I had a duty of care to protect participants from harm. To do this, the research information sheet informed participants the interview had the potential to feel difficult at times and bring up different emotions. Participants were made aware they were not required to answer any questions they felt uncomfortable answering. Following interviews, all participants were provided with the research debrief sheet. This reiterated the purpose of the research and I provided a list of third-sector organisations that are specifically aimed at supporting carers and people with learning disabilities. I have gained valuable skills in supporting patient distress through my Clinical Psychology training. Whilst these skills were helpful in supporting participants in their interviews, I was clear that my role was a researcher within this context.

Chapter Three: Results

This section aimed to outline the results of the individual and group analysis of all six interviews. Table 2 highlights the demographic information for each participant. This is followed by a pen portrait and an individual analysis for each interview. The group analysis has been outlined, with Figure 1 representing a thematic map of the group experiential themes and group-level sub-themes. Table 3 represents the group experiential themes, the group-level sub-themes and the participants in which these themes were found. Further explanations of the group experiential themes and group-level sub-themes and included relevant participant quotes have also been included.

Table 2: *Demographics of participants*

Pseudonym	Age	Place of birth	Ethnicity	Religion	Relationship to familial member with LD	Gender/age of familial member with LD
Aisha	40	UK	British Asian Pakistani	Islam	Mother	Daughter aged 19
Safa	54	UK	British Asian Pakistani	Islam	Mother	Son aged 30 Daughter aged 25
Sara	66	Pakistan	British Asian Pakistani	Islam	Mother	Son aged 39
Nicky	51	UK	British Asian Pakistani	Islam	Mother	Daughter aged 32
Rita	51	UK	British Asian Pakistani	Islam	Mother	Son aged 25 Daughter aged 28
Avani	50	UK	British Asian Indian	Sikhism	Mother	Son aged 18

Individual Analysis

This section will introduce each participant in the form of a pen portrait. A pen portrait condenses a large amount of data into a smaller account and highlights the context of each participant and key themes from their story (Sheard & Marsh, 2019). Although the group analysis highlighted themes across all participants, I chose to include pen portraits to honour the unique stories shared by each participant. I wanted their individual voices to be heard and their input to be a contribution to the literature within this area. I have also highlighted the main themes emerging from each interview in bold to aid the reader.

Aisha

Aisha is a 40-year-old Muslim female born and raised in the UK. Aisha is a mother to three children with an LD, including her eldest daughter who passed away and her son was under the age of 18. Her interview focussed on her experiences with her daughters. She participated in the study to share her experiences and highlight the challenges of accessing services for support.

Despite all three of her children having an LD, Aisha balanced multiple tasks. She described differences in their medical needs and the challenges she faced when navigating different teams of professionals. This included travelling across different catchment areas to access support and liaising with different services over who would supply her children's medication due to funding. She spoke of the varying the support required with her children's activities of daily living. Aisha felt the various tasks of her caring role were unrecognised and unappreciated by family members. She felt unsupported by some family members and professionals and described how her caring role meant she did not have a life of her own outside of caregiving.

Main Themes. A theme emerging from Aisha's experiences was in relation to *the individual needs of her daughter not being considered*. Aisha had multiple children with LDs' and spoke about how they were often grouped together in regard to their support plans. One example she gave was around transportation needs and how her daughters were put onto the same support plan as oppose to having separate support plans, "*if you're doing transport for a child, I know the sister's going on it, but they both have their own needs and they're completely different people*." (Aisha); "*you would be doing their own statement and their own paperwork and everything and their own conditions and stuff because everything is different*" (Aisha).

Another theme emerging from Aisha's experience was *managing multiple medical needs*. Aisha's children experienced multiple medical needs, particularly her eldest daughter who relied on medical interventions and became accustomed to this, "*she was actually better*

with the [medical treatment] than she was ever without, when she was off [medical treatment]. And I think, I don't know, because she's always not known anything different." (Aisha).

However, when managing multiple medical needs, Aisha felt her *training needs were dismissed*. "*We've been having issues trying to get bagging training.*" (Aisha), *"it changes, like medication changes every year or every couple of years. Certain things, new things come out or new rules come out or something happens, but they've not trained us up*." (Aisha). When this was raised with professionals, Asiah felt she was dismissed, "*the nurse that did it there said that she won't do it for people that are outside, like general people*." (Aisha).

Aisha spoke about her *unrecognised wishes* in managing her eldest daughter's medical needs. Unfortunately, Aisha's eldest daughter passed away. Aisha expressed how there was a plan for her daughter's final moments but these were not honoured by the medical team, "*she was supposed to come home for end-of-life care. They didn't want to fill the paperwork out so they sent us to [hospice].*" (Aisha); "*it would have been a bit less than 24 hours, but we would have had more than that and because of what happened we got less time with her*." (Aisha).

Difficult experiences from health and social care services created a sense of *mistrust* with some professionals and health and social care services, "*after what happened to [daughter], I think that would just put you off having to go back there again*." (Aisha). Aisha's second daughter also has medical needs and there was a sense of mistrust around those who could not understand this.

Despite Aisha's difficult experiences, she used her knowledge to *support other carers,* "*I've got a lady that I help, she's a single carer who don't speak the language.*" (Aisha), "*there's a neighbour, I'll help her as well with certain things.*" (Aisha); "*they just all come to me and they think I know everything and I said to them, I don't know anything. I learn as I go along*." (Aisha).

Aisha expressed how she always wanted to support children with LDs' and when she had her own children, she felt this was *a test from God*, "*I think it's like a test for you to see what you can cope with, and certain things, and I believe that I was given these kids for a reason because I can cope with them.*" (Aisha). Aisha felt that having her children was a blessing, "*I don't think it's a punishment having these kids, it's a blessing*." (Aisha).

Reflections on the Interview. Despite completing a trial interview with Arya (trial interviewee), I felt nervous because it was my first research interview. Going through the demographic questions helped my nerves to settle because it allowed me to build rapport with Aisha and get an understanding of her background. In the trial interview, Arya highlighted that sharing my personal experiences may help rapport building, and Aisha expressed appreciation for me sharing my story and the research being completed. Moving forward, the interview felt

conversational and I felt comfortable talking to Aisha about her experiences. I was particularly struck by Aisha's experiences of caring for multiple children with LD. I had not considered how difficult this may have been in comparison to caring for one child with an LD. I was struck by her strength as a mother in managing the circumstances around the passing of her daughter, particularly with little support from some family members and professionals.

Safa

Safa is a 54-year-old Muslim female born and raised in the UK. Safa is a mother of a son and daughter with an LD. Safa participated in the study to share her experiences of being a carer and highlight the difficulties around her daughter being moved into residential care.

Safa learnt to adjust to her children having LDs' which began in infancy when she saw both her children struggling to reach their developmental milestones at certain ages. She hoped this would change as they got older but realised this was not the case. She felt she had little information around LDs' and wanted additional support with this. Safa also experienced a difficult relationship with her family and husband, where she felt alone and unsupported when caring for her children's need.

Safa spoke about her challenges when working with professionals. When her daughter was in residential care, she described feeling ignored by professionals when raising concerns about her daughter's care. During this time, Safa continued to support her son's needs at home, but felt alone in her decision making, often talking about how she did not have all the information she required to make an informed decision about her children's care.

Main Themes. A theme emerging from Safa's experiences were *processing* her children's LD, "*they were like oh, no, he's going to be unique. he's going to have this and that and it was just going over my head*." (Safa); "*we just thought he's going to get better as time went on along. But his development just got that delayed that he's a [age] year old man now but he's way behind his years*." (Safa). Alongside this, her children experienced different medical needs, some of which were experienced for the first time by Aisha, "*that summer she had her first seizure. I've never seen a seizure. None of our family members have seen a seizure. So we were like what's happened? Is she having a heart attack?*" (Safa).

Aisha also experienced *self-blame* for her children's difficulties, "*I just sat there thinking well that's great, someone's cursed me*." (Safa); "*when [daughter]'s problems started, I kind of, I wouldn't say I became depressed, but I just felt like, oh my God, why me again*." (Safa). She felt *alone* in managing her caring role and the needs of her children, *"I just felt like there was nobody out there to kind of help in a way*." (Safa); "*even though my parents live [location], I just felt alone*." (Safa).

Safa described experiences where *professionals decided for her* in regard to how her children should be supported, "*they just said he wasn't for mainstream and we'd like you to look at some schools and I thought ok then*." (Safa). During the COVID pandemic, Safa was offered supported living for her daughter as she was considered vulnerable, "*they were like we're not taking your child away, we're just going to care for her until your family get over the COVID period and this and that. I thought ok*." (Safa). At the time, Safa felt she had little information about this plan and expressed feeling pressured into making this decision, "*we've got a property we can take [daughter] to. And I'm like what? I didn't understand at that point what they were saying to me. I do feel like I was pressured into making a decision*." (Safa).

When Safa's daughter was moved into supported living, Safa experienced *separation and loss* describing how difficult this was, "*I never spent a night without her so to me it was like, where's my daughter, what's happening? And because it was COVID, you've got to limit your visitors and visiting and this and that, and I'm like but she's my child*." (Safa). Safa spoke to her husband about bringing her daughter to a residential home that was closer but felt this idea was dismissed, "*he's like, no she's fine where she is, she's happy, but I don't feel she was happy at that point. And he said no. I was very depressed at that point, I was constantly crying*." (Safa).

When Safa's daughter was in residential care, she felt her daughter's physical needs were *neglected* by professionals, "*they neglected her hair to the point here were big knots in her hair and I just used to cry. I'm like what are you doing to my daughter*?" (Safa). Safa approached professionals with her concerns, but experienced times where she was *dismissed*, "*we had this big meeting.....I said they've ruined my daughter's hair, she always smells. She's neglecting her, I said this is abuse. They said it's not*." (Safa); "*it took us one year to get rid of that evil person. Every time I rang up they said she's the best we've got. I said no she's not. Don't sit there and tell me she's the best you've got. She's ruined my daughter*." (Safa).

Safa expressed a need for *more ethnic minority health and social care professionals* to support South Asian carers when understanding LDs' and accessing support, "*I wish there was another Asian person there to explain to us what's happening. I just felt there was nobody there to really explain*." (Safa). Sara also expressed how more ethnic minority professionals can become advocates for South Asian carers, *"it just feels like a blur at the moment I think for Asian families, especially when a specialist comes out or there's a meeting, there should always be another Asian person there, or a translator or whatever, or even a specialist just to explain in more in detail I think*." (Safa).

Reflections on the interview. I felt slightly more confident going into my second research interview with Safa. During Safa's interview, I experienced a range of different emotions, including sadness and anger, in relation to the difficulties she experienced with services whilst trying to protect her children, especially her daughter. It felt that her experiences consisted of feeling very hopeless, powerless and isolated. At the end of the interview, Safa asked more about my experiences as a carer which I was happy to share. It felt validating that we could connect with each other's stories, and I was mindful to remain in the position of a researcher.

Sara

Sara is a 66-year-old Muslim female born in Pakistan; she moved to the UK in the 1960s'. Sara is a mother to a son with an LD. Sara wanted to participate in the research to share her story of being a carer. She felt it was important for the carers voice to be heard and for professionals to understand their experiences.

Sara spent many years trying to conceive a baby. When this happened, she reported feeling excited. She spoke about helping family members raise their children and from this, she gained an understanding of the needs of a child. When her son was born, she quickly noticed differences in his development. When seeking support, she felt dismissed based on the premise that her son 'looked healthy'. However, Sara continued to fight and when she eventually accessed support, she was informed her son had an LD. Sara described feelings of shock and loss associated with this.

Sara began the process of adjusting to her son's diagnosis. She was met with new changes, including having conversations about specialist educational schools and implementing adaptations, such as a wheelchair, for her son to use. She noticed that having an LD was not welcomed in the South Asian community. She spoke about feeling unsupported by her ex-husband and having to raise her son alone. Over time, Sara has developed knowledge around managing her son's needs and spends time supporting other carers who are in similar positions. Despite her difficulties, she ensured her son was always looked after and given the same opportunities as other people without an LD.

Main Themes. Following the birth of Sara's son, she noticed some developmental delays when *making comparisons to a family member*, "*I had a [family member] that was born at the same time, similar time. She was two months younger than him so I could see lots and lots of, you know, milestones that she was reaching*." (Sara); "*I was flagging up that these are things that he's not quite same as others, and then little [family member] she started to walk at 10 months and [Sara's son] was barely just sitting*." (Sara).

When Sara approached health and social care services for support, she was dismissed by professionals as *her child looks ok*, "*it was a hard time convincing people that he isn't feeding because he looks so well*." (Sara), "*there's nowt wrong with him. He's fine. You know, he's all right. He looks well fed and well-kept and whatever*." (Sara); "*I've mentioned the fact that he wasn't feeding. Oh, it'll be OK. Don't worry because he looked like a very a chunky baby. Very healthy*." (Sara). Sara fought for medical investigations to take place with her son as she felt a *diagnosis meant a cure* for her son, "*why are you taking so long? The sooner we know what's wrong, the sooner you know he'll be comfortable and you know things will start getting sorted. You know, without having to live like this*." (Sara); "*I valued that label because it meant that there was something that they recognised and they would be able to do something about that, be able to support me, be able to support my son*." (Sara).

When Sara's son was diagnosed with an LD, she noticed how she was *balancing multiple roles* as a mother, carer and wife, "*I'd gone back to work....it was something that needed me back, although it wasn't something I wanted to do*." (Sara); "*I was made to feel quite guilty about not being at work. My emotions were with my son, and then I have the guilt of not supporting my husband, so I was, like stuck between both my commitments*." (Sara).

She spoke about the *unrecognised carer responsibilities* she had**, "***he'll realise how much I do for my boy*." (Sara), "*I'd help him get him out, get him his breakfast, get him out, let him go. I'd get to see [person] do the housework, make some food, see [Sara's son] off, get to the next town to join him and he would give me a dirty look and think, I've been here two hours and you've just turned up, but not recognising what I've done in them two hours*." (Sara). She spoke about a time where her son went for surgery and how the emotional toll of this was unrecognised by her family, "*that feeling, that thought, that process, nobody saw or what, you know how it virtually killed me as a mother, what I went through*." (Sara).

Sara shared her *worries for the future* in regard to her son's care, "*what's going to happen? Obviously I'm getting older, he's getting older, his capacity is declining*." (Sara); "*we don't know what's going to happen to him afterwards, where he's going to be passed from pillar to post to do this, to do that.*" (Sara).

Reflections on the interview. Prior to Sara's interview, I was feeling confident, having developed a rhythm following previous interviews. I admired her advocacy for other carers and her appreciation of the research to get the Carers voice heard. At times, she became upset, particularly when talking about her son's difficulties. I could hear the pain in her voice and although I felt an urge to comfort her, I remained mindful of my role. I resonated with some of the emotions and experiences Sara had faced. It was evident that she had been through a lot of

difficulties, and she was continuing to push for her son to have equality amongst those without an LD. I could feel the strength she had in being able to adjust to her son's diagnosis and becoming a carer, particularly as this was not what she planned.

Nicky

Nicky is a 51-year-old Muslim female born and raised in the UK. Nicky is a mother to one daughter with an LD. Nicky participated in the research to share her experiences of being a carer, particularly when accessing health and social care services for support. She felt it was important to highlight the difficulties she experienced with the hope of bringing changes to how carers and people with LD are supported.

Nicky spoke about experiencing a difficult birth, her daughter being taken to intensive care and being separated from her. Nicky felt unconnected to her daughter until she met her and their bond was established. Nicky's daughter was born with severe medical complex needs and required many different forms of medical treatment. Nicky balanced these whilst caring for her younger daughter who did not have an LD.

Much of Nicky's experiences centred around feeling unsupported by her medical team to meet her daughter's complex medical needs. Nicky felt that gaining access to support was not easy and spoke about having to do multiple referrals for her daughter. Many health professionals involved in Nicky's daughter's care had left the service and she felt she was not informed of this. Nicky felt she was passed between different professionals which meant she needed to do additional referrals and re-tell her daughter's needs. Nicky described feeling deflated as a carer but continued to balance both her daughters' needs. Nicky expressed how carers need to be supported in their role, particularly when there is a person with LD who has complex medical needs.

Main Themes. Nicky's daughter was taken to intensive care following her birth. She described there were *missed opportunities for bonding* with her child, "*I got her shoved in my face like this, took off me straight into intensive care, and I was given a polaroid picture.*" (Nicky); "*I didn't see her for about 3 days because she was in intensive care*." (Nicky). When Nicky met her daughter, she spoke fondly about a nurse who placed her daughter in her arms. This was three days after her daughter's birth and Nicky spoke about the impact of the first touch and how this helped her to bond with her daughter, "*that is how I connected with my daughter and it's that beauty of that, just that first touch. I didn't get that touch. I mean, she was born and they took her straight to intensive care. They give me a photograph and how was I supposed to connect*?" (Nicky).

Nicky described having *difficult experiences with her medical team* during this time, "*they spent a lot of time, the doctors, filling my head with she's got this, she's got that. She's got no ears, her feet like this. Her hands are like that*." (Nicky); "*you've filled my ears, you know with a lot of negativity*." (Nicky). Nicky also described feeling her daughter was *not worth medical treatment* because her of her LD and complex medical needs, "*they're thinking right well, she's already got this disease and this is what's happened to her and she's not going to survive anyway. So what's the point in wasting the money. I think it's disgusting. That is discrimination, really bad discrimination. Why is it like that*?" (Nicky). Nicky sought support from her family whom she described as feeling a similar way to her, "*when a dog gets knocked down on the street, what's the first thing you do? She goes, well you'd call someone to sort it wouldn't you. Right so why is my niece not worth it*." (Nicky).

A lack of urgency to intervene with medical treatment and support was also a theme from Nicky's experience, "*she's got severe, complex care needs and I need support in respect to that. And if I'm asking you for something and it needs doing, I need to know why you're taking so long to sort something out for*" (Nicky), "*The fact that they think it's OK for somebody to go on having seizures with complex care needs and not have anything in place for that person again, it's down to the fact that there's no urgency*." (Nicky); "*what are you waiting for? Are you waiting for my daughter to die?*" (Nicky).

In Nicky's experiences, she described feeling *unsupported with medical procedures* as part of her caring role, "*not having any proper training, because what I want to know is like, what if it happens when she's eating, what would I do if she bites her tongue. What do I do if you know, all these kind of like situations I've got in my head and I need to know about*." (Nicky). Nicky felt she was required to make decisions as a non-medic and based on what she knew, "*I've got no support, no support. And I'm sat making decisions as a non-medic about what's right for my daughter*." (Nicky); "*I did what I had to do on the back of what I just knew, but I'd never dealt with this before. So I literally were thrown in the deep end*." (Nicky).

Nicky shared how she *struggled to rely* on health and social care professionals to support her and her daughter when they were accessing services based on her experiences, "*I did pull one of them, the higher up nurses into a private room and I said to her, how dare she speak to my child like that. If this is what they're like with me here, I dread to think how you would treat her when I'm not here, which is why I wouldn't leave her here in the first place on her own*." (Nicky); "*I don't want to go hospital. The fear I have of going to hospital for my daughter, I know they're either going to cock her up even worse than what she is.*" (Nicky).

Nicky also spoke about *feeling deflated* at times and how she felt she could not fight anymore, "*I shouldn't be pushed to the point where I can't fight anymore. Do you know what I mean? I can't scream and I can't shout anymore because you've just deflated me. You've just absolutely, literally pulled the plug on me*." (Nicky), "*I feel like literally as they say, you know, the straw that broke the camel's back*." (Nicky); "*the stuff that went wrong there was horrendous, horrendous, absolute horrendous. But I didn't have the mental capacity to deal with it*." (Nicky).

Reflection on the interview. Nicky asked for a face-to-face interview which I was pleased to accommodate. She welcomed me into her home and immediately, I felt comfortable. I felt more confident than previous interviews because it was face-to-face and more familiar as a way of working to me. The interview flowed well as a conversation. Her story was extremely moving and impactful, particularly in relation to her accounts of feeling dismissed when seeking support for herself and her daughter. It was evident she was trying to do the best she could and I could somewhat relate to her experiences of feeling deflated and alone.

Nicky mentioned how grateful she was for the research taking place and she shared this with me towards the end of the interview, "*you told me yourself that you've been in a caring role yourself, do you know what I mean? You've got that understanding and that makes a massive difference. You know, like, because you understand what I've been through. You've been through it yourself as well and that makes me feel, you know, like, right, OK, at least she'll understand me, she knows what I'm coming from. She knows how I would feel*." (Nicky). This helped to reminded me of the importance of this research and I appreciated Nicky's kind words.

Rita

Rita is a 51-year-old Muslim female born and raised in the UK. Rita is a mother to a son and daughter with an LD. Rita participated in the research to share her experiences of accessing services when her children reached adulthood.

Rita spoke about feeling supported by paediatric services when her son and daughter were children. She did not encounter many problems and felt this was a manageable time for them. However, when Rita's children reached the end of their education, she felt things started to become difficult. She felt the education system did not account for their learning needs and expressed how people with LD can benefit from a longer time in education so their skills could be developed and utilised in society.

Rita felt she needed to be proactive when her children reached adulthood. She spoke about them attending colleges outside of her area as she was unhappy with the provision provided where she lived. She was determined to ensure her children gained an education and

utilise their skills in society. Rita learnt how to navigate access to adult services and used the knowledge and skills she developed to support other carers in her working role. Rita felt mainstream society did not cater to the needs of people with LD. She expressed how further adaptations in society are required to ensure people with LD feel fully incorporated into society, particularly as she felt caring for people with LD in society was better than institutionalised care. Rita was determined to ensure that the needs of people with LD were tended to, while recognising the caregivers input.

Main Themes. A theme emerging from Rita's experiences was an *un-adapted education system* for people with LD. Rita felt people with LD can take a longer time to learn, "*if you've got learning disability, it just takes longer to learn things*." (Rita); "*it takes two years, three years. It could be for someone with a learning disability. It might take 16 years*." (Rita). Rita felt the education system in the UK is not extended for those with LD, "*why can't it just be longer process for them to get their learning in?*" (Rita) and this can limit their opportunities for further education, "*so then at 16, 17, 18, 19, that's it. You do your own thing now. I can go to uni now, I can do my masters. I can do my PhD. If you've got someone with LD, they can't really do that*." (Rita). She expressed many people with LD have vast amounts of skills that are not being utilised within mainstream society, "*when I say people with LD are more vulnerable, it doesn't mean that they don't have huge amounts of vaster reserves of unused potential that can be utilised and productive for society*." (Rita).

Rita also felt her *children's individual needs were unconsidered* by local authorities when they reached adulthood. "*I didn't want my daughter to be in a provision where there's every single disability because how do I know they provide support for everybody? How is it individualised when there's such a vast*." (Rita), "*people with LD are considered to be the same*." (Rita); "*it's like saying all African people are the same when there's more diversity in Africa than the whole of the world. This such a genetic difference between people. There's such a huge difference in disability*." (Rita).

This was also related to the *difficulties of carers meetings*, as Rita highlighted how the views in carers meetings may not reflect the views of all carers, "*your child may not need this service but by you being on a panel that the local authority makes decisions on, because not having a taxi to school is not something your child needs, that is not in the best interest of all disabled people, it's very individualised. So I don't believe that carers or having carers or carers groups is always in the best interest*." (Rita). She felt there was a need to have something in place where all views of carers can be considered, "*we need to get the voices of the people that are not attending these groups that are not available*." (Rita).

When Rita's children reached adulthood, she also felt the provision available in her area was not appropriate, *"[city] provision is absolutely diabolical. It's dire*." (Rita). Rita started *travelling out of area for support* so her children could access services appropriate for their needs, "*my children were rejected from colleges and school. So that's why I travelled to two towns. So none of [city] colleges would accept my children. They were too disabled. That's why I travelled so far, I said my kids will go to college and they did*." (Rita). Rita reflected on how difficult this was but how it was also her only option to ensure her children were supported as adults, "*you have to have time, energy, effort*." (Rita); "*And that probably wasn't the best, but it was better than all the options available in [city].*" (Rita).

Rita expressed a need for professionals to be more *inquisitive* when supporting family members from South Asian backgrounds, "*surma is used now for therapeutic purposes and it's supposed to be very good for your eye. So did you check and see? Did you tell the parents what's inside? Have you said to the parents where did you get this from? It'd be wise for you to check what kind of ingredients in there and you know, go on in an educational way*." (Rita), "*is there something around this particular person's faith or culture that requires that? And look into it.*" (Rita); "*you have to look at and weigh things up in a very nonjudgmental, culturally sensitive way and understand different cultures have different things, and they're not necessarily bad*." (Rita). She related this to the Islamic tradition of fasting, "*you might not agree with certain practises of certain religions, but if it doesn't harm the child and what do you think can harm the child? You know, you might think no 13-year-old, healthy or otherwise, should be fasting. Now fasting is considered kind of a good thing*," (Rita).

Rita also highlighted the importance of being inquisitive as people from South Asian backgrounds with an LD can face a *double impact*, "*some things affect all people with families with LD but doubly impact South Asian or ethnic minorities*." (Rita); "*if a South Asian person is struggling with some issues, the person with the learning disability who is from a South Asian background is going to face it doubly because they won't have the kind of skills needed to protect themselves*." (Rita).

Reflection on the interview. Prior to Rita's interview, I was feeling comfortable as this was the fifth interview I was completing. Rita quickly told me she did not encounter many problems during her children's childhood and instead emphasised the challenges of adulthood. This was different for me to hear as my previous interviews had mentioned some difficulties during childhood. I was particularly fascinated when hearing her experiences of gaining access to support because of the level of detail she went into. I had little knowledge about how finances for carers and people with LD were arranged. After Rita explained this to me, I could

feel how exhausting this process is. It helped me understand why anyone claiming financial support from local authorities may choose to give up as it can feel like a fight. This deepened my appreciation of carers' persistence in securing their entitlements while managing ongoing responsibilities at home.

Avani

Avani is a 50-year-old Indian female born and raised in the UK. Avani is a mother to a son with an LD. Avani participated in the research to share her experiences of being a carer.

When Avani's son was diagnosed with an LD, she felt reassured by her family and health and social care professionals that things will be ok. She felt this helped her confidence in managing his needs and being a good mother. When developmental delays started to show, she felt she had a lack of information to support her during this time. She expressed a need from professionals to support carers and educate her on how her son's needs may be different to other children. Avani recognised her identity of being a carer early on and felt this had taken some time to adjust to. She felt some members of the South Asian community did not want to associate with her because of her carer identity and her son's LD. Avani did not want to rely on her family for support and often managed on her own.

When accessing support from services, she encountered some difficult experiences where she felt her son's life was devalued because of his LD. She experienced a power difference when communicating her needs with professionals. She felt that because she was a South Asian woman, she was often waiting longer for a response from professionals. She compared this to her ex-husband who was White and felt his queries were answered more promptly. Avani has reached a stage where she is ready to access adult health and social care services but explained how she was unaware of what is available for her and her son. Avani was aware she needed to search for what was available and was determined to ensure her son is supported as an adult in mainstream society.

Main Themes. Avani spoke about the *benefits of reassurance* from her family. Avani reflected on how she felt some of her family were supportive and how grateful she was to have this, "*she'd go, he's a bit different, but he's absolutely fine and look at all the brilliant things he can do, and she would always talk about the positive. And I was really grateful to my grandma for that.*" (Avani). Avani recognised that not everybody had the family support she had, "*I felt really blessed that my family stood by me and have always cheered [son] on…you know, it's brilliant. I feel very, very lucky and I feel sad for people who don't have that support*." (Avani). Following her son's diagnosis, Avani felt reassured by professionals which she found helpful, "*for me to have that news given to me in such a nice way and not to be told that, you know. Oh, I'm sorry or any*

kind of commiserations just made me feel, actually, do you know what this is going to be fine." (Avani).

Another theme which emerged from Avani's experiences was *adjusting to the carer identity*, "*it was only when I was kind of like filling in the forms that I kind of realised oh, actually I've got this title now, I'm his carer*." (Avani). Avani initially did not want to be identified as a carer, "*at the beginning I didn't want to be a carer, I wanted to be mum*." (Avani); "*I think it just took away from that natural feeling of what mums do naturally, but then being a carer was kind of, oh well she's having to do so much more*." (Avani). Overtime. Avani felt she adjusted to her carer identity and felt a sense of pride for being her son's carer, "*I felt prickly calling myself a carer in the in the early days, whereas now I kind of go, yes, I am his carer*." (Avani); "*I'm much more proud to say, yeah, I'm [son]'s carer and look at what a brilliant job I'm doing*." (Avani).

Whilst navigating her role as a carer, Avani also felt it was *difficult to ask for help*, "*when you're exhausted or you've run out of all the resources around you kind of go, I'm going to have to ask somebody now. You can feel a little bit battered and be like I didn't really want to do that, but I have to because [son] needs that help*." (Avani). She expressed a need for professionals to recognise that asking for help may not be easy for some carers, "*be supportive. You know, realise that we're coming to you because we need support and it's actually hard to ask for support when you're a carer*." (Avani).

Avani also spoke about her *disappointment with carers allowance* and how this devalues the role of a carer, "*carers allowance, it's pitiful and it needs sorting out it. I think it's a crying shame that they devalue us to the point where, you know £90 a week is enough*." (Avani); "*I really don't understand how any government in its right mind thinks that that is acceptable*" (Avani). She expressed a need for changes to be made, "*it's just carers allowance really does get my heckles up. I get really annoyed at that. So it's kind of like, please just sort it out, just resolve it*." (Avani).

A final theme emerging from Avani's experiences were *worries about the future* in regard to who will support her son, "*as a parent carer, your dread is when you're not around and who's going to look after your child*." (Avani); "*parents are having the same worries that I have. You know who's going to look after him when I'm not around and that never leaves you. That's always there in the back of your mind.*" (Avani).

Reflection on the interview. Avani's interview took place after a few months of no recruitment. Prior to her interview, I spent time reading and practising the interview schedule. I felt nervous going into the interview because of how long it had been since I interviewed a participant. However, upon meeting Avani, I quickly settled into the interview, and this felt

conversational. I appreciated Avani's openness and honesty when sharing the emotional challenges of being a carer. At the end, Avani asked how I managed my carer role. I informed her of the circumstances surrounding my parents and she expressed her condolences which I appreciated. Similar to Safa, it felt validating that we could connect with each other's stories, and I remained mindful of my position of a researcher.

Overall reflection on interviews

I was aware of the positioning I had when coming into this research, given my own personal circumstances and identity as South Asian. During the interviews, I experienced many emotions, ranging from sadness, anger and frustrated. But I also felt immensely proud of all participants because being a carer is not easy. Their strength, determination and fight to continuously battle for their children to be supported was truly inspiring. It showed how self-less and resilient carers are and have to be, especially in the context of undertaking a role they may not have been prepared for. I was also aware of how my feelings may have impacted on the data analysis. As part of owning one's perspective (Elliott et al., 1999), I wrote in my reflective journal after all interviews and spent time with my supervisors to reflect on alternative perspectives and interpretations to the participants experiences, prior to competing the group analysis.

Group Analysis

Whilst each participant presented their own unique experience, similar experiences were identified across multiple accounts. These have been presented as group experiential themes (GETs) and each have their own group-level sub-themes. Each GET highlights different aspects of the carers experience, including carers feeling there was a lack of support to help them in their carer role, carers feeling disempowered, the hidden experiences which carers may experience and carers feeling abandoned. Figure 1 shows a thematic map of the GETs. Table 2 highlights each GET, it's group-level sub-themes and which participants' accounts these was found. In the following sections, each GET will be presented with its group-level sub-themes and relevant quotes from participants.

Figure 1: *Thematic map of the GETs and group-level sub-themes*

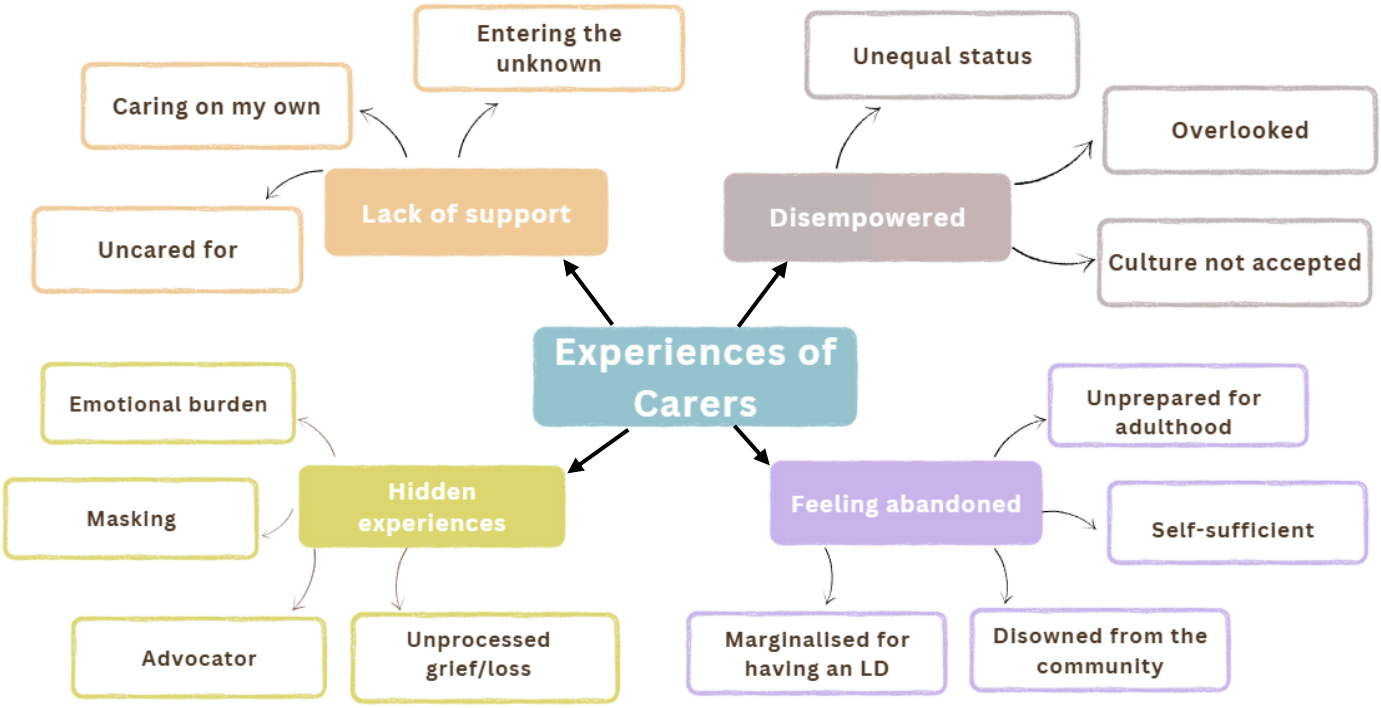

Table 3: *Table of GETs, group-level sub-themes and participants expressing these themes.*

Group Experiential Themes	Group Level Sub-Themes	Participants					
		Safa	**Aisha**	**Avani**	**Nicky**	**Rita**	**Sara**
Lack of support	Entering the unknown	X	X	X		X	X
	Caring on my own	X	X	X		X	X
	Uncared for	X	X	X	X	X	X
Disempowered	Unequal status	X	X	X	X	X	X
	Overlooked	X	X	X	X	X	X
	Culture is not accepted	X	X	X	X	X	X
Hidden Experiences	Emotional burden	X	X	X	X		X
	Masking			X	X	X	X
	Unprocessed grief and loss	X	X	X	X		X
	Advocator	X	X	X	X	X	X
Feeling abandoned	Unprepared for adulthood	X	X	X	X	X	
	Self-sufficient		X	X	X	X	X
	Disowned from the community			X		X	X
	Marginalised for having an LD			X	X	X	

GET 1: Lack of Support

The theme, "lack of support" was highlighted amongst all participants' experiences during childhood, the transition period (age 16-18) and adulthood. This theme was in relation to participants expressing there was limited access for assistance in their caring role from the systems around them, for example, spouses, family members, health and social care services and professionals. Participants described how they had reduced knowledge and understanding about LD, their entitlements as carers and what support services were available for them to access. Many felt they needed to be self-sufficient in researching what was available to them and proactive in making queries and referrals themselves to access support. Some participants described feeling unsupported by family members, spouses and professionals in their caring role. Some participants expressed how they would have also preferred for professionals to have provided more information to support them and contact carers to check how they are.

Sub-theme 1: Entering the unknown. The sub-theme, "entering the unknown" related to some participants expressing they did not have knowledge around what an LD was when their child received this diagnosis in childhood. Some participants had experience of raising other children in their family who did not have an LD. When their child was born, this was their first experience of seeing someone with an LD, "*I didn't know nothing of disability. Known anybody that was disabled. I've not known anybody with learning disabilities.*" (Sara); "*I never knew what it meant. We never knew any disabled people before this*." (Safa). Following diagnosis of an LD, some participants were given some information in the form of a letter or a leaflet, but they felt this was not enough to support them, "*they just gave me a letter to confirm that she had that, but they needed to tell me more information*." (Aisha); "*they just would throw leaflets at you*." (Avani).

Some participants felt they were unaware of their entitlements or rights as a carer throughout childhood, the transition phase and adulthood/the present day, "*they didn't tell me as much even if they didn't, it didn't bother me because I wasn't aware of it*." (Aisha). Safa spoke about not knowing what entitlements were available when she became a carer, "*there's nothing saying what we were entitled to or if we needed anything*." (Safa), nor was she given any information to explain what additional support she could apply for during the childhood and adulthood phases, "*we were never given information about mobility cars. We were never given information about funds we could apply for. So yeah, it was that very lack of information*." (Safa). Aisha also spoke about not every carer being aware of different funds they can apply for, "*Certain priorities like family funds, not everybody knows about it*." (Aisha).

Alongside, this, some participants expressed they would have preferred more information throughout their journeys to help them understand their rights, "*families, they need to be, they need literacy in welfare rights*" (Rita). Other participants felt they would have preferred more information around supporting them in their overall caring role, "*I think if they can just give more information out, maybe booking appointments with parents*." (Aisha); "*I felt more could have been done to just kind of support me and just give me information, just basic things, you know*." (Avani).

Some participants spoke about seeing this need delivered from professionals in both paediatric and adult services, "*what I really needed was just somebody to kind of explain things to me because I felt slightly lost*." (Avani). Aisha also described a similar need, "*I think the understanding wasn't there and it wasn't explained properly, so maybe if it was explained more*." (Aisha).

Sub-theme 2: Caring on my own. The sub-theme "caring on my own" related to some participants expressing they did not have support from their families and spouses whilst navigating their role of being a carer for their child with an LD, "*I've worked so hard. I've done so much and no one appreciates me from his side of the family.*" (Aisha). This sub-theme was found across childhood, the transition phase and adulthood/the present day.

Some participants expressed they were unsupported by their spouse within their caring role when their child was diagnosed with an LD and reflected on how they felt this has not changed in the present day, "*my boy, since he's been born, his father wasn't much of a helper or consider*." (Sara); "*my husband's not very understanding with these things... I think if your partner's good with you then you can do whatever. But I still say to him that you never did enough*." (Aisha). Sara spoke about the differences between mothers and fathers when undertaking the carer role, "*not that the father doesn't love this child, but their input, their thoughtfulness is completely different to what a mother's is*." (Sara).

Safa experienced blame from some members of her family when her child was born, "*my mother-in-law said I was cursed for giving her ill grandchildren*." (Safa); "*oh God what are you giving birth to? I've had a lot of that from his side of the family, that negative, you're giving us all poorly children this and that*." (Safa). Rita spoke about meeting families with an immigrant status who did not have the means to have a family network that could support them throughout their caregiving journey, "*as Asian families will have lots of family members that can do that care. You know, but it's very hard for new immigrants that are coming or people that don't have a family network that can support and that makes it very difficult*." (Rita).

Avani expressed there was an assumption from some professionals in paediatric and adult services that family support was accessible from the point of first diagnosis until the present day, "*that's the assumption that all South Asian families have got. Oh, we've got relatives everywhere. We all come and help. Actually, that's not really the case for most people. We're doing it on our own*." (Avani). Other participants had family in the UK but did not live close by to access support, "*my mum and dad, they do live in the UK, but they don't live nearby.*" (Aisha).

Sub-theme 3: Uncared For. The sub-theme, "uncared for" related to many participants feeling uncared for by some health and social care professionals particularly during the transition phase and adulthood/the present day. Some participants expressed some professionals had reduced understanding and experience of working with people with LD, "*you need the professionals to have a real understanding. Learning disabilities are incredibly diverse. It's not one-size-fits-all*." (Rita); "*I need to know that why people who work in hospitals don't have*

experience with working with people with special needs or complex care needs. Why is that not paramount." (Nicky). Avani spoke further about adaptations not being made for her son with an LD as he went through the transition phase and in the present day as an adult, "*he's never once been given anything in easy read information, even though I've requested it, he's never been given that*." (Avani).

Some carers expressed a lack of urgency from professionals to implement support when this has been asked for, more so during the transition phase and adulthood/the present day, "*they need to sort out things as quick as possible if they can, and if they can't do it not to fob them off*." (Aisha). Some participants felt they needed to chase professionals more so in adult services for support to be put in place, "*I constantly feel like I'm actually doing everybody else's job for them as well as being a carer. Do you know what I mean? And I think that's really disgusting at the end of the day. Do your job and do it properly*." (Nicky); "*try and repair not having to chase it up as much. I'm having to chase it up a lot. A lot more than a lot of people used to have to.*" (Aisha).

When getting in contact with professionals during the transition phase and adulthood, some carers felt ignored and left on their own to manage the needs of their children, "I'm thinking to myself, I need someone to answer it so I can do something about it or sort it out at least. I don't know what I'm doing?" (Aisha); "*just a little bit more support from the healthcare and you did kind of feel like you were just left to get on with it.*" (Avani). Many participants expressed a need from professionals in paediatric and adult services to check in with participants throughout their caregiving journeys to ask how they were managing, "*I felt very alone. I felt that nobody came to see how I was. I just felt I needed someone to talk to*" (Safa); "*I don't think anybody's ever checked in and said, are you OK? Do you need any help with anything? I don't think I've ever had that. And I'm talking from a professionals and services viewpoint*." (Avani). Nicky expressed a need for professionals across paediatric and adult services to be accessible particularly during times when they needed support, "*I don't want to be in contact with you all the time. But I want you to be accessible*." (Nicky). Avani spoke about how carers do not ask for much from professionals, "*it's little things. I don't think any of us ask for massive things, it is just the little things*." (Avani).

Many participants reported feeling some professionals across paediatric and adult services were not empathetic towards them throughout their journey as a carer, "*why have you taken this job? Because your behaviour is not telling me that you actually care or that you actually understand*." (Nicky); "*you have to be like strongly empathic. You have to think, how would my child feel*?" (Rita). Avani shared a story from when she felt her son's life was devalued

by a health and social care professional from paediatric services because of his learning disability, "*he just looked at me and he said your son has a learning disability. Does it make any difference if he can hear you or not*?" (Avani).

GET 2: Disempowered

The theme "disempowered" was highlighted within participants' experiences through childhood, the transition phase and adulthood. This theme specifically encapsulates participants' experiences when meeting and working with health and social care professionals. This theme was distinct from the previous theme of "lack of support" which referred to participants' overall experiences of having limited assistance from the systems around them, for example, spouses, family members, health and social care services and professionals. Participants relayed experiences where they felt their status as a parent and carer held less power in comparison to professionals. Many participants felt their identity as carers and parents meant they were overlooked by some professionals, regarding their needs not being considered and feeling they were not listened to. Culture also impacted some participants as they felt their South Asian background lowered the power they held, and they were treated differently by some professionals because of this.

Sub-theme 1: Unequal status. The theme, "unequal status" related to a power difference in status between carers and health and social care professionals, which they experienced throughout their journey as carers. When working with multiple professionals across her caregiver experience, Safa felt the opinions of professionals were valued more than hers when she felt her daughter was being mistreated, "*I just feel like social worker, she's listening more to them than us. I was fed up*." (Safa); "*I just feel like because they're white and she's white, she's going with them and not us. But yeah, just thought it was a bit of racism there*." (Safa). Avani expressed there was a lack of accountability from professionals when mistakes occurred around the care she received for her son during his childhood and the transition phase, "*I never get an apology for anything, and I'm kind of going just say sorry, you've made a mistake*." (Avani).

Rita reflected on how she felt professionals across paediatric and adult services will protect each other when facing families, "if it's social services, they have to safeguard each other, they have to look after each other. Professionals will amalgamate information as well." (Rita). Rita also compared carers to foster families and expressed how carers have less protection, "*foster families have a foster family union and they have legal indemnity. So, if anybody makes accusations or whatever, anything, they're supported by that. So you can imagine that a family that's from a culturally different background. No language, no union, no*

support services, nothing. And you're met by antagonism with the nicest intention people." (Rita).

Some participants discussed the differences in repercussions between themselves and professionals across paediatric services. Avani described an experience where she was attempting to her son an Education, Health and Care Plan (EHCP) but professionals missed their deadlines for this, "*I'm currently trying to get his EHCP updated after annual review. They've missed all their deadlines on that. If I miss a deadline as a parent, you know, I get a smacked wrist and told no, nothing's going to change. They miss a deadline, oh well, you know, it couldn't be helped*." (Avani); "*I'm trying to sort something out right to keep my daughter safe. I'm trying to keep her safe. Yeah. It'd been a different story if I wasn't keeping her safe. You'd be on me like a tonne of bricks*." (Nicky). Nicky also described how she was worried about the power in which paediatric services had in removing her children from her care when they were younger, "*really you probably would have taken her off me if owt would have happened to her*." (Nicky).

Some participants felt unable to challenge professionals within paediatric and adult services, one reason being the professionals was seen as the experts, "*if the professionals said something, that was that was it. You know, they're the ones that are experts, you know*." (Sara); "*I was always very much well, they're the health professionals, they're the people in charge. Who am I to kind of challenge them*?" (Avani).

Rita reflected on her caregiver journey and felt there was an overall need for equality between themselves and professionals across paediatric and adult services, "*to advocate for people with disabilities or learning disabilities, you have to not care about any of the stuff. You have to be on equal capacity to the parents*." (Rita). Some participants experienced moments where they had a health and social care professional on their side supporting them and how helpful they found this when advocating for their children's needs, "*the company themselves were like, oh, no, we feel this isn't right. The OT turned round and said, the house is beautiful, what are you talking about and I'm like oh thank God, someone's spoken up*." (Safa); "*I do have one person working with me, which is speech and language therapist she is, while I've got contact with her, she's managing to open other doors for me*." (Nicky).

Sub-theme 2: Overlooked. The sub-theme, "overlooked" related to many participants expressing overall how they did not feel listened to by professionals through childhood, the transition phase and adulthood/the present day, "*you're forgetting that I'm physically one person and I'm having to take all this on myself, and I feel like I can scream and shout as loud as I want and nobody's listening*." (Nicky). Other participants spoke about being labelled by some professionals in paediatric services when they were concerned about their child's early

development, "*I got the same statement about oh, mum was just, you know, she's just over worried. There's nowt wrong with him. He's fine*." (Sara); "*I said to her, I said, do you think it's that? She goes oh, no, no, no, mum, you're just overreacting. It's nothing like that*." (Safa)

Some participants spoke about their parental views being dismissed by some professionals in paediatric and adult services. They found this particularly hard as they felt parents knew their child more than professionals, "*they wouldn't listen to me as a parent, which I didn't like because the thing is, a parent knows the child best. If the child's got special needs, the parent will know this more.... the doctors only know them for half an hour or 20 minutes, whatever. Sometimes they don't even know them, they only read a piece of paper or something on the computer*" (Aisha). Other participants spoke about their role of a parent being overlooked by some professionals in paediatric and adult services. Participants expressed a need for professionals to remember that parents and families are important in their child's care, "*that's still my child. I'm still her mother*." (Nicky); "*they need to know first off that families genuinely are the experts, don't overlook the value that a family brings*." (Avani). Avani also reflected on how her parental view would be dismissed further as her son was 18, "*nobody is kind of reaching out and saying, oh well, do you know that once you know he's 18, you can't make these decisions and it's kind of like, no, I have no idea. But now I'm feeling really, I'm feeling really lost and a bit scared actually, because he's an adult in his own right*." (Avani).

Some participants felt their own needs as a carer were unconsidered by some professionals throughout their caregiver journey and felt they also needed to be asked how they were managing, "*I brought him here. I'm the one who's supporting him in answering all the questions, I'm giving you all the information about his medication to the consultants, the XYZ. And you've not once even asked me if I'm OK.*" (Avani); "*I've looked after [daughter] for so many years and I've never asked anybody for anything. I says, now I'm telling you, what about me? What about me?*" (Nicky). Some participants felt there was a lack of acknowledgement of how difficult the carer role can be from some professionals within paediatric and adult services and wanted professionals to have more empathy and understanding around the role they are doing, "*there was nobody to reciprocate my thoughts, or I think, or you know this has been really, really tough*." (Sara); "*we've already got a lot to deal with. Why are you making it even harder? Do you know what I mean? And it's not fair*." (Nicky).

Sub-theme 3: Culture not accepted. The theme, "culture not accepted" related to some participants expressing how they were treated differently by professionals because they were South Asian, and this was noticed during the childhood, transition and adulthood phases. Rita spoke about feeling there was some overall resentment towards the South Asian

community, "*often people who are from other countries, even if they're not Pakistani, for instance, they'll be called P**i. So that's a key group, there's a lot of resentment towards. So you can imagine how it feels if they're accessing services*." (Rita); "*some people are, quite maybe antagonistic to people of different cultures, or like you think, look at them all coming to this country and trying to access our services and stuff*." (Rita).

Some participants felt unprioritized by paediatric and adult services because they were South Asian. Safa spoke about feeling her opinion was not considered because she was South Asian, "*I just thought because we were Asian and they were all white, and I just felt they were like, oh we'll let her talk, they'll be quiet in a minute. I just feel they underestimated us, and they didn't think much of our opinions because we're Asian*." (Safa). Avani shared a similar experience but noticed a response by paediatric services was quickly given when her son's father (who identified as White) reached out for support, "*I've been kind of like writing emails, and I need a response for this, please, could you help me with this? You don't get anywhere. But the minute I get [son]'s dad, who is white to write a letter, he'll get a response. But I've been knocking that door for weeks and nobody's replied*." (Avani).

Some participants felt professionals across paediatric and adult services did not understand or show interest in their cultural needs, "*the one thing that professionals are not very good at is they're not inquisitive enough about our kind of cultural needs*." (Avani). Sara experienced a time where her son's Islamic faith was not taken into consideration when adult services were arranging different activities in the community for him, "*I said well he won't be going because you know I'm a Muslim, I'm practising myself. I don't go in a pub. Why would I not take consideration for my son and his faith? So they don't like it. They don't. He doesn't have to drink. Well, he doesn't have to go in the pub neither*." (Sara).

Other participants felt they were viewed suspiciously by some professionals across paediatric and adult services when asking for support for their children, "*I'm asking you about just filling in a form and doing an assessment and it got turned around very quickly to, oh, well there must be something, you know, suspicious going on in the family that she's contacted us rather than I just need a bit of support with this form*." (Avani). Rita spoke about how certain cultural traditions can be considered normal in South Asian culture, but viewed as inappropriate within Western culture, raising suspicions amongst some paediatric and adult professionals and becoming a cause for concern for some, "*hand feeding can be classed as neglect because you're not providing utensils, eating on the floor might be classed as neglect because you're not eating on a table, but culturally a lot of Asian families might eat on the floor like a family camaraderie*." (Rita).

Some participants spoke about a need for more cultural understanding within paediatric and adult health and social care services. Safa specifically expressed a need for more health and social care professionals from different ethnic minority backgrounds to have a presence in paediatric and adult services to support carers in their role across the lifespan of their children as she felt this may help carers feel advocated for, *"I've never saw one Asian person come to any meetings or be there for us. That should change. There should be more people available, especially out of the different cultures*." (Safa). Other participants expressed dissatisfaction around diversity training for professionals in general and a need for them to have more training on cultural awareness so they can support families accordingly, "*all into diverse training and diversity and everything, but where you know, where are you applying it*?" (Sara), "*I think professionals really need to look at training on bias, prejudicial bias. And it can be to go and learn about cultural sensitivity*." (Rita).

GET 3: Hidden Experiences

The theme "hidden experiences" highlights the experiences from participants that were held internally throughout childhood, the transition phase and adulthood. Many participants spoke about feeling emotionally exhausted and the need to appear as though they were coping with their caring role. Many participants expressed the physical and emotional toll of their caring role and how there was no time for a break. Some participants spoke about the difficulties in adjusting to their children having a learning disability, and how they hoped for a cure. Many participants spoke about how they became a voice for their children and how there was a motherly instinct to protect them from potential disadvantages in society.

Sub-theme 1: Emotional burden. The theme, "emotional burden" related to many participants' experiences of the emotional toll of caring, which they reflected on in the present day. For many carers, they felt the caregiver role in general impacted their mental health, "*my mental health just deteriorated. You know what I mean? And that's what makes me angry, it's why have you allowed me to get there?*" (Nicky). Some participants spoke about feeling alone, "*I used to cry a lot on my own*." (Safa), "*it presents like I'm really strong. I'm not. I'm not as strong at all. I'm broken inside*." (Sara); "*caring is lonely*." (Avani).

Asking for help across the lifespan was varied among participants. Safa expressed that she did not want to admit she needed help during the childhood phase when she was struggling to manage her daughter's behaviour, "*her behaviour became that much that I couldn't cope. I didn't want to admit that I needed help. I hid it from anyone*." (Safa). Sara expressed, she wanted her emotional needs to be recognised as she was learning to support a child with LD, "*I need help as in emotional help and support in holding my hand, and saying, you know, we*

understand, or you know we're here." (Sara). Nicky expressed future concerns for her daughter if her own health was impacted as she recognised that she was getting older, "*my other worry as well is I'm not well in myself. If anything happens to me, what happens to my daughter*?" (Nicky).

Many carers felt there was no break for them from the moment they became a carer and spoke about having many tasks to complete, "*I've got a long list of things to do every day and I'm thinking, I've got this to do. I've got that to do.*" (Aisha); "*my phone's going to go off in a minute. Somebody's going to text me in a minute. I'm going to get a phone call. So I can't relax*." (Nicky).

Some participants spoke about others not understanding the overall demands of being a carer when supporting a child with LD, "*I remember, you know, saying to this neurologist I said, you know, you sleep at night. I don't, you know, every day is like a year*." (Sara); "*15 years that I've been pushing along on my own. I was pushing along, pushing along, pushing along, at the end of the day, like I've been trying to tell them, I'm a human being. I'm not a machine. And you need to understand that and realise that*." (Nicky).

Some participants highlighted that the demands of their caring role between childhood and the present day meant they did not have other activities outside of caring. They felt they also deserved to have a life and acknowledged the sacrifices they have made to ensure their children's needs were met, "*because I've got disabled kids doesn't mean that I'm not allowed to have a life*," (Aisha); "*I'm his carer and you know it's a job and it's a blooming hard job and you know I've had to sacrifice a lot to be the best carer that I can be*." (Avani). Avani further highlighted the exhaustion faced by carers throughout their journey and the need for a break, "I'm a mum to three, you know, there was two years between the boys and I was like, I'm knackered, I just want a break." (Avani).

Sub-theme 2: Masking. The sub-theme, "masking" related to some participants feeling they had to appear strong on the outside but felt emotionally different on the inside. This was something which participants reflected on in the present day when looking back at their journey as a caregiver, "*it presents like I'm really strong. I'm not. I'm not as strong at all. I'm broken inside, you know, I'm weak but if I break, I'm weak*." (Sara). Some participants felt they needed to appear they are coping with their caring role, "*if you're caring you have to show how you're caring, what you're doing*." (Rita); "*inside you're thinking you know, you've got to appear as though that you are just on the ball all the time with everything*." (Sara).

For other participants, looking and appearing strong related to them wanting to avoid raising further suspicions with professionals, particularly in paediatric services as they feared their children will be taken away if they appeared as not being able to cope with the demands of being a carer, "*I didn't say too much because then I didn't want to put myself in a situation where*

there's a red flag and call social services." (Nicky). For Rita and Avani, there were concerns that if they did not look as though they were coping with their caring role, there was a fear that social services would remove their children from their care, "*I might need to ask somebody to come and help and, you know, just help me get him in the shower and do those little things. But then I get really fearful and go, oh but that might escalate into something else. They might go well, she can't look after him, so we'll have to take him away*." (Avani); "*if they found that there was concerns over one child, all their children would have been taken, including the healthy ones*." (Rita).

Sub-theme 3: Unprocessed grief and loss. The theme "unprocessed grief and loss" related to some participants looking back in the present day and reflecting on how having a child with LD was unexpected. "*me and my husband didn't sit down one day and say let's have a child that's disabled*." (Sara).

Participants expressed they had some hope particularly during childhood that their child would have been cured of their LD, "*we used to go [hospital] to see the consultant and they were like, he's getting better, this and that. But when I thought he's going to get better, I just thought it's going to go back to normal*." (Safa); "*wait for the summer, he'll be loads better because you know children do pick up, you know when they've past 6 months old. And I remember saying to my mum for many, many years, just mum, which summer were you talking about?*" (Sara).

Sara and Safa also reflected on their children's developmental delays and how they hoped this would have improved as their children got older, "*it's not getting easier because you know, obviously, age wise, his mobility has declined considerably, which they promised me it wouldn't change. So he's virtually he's not without a wheelchair at all now.*" (Sara); **"***we just thought he's going to get better as time went on along. But his development just got that delayed that he's a 30-year-old man now but he's way behind his years*." (Safa).

For some participants, it took them time to adjust to their child's LD diagnosis when they first got this in childhood, "*it took him a while to kind of get his head around it and he needed that time*." (Avani); and realising there was not a cure, "*I believe that this whatever was happening was some, would get identified and would get cured. Ever thought this would be a lifetime thing? Never ever.*" (Sara).

Sub-theme 4: Advocator. The sub-theme, "advocator" related to many participants becoming a voice for their child to ensure their needs were met, "*there's no bigger voice for her than me, there isn't, and I will shout and scream as loud as I can because I have to, because she can't do it*." (Nicky). Some participants felt unable to do this in the beginning, but overtime they

developed the confidence to advocate for their children, "*he says to me, I speak too much and talk back so much and I said you've made me what I am now.*" (Aisha).

For some participants, there was a need to ensure their children were provided with the right level of care and resources throughout their lives to support their needs. They felt this encouraged them to become advocators, "*it's about making sure he has the best*." (Sara); "*if I didn't love my son the way that way that I do, I wouldn't have given up my job. I wouldn't have spent the last 17 years fighting and just making sure that I'm bringing up the best person that I can and giving him the best.*" (Avani).

Other participants reflected on their need to protect their children particularly when facing disadvantages in society as children and adults, "*[daughter] can't fight for herself, but I will take you to hell and back for my child, because you're not doing that to her*" (Nicky); "*I don't care if I'm blacklisted or if there's a red flag that says, you know, crazy mum incoming, it's kind of like no, this this is me and I will attack you. I will go for you if you ever do anything that's going to be detrimental to my son's life, or his health*." (Avani).

GET 4: Feeling abandoned

The theme, "feeling abandoned" highlights the experiences from participants during childhood, the transition phase and adulthood. Their experiences indicated they were left on their own by health and social care services, professionals, their communities and family members to manage their caring role initially and throughout their journeys. Some participants spoke about feeling disowned from the South Asian community. Some participants expressed how there was a stigma around LD and how being a carer was devalued within the South Asian community, resulting in some carers feeling a loss of connection. Some participants spoke of their experiences in being unprepared for adulthood. Many participants felt there was a lack of transition into adult health and social care services when their child reached adulthood, and this was something they felt unprepared for. Some participants felt their child was marginalised in society because of their LD. Many participants felt their child was devalued and unprioritized in mainstream society and how there were reduced opportunities for PWLD as they reached adulthood.

Sub-theme 1: Unprepared for adulthood. The sub-theme, "unprepared for adulthood" related to some participants feeling they and their children were unsupported as their children became adults. Looking back, participants felt children's health and social care services provided better practical support in comparison to adult services, "*as we were in children's services, we got all the support we needed. I can't fault them for that*." (Nicky); "*so everything until 16 you'll get everything sorted*." (Rita). However, many participants felt there was an

unexpected ending from children's services and no transition to adult services when their children turned aged 16-18, "*everything was OK when they were young.... but then all of a sudden, everything's gone*." (Rita); "*they didn't pre-warn me, that just happened*." (Aisha); "*I found when we got to 18, it was like everything just got stripped off us*." (Nicky); "*I hate that word transition because [son] hasn't transitioned into adulthood. He's just kind of been thrown into it, and I've been thrown into it as well*" (Avani).

Some participants expressed a sense of abandonment from services during this time and feelings of unpreparedness when their child became an adult, "*I genuinely feel that 16 to 18 phase for us has been one of just being completely left on our own*." (Avani); "*a lot of parents find, it's a big bad world out there. And what do we do? We haven't got like a plan of action*." (Rita). Nicky spoke about how she felt unsupported by adult social services, "*support wise from adult social services has been absolutely disgraceful*." (Nicky). "*I just feel like where social services are concerned, that they haven't had my back at all*." (Nicky).

Participants were unclear on what support was available and how to access this when their children became adults, "*there is no support for people who are, quote, unquote, unpaid carers. There's nothing there, why is there nothing there?*" (Nicky), "*social care is non-existent. I don't even know how to pursue it*." (Avani); "*I kind of asked around and you know, the Council just weren't willing to give anything.*" (Avani); "*these important things in society, they can't be just hidden away*" (Rita); Rita highlighted access to adult services may be harder for carers who are not born in the UK as they be unaware of what support is available, "*if you're from a different country, you probably don't know what systems are available*." (Rita). Rita also spoke about this idea of gatekeepers to adult health and social care services, "*there's gatekeepers to services. There is gatekeepers. That's how it is.*" (Rita).

When adult services were known to participants, some felt access was difficult, "*there's a brick wall up against me every single time*." (Nicky). Rita spoke about adult services having complex rules to follow when gaining access, "*there's so many rules, regulations or so many prohibitions, some prescriptions that you need to follow*." (Rita). Some participants felt they needed to be in crisis to gain access to adult services, "*I've never had a carers assessment. I've asked the local authority, and they keep saying we'll only do one if you're in crisis and I kind of go but hold on, wouldn't you rather avoid a moment of crisis?*" (Avani). Nicky experienced a similar scenario and felt adult social services should be preventing a crisis, as opposed to intervening when it reaches this point, "*unless you're in a crisis at that moment in time they will not intervene until it's actually happened, do you know what I mean? And then do you know what I call that, I call it's too late...prevention is the cure and why you don't live by that I do not know.*

It's disgusting and it's ridiculous." (Nicky). Nicky also experienced a time where she consulted with her Member of Parliament (MP) in order for her to gain access to adult services. However, she felt this should not have occurred in order for her child to receive support, "*why do I have to threaten you every single time with getting in contact with my MP before you realise or why social services had to be threatened from domiciliary care with duty of care before you saw red flag?*" (Nicky).

Participants spoke about the implications on them and their children when they do not have access to adult services for support. Rita felt children with LD are more likely to deteriorate if they do not have access to support, "*if you haven't got access to even that and you've got no equipment, nothing and then you can't. So it compounds disability but makes people deteriorate health wise and physical wise and mentally.*" (Rita). Nicky expressed how the pressure on carers would also reduce if access to adult services was easier, "*if the carers were given much more support, the level of pressure that that would be taken off the carer would be immense…it makes their life a little bit easier and they're able to access things a little more easier and don't put blockers in the way of being able to do something. Offer us to access*." (Nicky).

Sub-theme 2: Self-Sufficient. The sub-theme, "self-sufficient" related to many carers feeling they needed to find out about adult health and social care services and entitlements on their own during the transition phase and adulthood. Most carers felt they needed to research what was available to them because this information was not easily accessible, "*there's not a lot of information given. I think it goes downhill after that unless you find out yourself*." (Aisha); "*I just felt that the ownness was always on the family to go out and search for that stuff.*" (Avani). Rita spoke about the need for carers to have certain skills in order to find what support was available when their children became adults, "*there's such a lot of skills to expect from carers who didn't know that they were going to have a disabled child*." (Rita); "*a key thing for ethnic minorities, well a key thing generally might be just class as well, but you do have to be incredibly knowledgeable. You have to have incredible communication skills and you have to be competent and organised. These are skills you need to access services. Makes your life easier*." (Rita).

For some carers, they were required make their own referrals to access adult health and social care support. For Aisha, she felt finding the right professional to complete the referral to adult services was time consuming and completed this herself, "*that took me probably a couple of weeks to try and find the right person to get through to and then eventually I did the referral for that myself*." (Aisha). For Rita and Sara, they felt a need to complete their own referrals for adult

services to ensure their children's needs were met, "*my children accessed lots of services, they went on trips and they did things, so they accessed things. But I had to make them happen uniquely myself*." (Rita); "*most of the time, I've just been proactive myself.*" (Sara).

Avani highlighted that when carers are having to be self-sufficient, particularly when accessing adult services, this can be time consuming, "*you haven't got the time or the energy to sit and kind of trawl through a website or, you know, look through a specialist magazine or whatever You're just you're so tired*" (Avani). Participants expressed a need for more information around managing aspects of adulthood to support them and their children, "*I wish that point, like the schools would have given information, like basically you might need this in the future, power of attorney you might need. There's no information leaving high school for what was ahead*." (Safa); "*I've had no information to say who she's going to see in adult services. I have nothing. I don't know who I get in touch with*." (Aisha); "*if you know there's a family who's got all these issues they're dealing with, then just give them that information, don't say to them you need to go and find it yourself because that's failing people*." (Avani).

Sub-theme 3: Disowned from the community. The theme, "disowned from the community" related to some participants feeling a lack of acknowledgement and connection within the South Asian community throughout their journey as a carer, "*the one thing that I learned very quickly after [son] was born was that my community kind of just a lot of people moved away very quickly, didn't want anything to do with me*." (Avani).

Some participants described the South Asian community as having high expectations. A sense of abandonment first came when they had a child with an LD, "*a lot of Asian families, they might not give value to people with learning disabilities because they've got their children who need to be doctors or you know, solicitors*." (Rita); or when they became a carer, "*I remember somebody saying to me, oh gosh, you know, you're a carer now and you know you haven't got that high flying job that you did and all of this, and it was kind of almost frowned upon that I'd taken on this other role*." (Avani).

Some participants spoke about the stigma surrounding LD with the South Asian community which they felt became more noticeable as their child progressed from childhood to adulthood, "*if they live in the community environment, they're less likely to tell us their difficulties and challenges because they're worried that they're going to get stigma*." (Rita); "*there's a genuine fear of disability. There's a need in our communities to always be better than the next person, and when they see somebody who's got a disability or a family member who's disabled, it's kind of like that family's failed*." (Avani).

Sara shared her experiences on when she tried to encourage her ex-partner to support their child in the community when he was an adult and how difficult this was, "*I wanted him to look good in the community as well. Saying oh, look what he's doing, he's brought his son to do this. Because he's my husband I want him to have respect*." (Sara); "*with a wheelchair was something that became a stigma because on a couple of occasions saying, OK, then I'll take you. If you walk with me, you know which is good. That's good encouraging him. But not. Oh, I'm not taking him out because people will see him in a wheelchair and stuff."* (Sara).

Sub-theme 4: Marginalised for having an LD. The sub-theme, "marginalised for having an LD" related to some participants feeling society does not support the needs of adults with LD, "*people with disabilities should be included in mainstream but it's not happened because it's too much. You have to re rethink the whole of society to do that*." (Rita).

Some participants felt the lives of adults with LD were not valued in mainstream society, "*when we were in COVID and I just kept thinking people with learning disabilities are dying here and now I can see why because those attitudes still persist. There's no value to these people's lives*" (Avani); "*it's not in the local authority's best interests to work with disabled people and their carers*." (Rita). Both Avani and Rita felt physical needs over LD were also prioritised more in mainstream society because they are visible, "*I do think that people with learning disabilities aren't a priority. I just think they fall through the gaps too quickly. People seem to kind of support a person with a physical need much more quickly, maybe it's because it's more visible*." (Avani); "*we tend to cater for physical disabilities much better than with learning disabilities*." (Rita).

Many participants spoke about a lack of provision in mainstream society for adults with LD, "*I don't think there's much in place for kids with additional needs when they get to adult services*." (Aisha), "*there's the whole of adult life and adult life should not just be day centres*." (Rita); "*what do you want her to do now? Do you want her to be a recluse and stay in her room for the rest of her life, because that's not a life and she would never like that."* (Nicky). Avani reflected on how some people with an LD may have different life trajectories than those without a learning disability but society has not catered for the needs of adults with LD, "*does society understand that just because you reach 16, you reach 18, you reach 21, that you're not suddenly able to do what other people can do at that age?*" (Avani).

Nicky expressed how she felt adults and children with LD overall were targeted in society as opposed to being supported particularly when they are considered to be vulnerable, "*why are disabled people, or nonverbal or non-supported constantly being targeted? Why are we the easy target? Why? Why? I need to know why you think that's OK*" (Nicky) and spoke about how funding is less likely to be given to those considered as vulnerable such as people with LD, "*if*

they're taking it from anywhere, you shouldn't be taking it from where the vulnerable society is. Do you know what I mean? That needs to be paramount to make whatever life they've got left an enjoyable one as opposed to being a burden on society, or a drain on resources." (Nicky). Rita expressed concerns around adults with LD having less funding from the UK government to support their needs, "*so that's something that's like very unfair, that disabled people and carers get the brunt of cost efficiencies*." (Rita).

Summary of results

This chapter has provided details of the individual experiences of each participant within the research and considered these for their individual journeys together with the different stages of those journeys from childhood through to the present day. Some of these experiences were shared amongst many participants and these have been summarised into GETs and group-level sub-themes, alongside supportive quotes from the participants. The GETs and group-level sub-themes have been presented into a thematic map (figure 1).

The next chapter will discuss these results in relation to the research questions and existing relevant literature and the related psychological theory.

Chapter Four: Discussion

This chapter summarises the main research findings in relation to the research questions and wider literature. I have discussed the strengths, limitations and clinical implications of the research before outlining suggestions for future research and my conclusion and reflections.

Devapriam et al. (2008), Durling et al. (2018) and Heer et al. (2012) explored the experiences of South Asian informal carers (ICs) for people with learning disabilities (PWLD). Using quantitative methods, Devapriam et al. (2008) identified that South Asian carers for PWLD experience psychological and physical stress, however what was potentially contributing to their stress was not made clear. Durling et al. (2018) used qualitative methods to identify some of the experiences faced by Bangladeshi carers in London. Due to the small sample size, there were problems with generalisability, and their use of a thematic analysis meant individual stories could not be shared. Heer et al. (2012) investigated the experiences of South Asian ICs for PWLD aged 8-19. They also used qualitative methods; Interpretative Phenomenological Analysis (IPA), however, using focus groups may have resulted in loss of individual experiences being shared and participants potentially feeling unable to be fully open about their experiences.

This research aimed to add to the literature within this area and provide an account of the needs and experiences of South Asian ICs for familial members aged 18 and above with a learning disability (LD). Their experiences were explored during pivotal moments across the lifespan including childhood, the transition phase and adulthood/the present day. The research also explored how learning disability (LD) is viewed within the South Asian community, how the carer role feels for South Asian carers overall and what is needed to support carers in their role directly from the participants' perspective. A qualitative methodology using IPA was applied to allow the individual stories to be shared and to identify common group themes amongst all the participants. The research questions were:

- What are the experiences of South Asian ICs when looking after an adult family member with a learning disability across childhood, transition (age16-18) and adulthood?
- What are the experiences of South Asian ICs when accessing health and social care services for additional support in childhood, the transition phase (age 16-18) and adulthood?
- How do South Asian ICs navigate their role?
- What are the care needs of South Asian ICs?

Main research findings

This section will outline each research question and how they have been answered using the themes found within the results. Following this, I will relate these results to the wider literature to provide an evidence base for the findings.

Research question: What are the experiences of South Asian ICs when looking after an adult family member with a learning disability across childhood, transition (age 16-18) and adulthood?

The first research question focused on the overall experiences of participants when looking after their child with an LD across childhood, transition and adulthood. The group-level sub-themes which seem to answer this research question were, "unprocessed grief and loss", "emotional burden", "masking", "caring on my own", "disowned from the community", "unprepared for adulthood" and "marginalised for having an LD" and participants expressed these themes across the lifespan.

Participants expressed a need to appear strong externally but felt 'weak and broken' internally. They managed the practical and emotional toll of caregiving alone and with limited support from their family, spouses, and some members of the South Asian community. Some participants' family were not close by to offer support, and others spoke about not wanting to burden family members. Some felt unappreciated and blamed by family members, and described feeling disconnected from the South Asian community, attributing this to their identity as a carer and their child having an LD meaning they were viewed as a lower status compared to others.

Having a child with an LD was unexpected for all participants, with many reporting associated grief and loss. When their children were delayed in reaching their developmental milestones, such as crawling and walking, participants spoke about feeling worried and confused as this was different to what they expected from a typical child development. This lends support to Lalvani (2015) and Summers and Jones (2004) who highlighted within some South Asian families, there are feelings of grief and loss over not having a "normal child" (Summers & Jones, 2004, pg. 688). Fernández-Ávalos et al. (2021) also found that a diagnosis of an LD was directly associated with emotions including guilt, anger, sadness, fear and search for meaning. Whilst their study was not clear on what the ethnicity of their sample was, this research has furthered our understanding around the emotions South Asian carers may be experiencing. This included learning to adjust to their child's difficulties whilst simultaneously processing their child was not going to get better but remaining hopeful.

This research has supported some elements of the grief cycle (Kubler-Ross & Kessler, 2005) as participants' experiences have highlighted similar emotions. All participants reported feeling shocked when their child was diagnosed with an LD and described having difficulties accepting this. Some participants blamed themselves and others felt they were blamed by family members for their child's LD. Participants had also expressed some form of denial in the context of struggling to accept their child's LD. Participants reached out to doctors and family members in the hope their child could be 'cured', and they would have the child they initially expected. Some participants were told to be patient and that their child's LD would 'rectify' in the future.

Over time, participants realised their child's LD was lifelong and this was not going to change. For some, this required a process of learning how to adjust to and manage their child's additional needs. This lends support to Dobson et al. (2001), who highlighted that some families go through a process of adjusting to not having the child they expected to have, and how they may not be considered a "normal family" (pg. 26). However, ethnicity was not included in their criteria and the current research has shown these views still stand today amongst some South Asian families within South-West Yorkshire.

Part of this adjustment included their child having an incurable diagnosis and learning how to manage their additional needs. Previous research has identified that PWLD are likely to experience co-morbidities (Valderas et al., 2009; Truesdale & Brown, 2017). Aisha and Nicky shared their experiences of managing their children's lifelong co-morbidities and learning how to support their children with various forms of medical treatment, often without adequate training. This lends support to Knowles et al. (2016), who identified ICs can also support a cared-for individual with their medical needs, particularly where there is evidence of a chronic illness or long-term condition. Payne and Ellis-Hill, (2001) also identified that many ICs are likely to undertake nursing roles as part of their IC role which was experienced by Aisha and Nicky. However, Payne and Ellis-Hill, (2001) and Knowles et al. (2016) based their findings on carers for people with physical health conditions including stroke, heart disease, diabetes and kidney failure. This research has shown that some carers for PWLD may face similar experiences when supporting the medical needs of their children without adequate training.

Participants' experiences may have links to feelings of depression within the grief cycle (Kubler-Ross & Kessler, 2005). All participants felt the caring role impacted their emotional wellbeing, with some reporting a deterioration in their mental health. Some participants felt they had to project an image of being able to cope with the demands of their caring role. Externally, many participants felt they had to appear strong and being able to cope, whereas

internally, they described feeling 'broken' and 'weak'. The idea of some carers masking their emotions to appear strong was not found to be described in the literature review.

McGaw et al. (2010) highlighted how some parents of PWLD were more likely have their parental rights terminated when caring for their child. Many participants felt if they appeared 'broken and weak', and unable to manage their caring role, it would raise suspicions with health and social care services and there was a fear their child would be taken away from them. Whilst this research lends some support to McGaw et al. (2010), it has contributed further to these findings by identifying the actions carers may take to minimise the risk of this happening, for instance hiding the difficulties they are potentially facing and ensuring they appear capable.

These findings may also relate to aspects of the Power Threat Meaning Framework (PTMF; Johnstone and Boyle, 2018). In regard to power, the findings from this research could suggest participants felt professionals had the power to take their children away from them if they appeared unable to cope with the demands of looking after their child. This perceived lack of power from participants in the current research may be experienced as a threat around losing their child or appearing as inadequate. Participants may have made sense of the threat by realising they had little influence over this decision and therefore choice to mask their emotions to appear strong on the outside and potentially minimise the risk of this happening.

Many participants in the current research did not utilise respite services either which may be related to this idea that access would have meant their children did not come back home, as highlighted by Hubert (2006). The current research findings suggest that there may be little space for ICs to process the additional responsibilities placed upon them and an expectation for them to adapt quickly, potentially resulting in unprocessed grief and loss continuing for years.

Twigg and Atkin, (1994) highlighted the different patterns which ICs have when engaging with health and social care professionals. One of these patterns was carers as a resource. This suggests professionals may automatically assume relatives and spouses will be available for the dependant individual when statutory provision is unavailable. Some participants in the current study shared their experiences of caring for their child without support from family as they lived further away in the UK. This lends support to Hubert (2006) who also identified that many professionals may assume family support is available for South Asian ICs but this is not the case for all families. Findings from the current research add to our understanding around available family support as some participants spoke about their reluctance to ask family members, such as parents, for support as they were getting older and participants did not want to burden them. Hubert (2006) also conducted their research with participants originating from

the Caribbean and India who were living in London. The current research demonstrates some similarity regarding the reduced family support amongst some South Asian families originating from the UK and residing in South-West Yorkshire. However, it is important to acknowledge that this may not be representative of all South Asian carer experiences given the substantial diversity within this population.

Participants expressed feeling unsupported by their spouse when tending to their children's needs. Some participants felt there were differences between mothers and fathers when caring for a family member. This lends support to Sharma et al. (2016) who highlighted that gender differences are apparent in family-caregiving. Traditionally, women are expected to adopt the role of a caregiver, something which has been ingrained into them from childhood, through social and cultural expectations. Women are likely to spend more time carrying out carer-related tasks than men and are therefore more likely to be exposed to greater physical and emotional strain and caregiver burden. All research participants were mothers, and some expressed how their husbands/ex-husbands had little or no contribution to supporting their child's care needs.

Findings from South Asian studies have highlighted some people with intellectual and developmental disabilities in India and Bangladesh were more likely to face discrimination in the form of being verbally abused and avoided in social interactions due to the stigma attached to their child's LD (Kalyanwala et al., 2019). In Pakistan, people with intellectual and developmental disabilities tend to be hidden from society as they are viewed to bring shame to the family and threaten the social status (Kalyanwala et al., 2019). The current research has added to this by identifying similarities amongst some South Asian families in the UK. Some participants spoke about the South Asian community having high expectations and they felt being a caregiver and having children with an LD, lowered their status in the community. Other participants spoke about the stigma and fear surrounding PWLD within the community. Chan et al. (2021) found stigmatisation around certain difficulties, such as mental health and alcoholism, meant some ICs felt reluctant to seek support from family. This impacted ethnic minority families more than white families. These findings have shown participants felt isolated from their families and a reduced sense of connection with the South Asian community. This dynamic may link with social learning theory (Tajfel & Turner, 1979) regarding participant's feeling they are separate from the South Asian community. Some participants spoke about members of the South Asian community not wanting to acknowledge them because they were a carer and because they had a child with an LD. Some participants described how they were viewed as failures within their community and felt they were disowned by the same due to the

stigma around their child's LD. Having a supportive community can contribute to positive experiences of safety and belonging. Aisha detailed how she used her knowledge to support other carers. This suggests that although many participants in the current study may have felt separate from the South Asian community, they may have felt included amongst other carers where they could share knowledge and resources to support each other.

Research question: What are the experiences of South Asian ICs when accessing health and social care services for additional support in childhood, the transition phase (age 16-18) and adulthood?

The group-level sub-themes which best answer this research question were, "entering the unknown", "lowered status", "uncared for", "overlooked", "culture not accepted", "unprepared for adulthood" and "marginalised for having an LD".

In summary, results found that when their children were diagnosed with an LD, participants described having little to no information on what this was and how to access support, becoming more prominent when their children were transitioning to adult services, only feeling heard and responded to at times of crisis, When interacting with health and social care professionals, participants felt there was a power imbalance between themselves and professionals in relation to knowledge and empathic understanding of their child's and family needs related to their. South Asian background. Participants expressed feeling less prioritized, uncared for, ignored, unconsidered and unnoticed, and that their cultural needs were not considered by professionals. Participants highlighted a need for more cultural awareness and diversity within health and social care services.

Participants described how their first experiences of being around somebody with an LD was when their child was born. Prior to this, they felt they had little knowledge of what an LD was and therefore unsure how to manage their child's needs. This lends some support to Durling et al. (2018) who found that LD was an "alien concept" (pg. 1136) for some Bangladeshi ICs and how this term is more well-known for health and social care professionals. The researchers highlighted that future research needed to expand to include other Black and Ethnic Minority groups and the current research has found other South Asian carers may also have limited knowledge on what an LD was. Participants in the current research felt the information they were provided following the diagnosis was not enough to support them in their caring role. They felt they would have preferred for someone to explain what an LD was and how to support their child.

Previous research highlights that community services were developed to support the needs of adults and children within the community (Pickard & Glendinning, 2002; National

Institute for Health and Care Excellence; NICE, 2018). The Care Act (2014) also states that carers should receive services to support their needs and the individuals they are caring for to minimise the risk of their wellbeing becoming worse (DHSC, 2016). In addition, the Care Act (2014) also states that adult care and support should be involved in treatment planning when the carer is likely to need support for their child when turn aged 18 (DHSC, 2016).

The current research highlights that participants felt supported by paediatric services and reported minimal concerns. When their children reached adulthood, usually around aged18, participants felt there was an abrupt ending of paediatric services, often without a warning, and lack of transition to adult services. Participants felt abandoned and unsupported, unless they presented in a crisis. Greenwood et al. (2015) also highlighted that many ICs felt social services were more likely to respond in a crisis, as opposed to when ICs generally ask for support. These results were found within a systematic review and results in the current study are consistent with these findings. This allows us to suggest that some carers feel they are more likely to receive a response from social services when they are in crisis as opposed to when they are seeking general support. It prompts questions around what may be occurring within social care that have created a shift from prevention and early intervention to the reality of responding in a crisis. Bottery (2025) indicates that there may be difficulties within the social care system that need attention, for example reduced number of staff, inconsistent levels of funding across localities and lack of integrated care amongst services. The experiences of South Asian carers in this research have indicated a need to making changes to social care to help carers receive support sooner and minimise the risk of escalation.

Merrell et al. (2005) identified many Bangladeshi carers were unaware of support services available to them when supporting a familial member with Diabetes, Cancer, respiratory conditions and cardiac problems. This research has Furthered our understanding for carers of a familial member with an LD. Carers felt there was a lack of clarity around what support and entitlements were available for them and their children particularly during transition. Participants also identified as Pakistani or Indian which indicates similarities regarding the experiences of lack of knowledge around available support services for South Asian carers.

To manage this, participants felt they needed to search for support themselves and/or manage their caring role without additional support from services. However, participants expressed feeling angry when describing how they felt unsupported by health and social care services, particularly when their children became adults. They felt that reduced support had the potential to deteriorate their child's physical and mental wellbeing which placed more pressure

on them to support their children's needs. Participants felt they would have preferred more information on what support was available from services and within mainstream society to support theirs and their child's needs. Previous literature (Van Houtven et al., 2010; Barbabella et al., 2016) has indicated that some carers may benefit from carer training programmes which can provide relevant information to support their role. Whilst this research did not include the use of a carer training programme, the results potentially highlight a need for South Asian carers to access such a programme should they require support in their caregiving role.

Twigg and Atkin (1994) identified a pattern between ICs and health and social care professionals where ideally, they collaborate with each other to benefit the dependant individual. To achieve this, there was a recognition for ICs to be involved in treatment planning. Nolan et al. (1995) spoke about ICs being the experts within their child's care. However, participants in the current research felt their parental views were not listened to despite having extensive knowledge of their children's needs which indicates that collaboration between professionals and carers may not be occurring in all settings. The current research has found that participants felt unable to challenge professionals' opinions as they were regarded as the experts and therefore their views held more value over theirs. This lends support to Payne and Ellis-Hill, (2001) who recognised that ICs may be less inclined to challenge professionals due to power and difference in knowledge. French and Raven (1959) outlined different bases of power, one of which being expert power. Many health and social care professionals hold professional power due to their education and skills and they are regarded as experts within their field (Kaini & Kaini, 2020). This suggests that someone is perceived to have more power due to their expertise within a certain area and this form of power can be held by many health and social care professionals (Kovach, 2020).

The theory of expert power may help to explain why some participants in the current research potentially felt unable to challenge professionals when discussing their child's care needs. Despite parents feeling they had more knowledge, they had limited influence over decisions regarding their children's needs. From a PTMF (Johnstone and Boyle, 2018) perspective, this perceived lack of power may have felt threating to parents, particularly in relation to fears of being dismissed or losing responsibility as their child transitions into adulthood. Participants may have made sense of this as their parental views being undervalued and unconsidered, meaning they held less responsibility over their care unless legal guidelines such as power of attorney were in place. Participants felt their views should be considered and listened to as they are valuable in their child's care.

In addition, participants also felt less inclined to challenge professionals as they felt they were likely to stand by and protect each other when facing families. Some participants, such as Sara, experienced being labelled negatively when they challenged professionals. Other participants, such as Nicky, felt professionals were protected if they made mistakes, whereas ICs may face harsher repercussions from services. Participants expressed a need for professionals to be on the same level as families, rather than being on opposite sides. This dynamic may link with social learning theory (Tajfel & Turner, 1979) regarding participant's feeling they are separate from professional groups.

Participants also felt their cultural needs were not considered by professionals. For example, Sara spoke about her son being offered to go to a pub as one of his activities which went against their religious practices. Participants also expressed their cultural traditions can be viewed suspiciously by professionals. There were concerns that this would prompt further investigations into the family as part of safeguarding which made them reluctant to access services. This lends support to Merrell et al. (2005) and Devapriam et al. (2008) who also found South Asian ICs were reluctant to access health and social care services due to their cultural needs not being understood by health and social care professionals. This research suggests that these views may be held amongst other South Asian carers in different regions of the UK, and potentially not limited to some Bangladeshi carers or South Asian carers from Leicestershire as found from Merrell et al. (2005) and Devapriam et al. (2008). Furthermore, participants in the current research expressed a need for health and social care professionals to be more inquisitive when supporting South Asian families. They expressed a need for professionals to have more training on cultural awareness and further interactions with the South Asian community to understand and respond to their cultural and religious needs. Participants also expressed a need for a more diverse workforce within health and social care services.

A difficulty with Social Identity Theory is that categorising individuals into groups presents a risk of potential stereotyping and prejudice towards out-groups (McLeod, 2023). Jaspal and Lopes (2021) note how significant societal events, such as the September 11th, 2001, attacks in New York, and the July 7th, 2005, bombings in London highlighted racism and discrimination towards the British South Asian community, and they were more susceptible to increasing Islamophobia. Participants in the current research felt there was resentment towards to the South Asian community. Labelling theory (Becker, 1963; Lemert, 1951) suggests labels can shape identity and behaviour and bring positive and negative responses. This research has identifiedthat being labelled as South Asian can also bring different responses as participants

felt their identity attributed to them being viewed suspiciously, treated differently and unprioritized by professionals. Participants felt this impacted on whether they were accepted into health and social care services for support and felt a need to wait longer to be seen than non-ethnic minority families.

Participants felt professionals had limited understanding and experience when working with PWLD and highlighted how the needs of PWLD were diverse and adaptations are required to meet individual need. This lends support to Ee et al. (2022) who identified that professionals have limited knowledge and training to work with PWLD and understand their health needs. They also found negative attitudes towards PWLD had also influenced their willingness to treat and provide care. Ee et al. (2022) highlighted a need for professionals to have increased contact with PWLD and further training opportunities to understand their needs better. However, the researchers have not accounted for ethnicity in their research. The current study has demonstrated that some South Asian carers feel a need for professionals to better understand the individual needs of their children. Participants also described feeling ignored and not considered from professionals when supporting them and their children. They described having to chase professionals for updates on their child's care and needing to manage their children's needs completely on their own in the interim.

Kaini and Kaini, (2020) highlight how medical professionals may be more likely to have a scientific approach to medical problems as opposed to a holistic approach which takes into consideration the physical, emotional, personal and behavioural needs of the individual. This research found many professionals appear to take a scientific approach to supporting families with an LD diagnosis. Participants expressed how they felt health and social care professionals lacked empathy and understanding around their role as an IC. Participants expressed a need for professionals to check in with them to ask to ask how they were, how they were coping with and managing their children's needs, whilst acknowledge the difficulties they may be facing within their caring role. The difference in approaches from professionals may help to explain why participants felt there was a lack of empathetic understanding from professionals, and why they may not tend to reach out to ICs to check how they are managing with their role. This also suggests that South Asian carers may prefer a holistic approach to supporting their needs. Relationship-based practice theory emphasizes that empathetic, trusting and compassionate connections between professionals and individuals, such as patients and families, can help to navigate complex situations and produce positive outcomes (Ruch et al., 2018). Applying this approach with South Asian carers can involve professionals establishing trust and rapport with the children and their families and using empathy to build a professional relationship. This can

promote collaboration and a holistic approach to care when supporting the needs of South Asian carers and their children with LD.

Previous literature highlighted a need to support PWLD to live in the community and have access to equal opportunities as people without LD do (Bibby, 2013; Jarrett & Tilley, 2022). These findings were obtained through a systematic review (Bibby, 2013) and historical review of LD (Jarrett & Tilley, 2022). However, these findings do not appear to give context to what may be happening for PWLD that means they need further support to live in the community and access equal opportunities. The current research can provide some clarification around this as results indicated participants felt their children's needs were devalued in society and they were not considered a priority with adult services. Participants felt adult services were not interested in supporting their children's needs, nor acknowledged how their needs were different to those without an LD. For instance, participants highlighted how mainstream society had limited community activities and educational opportunities for their children when they reached adulthood, whereas those without an LD, have more opportunities in mainstream society.

The experiences from participants within the current research suggest there may still be inequalities regarding access to opportunities between PWLD and people without LD. The experiences of many participants may also fit with the social model of disability as it highlights how PWLD may be more disadvantaged by societal attitudes as opposed to their impairments (The Physically Impaired Against Segregation 1976; Oliver, 2013). The current study also lends support to Kenyon et al. (2014), who found PWLD felt there were limited opportunities for them in society, one of which being access to community activities. Participants expressed an overall need for society to support them and PWLD, including their children. They expressed a need for better opportunities for their children and other PWLD when they become adults so they can feel more integrated within society.

Participants felt they were doubly discriminated against because of their identity as a South Asian and for having a child with an LD. Jaspal and Lopes (2021) highlighted that Ethnic Minorities are likely to face a double stigma due to the existing discrimination and prejudice they may face as a South Asian, and when faced with a mental illness. Whilst this study may lend some support to the researchers, LD is not classified as a mental illness, therefore this research has indicated that a double disadvantage seemingly exists for participants due to their South Asian identity and having a child with LD. In addition, Kalyanwala, et al. (2019) identified that South Asian families in India are also known to be "doubly disadvantaged" (pg. 24) if they reside in socioeconomically deprived areas and have a child with LD. Whilst the current research did not account for participants' socioeconomic status, this may suggest that South

Asian families looking after PWLD whilst living in socioeconomically deprived areas in the UK may potentially face a 'triple disadvantage'.

Jaspal and Lopes, (2021) highlight that perceived discrimination and racism from society can create a "racial boundary" (pg. 82) for some South Asian individuals. This is when they perceive mainstream society to be inaccessible for them and they develop a stronger attachment to their community as an alternative source of support and a sense of belonging and safety. However, as discussed, participants in the current research felt disowned by some members of the South Asian community due to their status as a carer and having a child with LD. Participants expressed a need for the stigma surrounding LD within mainstream society and the South Asian community to change. Whilst this may also reduce the isolation from the community, families, professionals and society, experienced by some South Asian carers, it is important to acknowledge that this may not be the case for all South Asian carers in the UK.

Research question: How do South Asian ICs navigate their role?

The group-level sub-themes which seem to answer this research question were, "self-sufficient", "advocator" and "emotional burden", as summarised below.

Many participants described feeling unsupported by professionals when seeking support for their child. They spoke about having to independently search for services, understand their entitlements and to find out about community activities for their children, who were more likely to rely on their primary caregiver for protection and comfort (Bowlby, 1969). This lends support to Fletcher et al. (2016) who found children and adults with LD tend to depend more on their primary caregiver.

Primary caregivers tend to be driven to respond to the needs of their child (Bowlby, 1969). Upon recognising that their children relied on them to support their needs, many participants in the current research felt a need to protect their child from discrimination and unequal opportunities within society. As a response, participants in the current study described how they developed the ability to become advocators and self-sufficient in response to limited support. They became a voice for their child to ensure their needs were met, especially when their children could not speak for themselves. These findings from the current research can relate to elements of the Power Threat Meaning Framework (PTMF; Johnstone and Boyle, 2018), as participants described becoming confident in advocating for their children overtime in the face of perceived disadvantaged and reduced power.

Consistent with Sharma et al. (2016), the current research highlights participants' sense of commitment and altruism when supporting their child's needs in the face of disadvantage, particularly when researching what adult services and entitlements were available for them

both. They felt a need to be knowledgeable, proactive, organised and have good communication skills to access services, and often completed referrals themselves as opposed to relying on professionals. However, whilst being committed and altruistic was viewed positively, it produced challenges as some participants described the balance between completing referrals, searching for support and caring for their child to be time consuming. Participants expressed a greater need for professionals to provide guidance and information on available services and entitlements for themselves and their children.

While all participants expressed love for their child, they described their role as constant, exhausting and often without a break due to the multiple daily responsibilities they held to ensure their child's needs were met. Many participants spoke of the physical and emotional demands of being a carer. They felt they sacrificed aspects of their own life and had limited opportunities for socialisation and employment due to time constraints. Participants expressed a need for a life outside of caregiving and noted how their responsibilities as a carer were poorly understood by others. Payne and Ellis-Hill, (2001) also identified that the demands of ICs can be strenuous depending on the needs of the individual being cared for. Whilst this was based on carers for people with physical health conditions, the findings from the current research have potentially indicated similar demands may be apparent for carers of PWLD. The current research also lends support to Sharma et al. (2016) who highlighted many carers may self-sacrifice their needs to support family members, and Plöthner et al. (2019) who highlighted carers' need for work-life balance. Although Plöthner et al. (2019) did not account for ethnicity, the current research indicates these challenges are faced by some South Asian carers.

Research question: What are the care needs of South Asian ICs?

The final research question focussed on the care needs of participants. Overall results from the GETs suggest that many participants expressed a need for more support from health and social care services to support them within their carer role. This included more information around the support available for themselves and their child, more training around supporting their medical needs and more regular contact with ICs. Many participants also expressed a need for equality between themselves and health and social care professionals. Some participants felt their views should be considered and listened to and for their cultural needs to be taken into consideration when discussing their child's care needs. Some participants also highlighted a need for increased empathetic understanding around the physical and emotional demands of being an IC. Many participants also expressed an overall need for society to support PWLD and ICs by reducing the stigma surrounding PWLD, preparing PWLD and families for

adulthood, and providing more opportunities for adult PWLD to feel more integrated within society.

NICE (2018) highlighted a need for health and social care professionals to provide information, advice and guidance for families and carers through telephone, face-to-face support, peer support and parent/carer forums. The Care Act (2014) also states that carers should be provided with information and advice to help them make informed decisions about the care and support they receive (DHSC, 2016).

Greenwood et al. (2015) identified that many ICs received a lack of information to support them within their role. This is supported by participants' experiences in the current research as they felt they had a lack of information to support them in their roles. This research has added to this understanding as participants expressed a specific need for professionals to provide supporting information and guidance on what an LD is, how they can support their child with their needs and what their entitlements are. Participants also expressed a need for more information to support their child in preparation for when they reached adulthood. Whilst this also lends support to Plöthner et al. (2019), these findings have been highlighted particularly amongst a South Asian population. Whist this may not be representative of all South Asian carer experiences, it has highlighted that some ICs have informational needs, which include a need for carers to have information about community services and support which they can access. They also highlighted that ICs have a need to be supported financially and to be made aware of financial support available to them, which is supported by the current research.

Participants expressed a need for additional training and to have the appropriate skills and knowledge to support their child's medical needs. From a PTMF (Johnstone and Boyle, 2018) perspective, this may be viewed as a response to perceived threats to their child's wellbeing. Their expressed need to be trained may help carers regain a sense of power and meaning within their caring responsibilities whilst ensuring their child was provided with the right level of care. Plöthner et al. (2019) also highlighted that ICs have educational needs. This included education around safety issues such as mobility and falls prevention, infection prevention and symptom management. Previous research has indicated carer training programmes can have some benefits on supporting carers in their role (Van Houtven et al., 2010; Barbabella et al., 2016). However, these carer training programmes were not completed with carers of children with LD. Whilst this research did not include the use of a carer training programme, it highlights a potential need for this to be trialled to ascertain whether this can support South Asian carers and their children with LD should they require this. Having carers with lived experience involved in training programmes may help professionals to learn more

about their experiences. This could help professionals become more empathetic in their understanding of the difficulties faced by some South Asian IC's and promote collaboration. From a PTMF perspective (Johnstone & Boyle, 2018), including people with lived experience into training programmes may help professionals to understand their experiences. It can break down barriers and reduce the power imbalance between professionals and carers by promoting collaboration. Professionals having opportunities to learn more about the lived experiences of carers can encourage them respond in ways which acknowledge and respect carers' perspectives with empathy.

Participants spoke of their experiences when working with health and social care professionals to meet theirs and their child's needs. They highlighted a need for services to be accessible and to support them in carrying out their role which supports Twigg and Atkin (1994) who highlighted for carers needs and wellbeing to be supported by services to enable them to carry out their role. However, results from the current research suggests a divide between some South Asian carers and professionals, potentially due to lack of understanding of need. From a social identity theory (Tajfel & Turner, 1979) perspective, the differences in social identity between carers and professionals may create potential stereotyping and prejudice and influence how carers navigate services and how professionals respond to carers. In this research, participants felt they were viewed suspiciously and their cultural norms were not understood. Whilst this may not be representative of all South Asian carer experiences, these factors may hinder the professional relationship. It suggests a further need for methods that promote trust and curiosity to develop the relationships between professionals and South Asian carers if they are affected so they can feel supported in their role.

Plöthner et al. (2019) identified many ICs have an overall need for emotional support around the physical and psychological distress of caring and a need for ICs to be respected, supported, encouraged and understood by society for the role they are doing. The current research is consistent with this as participants spoke about the practical and emotional demands of their role and how difficult this can be. They expressed feeling uncared for, unsupported, unappreciated and not listened to by family, spouses, health and social care professionals and their South Asian community.

Participants felt there was a lack of empathy and understanding around the difficulties they face. Participants expressed a need for more support from the systems around them to enable them to fulfil the duties of their role more effectively whilst supporting their child's needs. Bronfenbrenner (2000) highlights the ecological systems model which discusses the various interconnected environmental systems around an individual. These can include family,

friends, the local community, health and social care services, and societal policies and norms. Chan et al. (2021) highlights the importance of social support from families and community organisations for carers. A lack of support from family and spouses alone may impact the ICs level of stress and ability to support their child (Gleeson et al., 2016). Bronfenbrenner (2000) highlights that breakdowns within any of these systems can impact an individual's quality of life. The findings from the current research may suggest that a lack of support from additional key systems within the lives of participants and other ICs can further exacerbate the practical and emotional difficulties they may face within their role, linking with the stress-vulnerability model (Zubin & Spring, 1977).

Overall, the research has highlighted multiple support needs for many South Asian carers' to facilitate them to have a more positive experience in their caregiving role. From the perspective of the PERMA model (Seligman, 2011), participants in the current research primarily described challenges across the domains of the model, with limited positive experiences reported. Whilst they expressed love for their child, participants highlighted the demands of caregiving can limit the time they have for themselves and socialisation, whilst also impacting their physical and emotional wellbeing. Although they gain necessary skills such as advocacy and self-sufficiency, participants expressed a greater need for further support and recognition to enhance their wellbeing and ability to be a caregiver. This can be achieved through professionals providing emotional and practical support, involving them in decision-making, offering training to support their child's needs, offering support for them to access hobbies/peer networks and having opportunities to acknowledge the role they are doing.

Strengths and Limitations of the current research

Strengths

Individuals from South Asian backgrounds are likely to be underrepresented in research (Quay et al., 2017). Diverse representation within research can be difficult due to researchers struggling to gain access, engage with and recruit members from underrepresented groups, such as ethnic minorities and people with disabilities (Erves et al., 2017).

A key strength from this research was that it provided a space for six South Asian mothers to share their stories of what their needs and experiences are as an IC and when accessing health and social care services for support for their children. Engaging underrepresented groups in research, who are likely to face health inequalities, is key to highlighting their needs in the hope that improvements can be made to improve their quality of life (Erves et al., 2017). The experiences of participants in the current research will be adding to the literature that currently exists within this area, most of which is dated. With the increased

focused on carers and families in the current day, research adding to the evidence-base around decreasing health inequalities, particularly for South Asian families will be key.

Another key strength of the research was the use of coproduction with experts by experience (EBE). This is a collaborative approach between researchers and members of the public to generate research outcomes which are going to be beneficial for those involved in the research, to educated others, to reducing health disparities and to promote social change (Macaulay et al., 2011).

This research had support from two EBE's. Adam's input into the research was valuable as he supported me in gaining a prior understanding into the experiences of families who have children with LD, and the impact of LD within South Asian populations. Adam also supported me with developing the methodology for the research which included finding organisations who could support my data collection. This was valuable as without this, recruitment may have been more difficult.

Prior to interviews taking place, a trial interview was undertaken with Arya, another EBE who helped guide the development of the interview schedule. This was another key strength in the research as it allowed me to obtain feedback on the interview guide and make necessary changes to ensure the questions I asked were relevant in capturing the needs and experiences of participants. For instance, Arya encouraged me to ask more questions about whether carers feel their cultural needs are met when they access services and work with professionals, as these questions are often missed in research related to carer needs and experiences. She also encouraged me to use the interviews to ask what changes carers would like to see to help them and others.

My ability to be reflexive would also be regarded as a strength in this research. As part of quality checks for qualitative research, Elliott et al. (1999) highlight the importance of researchers being able to recognise their influence on the research. I was aware that my positioning in the research had the potential to create researcher bias. To minimise this, I stated my potential influence on the research in my reflexivity statement (see "reflexivity statement"). I kept a reflective journal throughout the research as part of IPA guidelines (Smith et al., 2022) to record the impact the research had on me. I also had regular supervision throughout the project with my research supervisors to reflect on all aspects of the research.

Limitations

Smith et al. (2022) advise that doctoral research projects incorporating IPA methodology should aim to recruit 6-10 participants. Whilst this research recruited a total of six participants which fits with the minimum recommendation from Smith et al. (2022), this is on the lower side

of recruitment. Ideally, there was an aim to recruit ten participants for the research to add more value and depth to the findings. Recruitment was stopped once six participants had been recruited and completed their interviews. This was due to time constraints as it was important for me to ensure I had enough time to complete a detailed data analysis and write-up.

It is also important to acknowledge the research sample consisted of 5/6 participants identifying as Pakistani-Muslim, and 1 participant identifying as Indian-Sikh. South-Asia is one of the most diverse continents in the world as it encompasses an array of religious beliefs, cultures and languages. Regarding how disability is viewed within Indian culture, this may be dependent on the type of disability alongside community/family/social dynamics (Kalyanwala et al., 2019). However, in Pakistani culture, any form of disability can provoke high levels of stigma and discrimination from the community (Kalyanwala et al., 2019). This indicates that there is not one commonly understood view of disability across South Asian culture which may have impacted on the responses which participants gave in their interviews. Avani (who identified as Indian-Sikh) appeared to have a more positive outlook and experience when her son was diagnosed with an LD in comparison to other participants in the study. Whilst this is only one participant, it potentially indicates that needs and experiences of being a South Asian carer for a child with LD may be varied across cultures. Therefore, it is important to acknowledge that these results may not be representative of all South Asian carer experiences of children with LD, and social care services in the UK.

Qualitative research is often critiqued for its inability to produce a representative sample (Yardley, 1999). I chose to recruit participants who were local within the South-West Yorkshire region, and all who took part were mothers. This has limited how much the results can be generalised to other populations within the UK. Recruiting participants on a national level as opposed to locally, could have provided broader experiences and demographics which may have increased how representative the results may be. However, this may have removed the ability to produce rich, descriptive data which may not have been analysed in depth, and this is a key element of qualitative research designs (Howitt & Cramer, 2010). Therefore, it is often preferable for qualitative research to recruit smaller sample sizes that focus on the individual and unique experiences of participants (Yardley, 1999; Smith et al., 2022).

Elliott et al. (1999) suggest for researchers to check their understanding of the participants' experiences with them to ensure clear understanding of their stories before moving forward with developing the GETs. This would have been beneficial to ensure the needs and experiences of participants were captured as accurately as possible but was not completed due to time constraints within the research. Throughout the research, I have spent time

reflecting with my research supervisors and expert by experience on the context of participants as part of my quality checks (see "quality checks"; sensitivity to context). Although I was unable to check for accuracy within individual accounts, I still felt it was important to share the individual stories of each participant as well as shared experiences. Following IPA methodology meant I could do this as accurately as possible to ensure the results I have presented reflect the needs and experiences of participants.

Clinical recommendations

The current research highlights the experiences of six South Asian mothers who were supporting the needs of their adult-aged children with an LD. All accounts shared some differences and similarities. In the following section, I will outline the clinical recommendations from the research.

Increased support and recognition for ICs

The experiences of participants can be mapped onto the power threat meaning framework (PTMF; Johnstone and Boyle, 2018). With regard to power, all participants experienced some form of power imbalance between themselves and professionals during their interactions, and often within the South Asian community where they felt their status was lowered due to their carer identity and their child having an LD. Participants felt unsupported, unappreciated and highlighted a lack of recognition for the role they unexpectedly acquired to support their children's needs. From a threat perspective, participants' experiences showed how they felt there is an assumption from professionals that family members and spouses will support them and their children, however this was not evident. Participants also felt unsupported by the South Asian community due to their status as a carer and their child having an LD. The impact of the power imbalances and reduced connections within the South Asian community had resulted in further isolation from key groups within their social system. This likely meant an increased risk of South Asian ICs feeling more alone, unsupported, uncared for and disempowered. As a response, and a strength, participants learnt to become advocators and self-sufficient in ensuring the needs of their children were met and their children were happy and safe, however at times, this was at the sacrifice of their own needs.

All participants recalled difficult experiences with professionals where they felt overlooked and uncared for. Whilst we cannot alter family and community dynamics, we can make changes to how ICs are supported by professionals. Applying the principles of the PTMF (Johnstone and Boyle, 2018) in services may help professionals to recognise the power imbalance between themselves and carers, whilst acknowledging the distress which many carers may be facing. This approach can involve carers in decisions about their child's care and

allow them to feel empowered whilst reducing the emotional and physical demands which caregiving can bring. The participants who spoke about feeling supported by professionals recalled these experiences fondly and expressed their gratitude for the support they received. Services may also apply the Triangle of Care (Hannan et al., 2016) and implement aspects from the NHS 10-year plan, including neighbourhood health services (UK Government, 2025).

The Triangle of Care. The Triangle of Care was an initiative developed by Carers Trust and the Royal College of Nursing (Hannan et al., 2016). The aim was to create a collaborative approach between patients, carers and professionals which promoted safety, recovery and wellbeing for carers (Hannan et al., 2016). The Triangle of Care outlines six core standards aimed to achieve better collaboration between patients with dementia or mental health needs, carers and professionals.

I will outline each core standard from Hannan et al. (2016; pg. 3), how these can be helpfully applied to LD services based on participants' experiences from the current research.

"Carers and the essential role they play are identified at first contact or as soon as possible thereafter." Participants felt professionals dismissed their views and did not consider their care needs. Participants also felt unprioritized and treated different due to their cultural needs and highlighted a power difference between themselves and professionals. The Triangle of Care and the NHS 10-year plan have highlighted a need for professionals to identify who the patient's carer is and recognise that their views, knowledge and needs are crucial (Hannan et al., 2016; UK Government, 2025). Involving carers within the care and treatment of dependant individuals early can support an accurate assessment of need so the correct care and treatment can be put in place for both (Hannan et al., 2016).

To achieve better collaboration between PWLD, carers and professionals, it is recommended that carers are identified sooner, their needs are assessed, and their views and knowledge are regularly sought to support care and treatment being implemented for themselves and their children. Riffin et al. (2021) also found a collaborative approach between carers, patients and themselves that is built on listening and being non-judgemental was beneficial for carers. The NHS 10-year plan have also highlighted a need for updates to the NHS mobile phone application to allow carers to book appointments and communicate with the professionals of the person they are supporting (UK Government, 2025).

Intersectionality highlights that individuals can hold multiple protected characteristics (Thomas et al., 2021). South Asian PWLD are also considered to one of the most neglected groups in the UK and can experience a "double discrimination" due to their LD and their ethnicity (NHS Race and Health Observatory; NHS-RHO, 2023b, pg. 11; Jaspal & lopes 2021).

Participants' experiences have highlighted how they felt society did not support their children's needs, and their South Asian identity attributed to them feeling unprioritized by professionals. The Triangle of Care recognises that professionals should consider the different identities which patients and carers hold, and they can intertwine and impact their experiences and needs (Hannan et al., 2016).

"Staff are 'carer aware' and trained in carer engagement strategies." Professionals are encouraged to be empathetic towards carers and listen to their experiences, concerns and views (Hannan et al., 2016). The model encourages for professionals to be trained in carer awareness to understand the impact of being a carer (Hannan et al., 2016).

Participants felt professionals lacked empathy and understanding around their role, their needs, and their child's needs. Therefore, it is recommended that professionals speak to carers and attend a form of carer awareness training to develop more understanding of their role and circumstances whilst welcoming the contribution carers bring when supporting PWLD. The NHS 10-year plan also highlights a need for professionals to continuously learn and engage compassionately with patients and carers and emphasises the importance of lived experienced consultants to support this (UK Government, 2025).

Carers Trust have published various carers stories, one of which details the life of a carer supporting her mother with mental health and Autism (Carers Trust, 2025). Although this is not an LD, Rebecca's story highlighted how validated she felt to have professionals listen to her experiences, her concerns and offer a carers assessment (Carers Trust, 2025).

"Policy and practice protocols regarding confidentiality and sharing information, are in place." Carers hold crucial information around the dependant individuals physical and mental health history and therefore carers should be encouraged to share this with professionals (Hannan et al., 2016). It also recognises that carers know the day-today impact of medical conditions on the dependant individual and are likely to take on additional responsibilities at home (Hannan et al., 2016). Confidentiality is recognised as a barrier to this standard being put into place as information disclosed within the professional relationship often cannot be disclosed without consent. However, the Triangle of Care have highlighted the importance of patients, carers and professionals having conversations together around advanced care planning and implementing lasting power of attorney to ensure decisions are made in the best interests of the patients.

Participants felt professionals did not listen to their views and felt unable to challenge them due to this perception that professionals were seen as the experts. To manage this, professionals are encouraged to involve carers in planning the care and treatment of their child.

This has also been recognised within the NHS 10-year plan (UK Government, 2025). Services must also ensure there are policies and protocols around information sharing and managing confidentiality. Professionals should also be encouraged to have conversations about advanced care planning with carers to ensure decisions are made in the best interest of their child. The Care Act (2014) also highlighted the importance of planning as this ensures individual needs are met (DHSC, 2016).

"Defined post(s) responsible for carers are in place." Becoming a carer champion is encouraged within NHS Trusts to promote carer engagement and ensure strong relationships with carers are maintained (Hannan et al., 2016). This helps professionals to be aware of the complexities of being a carer and coordinate a whole team approach that allows the necessary measures to be put in place to support the needs of carers (Hannan et al., 2016).

Participants often spoke about feeling abandoned, unconsidered and unsupported by professionals, which give a sense that strong relationships between them were not formed. Therefore, having a professional within an LD team that is trained to become a carer champion may be beneficial for carers to ensure their needs are met, understood and they feel supported in their role.

"A carer introduction to the service and staff is available, with a relevant range of information across the care pathway." The Triangle of Care identified that carers and patients may have limited knowledge of the medical diagnosis, such as LD, and what happens following diagnosis (Hannan et al., 2016). Participants in this research expressed how they did not have knowledge of what an LD was, what their entitlements and rights were as a carer and what services were available for them when their child became an adult.

To rectify this, professionals can write an introductory letter to carers and their children which outlines key information about their medical team and local support and advice which can be reassuring for families. Professionals can arrange an initial appointment with carers and their children to allow them to share their experiences and ask questions. Carer information packs could also be provided to help carers understand what an LD is, their rights as a carer, and the local services they can access. This information may be crucial within the transition phase as many participants expressed feeling abandoned and unprepared when their children became adults. Information provided to families could be within easy-read format to support PWLD, as well as other languages to support families from ethnic minority backgrounds.

Joseph-Williams et al. (2014) have also suggested that many individuals feel unable to participate in conversations about their healthcare needs because they do not know about their

condition or the treatment options available. Therefore, by providing information to families, this may help to facilitate conversations about treatment and care.

Carers can become distressed when their child is admitted into hospital (Hannan et al., 2016). Some participants spoke about difficult experiences with professionals when their children were admitted for medical treatment. Professionals can manage carer distress by listening to their concerns and offering reassurance They can also support carers by providing information on how they can be contacted, building layouts, ward visiting times and ward routines to manage feelings of overwhelm. Professionals are also encouraged to involve carers within discharge planning to ensure they and their children's needs are met within the community prior to leaving hospital.

"A range of carer support services is available." The Triangle of Care identifies that the complexities of mental health and Dementia care can be difficult for carers and bring feelings of grief and loss, so it is imperative that carers have access to support services (Hannan et al., 2016). As the current research has identified, this is similar for carers of those with an LD.

Participants' experiences have alluded to an idea that they were managing feelings of grief and loss around the child they expected to have. To support carers, health and social care services are encouraged to have carer support in place to support them with the emotional impact of their role. This can be in the form of carer support meetings to allow carers to network and support each other. However, not all carers may be able to attend these due to time constraints. Therefore, services are also encouraged to arrange one-to-one support for carers and this can support those who want to discuss their needs privately.

The Care Act (2014) states that carers have a right to an assessment (DHSC, 2016). However, previous literature has identified that only 25% of unpaid carers qualified for a carers assessment, with some waiting over one year for this (Carers UK, 2022a). Professionals encouraged to refer carers for an assessment of need, and the local authorities are recommended to complete this assessment as part of a carers rights so they can access their entitlements and support within the community.

The Neighbourhood Health Service. NHS England have recognised the importance of third sector organisations in supporting our communities and reducing hospital admissions (Bull, 2025). To support this, the NHS 10-year plan outlines a need to strengthen community-based care through the integration of neighbourhood health services (UK Government, 2025).

Neighbourhood health services aim to bring together all parts of the healthcare system to work together to support individuals' systemic needs. This includes primary care, social care, mental health care and acute services (Bull, 2025). The idea is to support people of all ages to

be healthy, active and live independently by providing better care for people within their homes and to promote early intervention to minimise health conditions from exacerbating (Bull, 2025). The NHS 10-year plan has recognised that PWLD have a shorter life expectancy and state the use of integrated neighbourhood services "will improve their life outcomes through more holistic, on-going support" (UK Government, 2025; pg. 36).

Previous literature suggests not all communities have access to high quality community services, particularly South Asian families, and this can deter people away from utilising their support (Greenwood et al., 2015; Jaspal & Lopes, 2021). Many South Asian families also reside in socioeconomically deprived areas which are likely to have poor quality services due to underfunding, and therefore face greater risk of closure with many families unable to access support (Jaspal & Lopes, 2021; Poon et al., 2022) Therefore, there is a need to establish neighbourhood health centres within the most socioeconomically deprived areas as a priority, which is recognised within the NHS 10-year plan (UK Government, 2025).

Reduced power imbalance between ICs and professionals

Participants spoke about the power imbalance between themselves and health and social care professionals. Many participants felt their opinions were not valued or listened to, despite having extensive knowledge of the needs of their familial member.

Joseph-Williams et al. (2014) suggest that despite carers and patients being well-informed, they can still find it difficult to engage in conversations with professionals about their healthcare needs. This was due to the power they hold and the idea that their knowledge is inferior to medical knowledge. They suggest "doctors are not immune to the power imbalance" (Joseph-Williams et al., 2014; pg. 1) and will often display a confidence that appears they are able to make decisions in the best interest of patients. Nimmon and Stenfors-Hayes (2016) found professionals learn to act in certain ways due to the medical training and education they receive, but not all professionals are aware of how their power influences their actions towards patients.

Professionals are encouraged to acknowledge their positions of power, particularly in terms of ethnicity and class and how this has shaped their view of others (Willmot, 2023). Kaini and Kaini (2020) indicated that medical training can lack a holistic viewpoint which takes into consideration the physical, emotional, personal and behavioural needs of the individual. Nimmon and Stenfors-Hayes (2016) highlighted medical training can be adapted to include an element on reflexivity to help professionals become aware of their position of power and how this plays out in their interactions with patients and carers. This can include reflecting on

contextual factors such as age, race and cultural background and how this can impact the professional relationship with patients and carers (Dodgson, 2019).

Joseph-Williams et al. (2014) also suggest patients and carers should be prepared to make informed decisions and be included in shared decision making to help reduce the power imbalance. They suggest that professionals could inform patients and carers about the importance of shared decision making, reassure them that their knowledge is valuable and emphasise they are also an expert. Engaging principles from the Triangle of Care can be implemented through introductory letters and initial appointments with carers and patients (Hannan et al., 2016). As discussed, using the PTMF (Johnstone and Boyle, 2018), professionals can also reduce the power imbalance by recognising the expertise which carers can bring, involve them in decision-making processes and provide clear information around services and entitlements. This can empower carers to fulfil the responsibilities of their role whilst feeling supported.

Increased cultural awareness

Participants felt their cultural needs were not considered by professionals and identified a need for professionals to have more cultural awareness. However, training programmes on diversity-related interventions have not been found to be effective as the information provided is often forgotten after a short period of time (Perrigino & Jenkins, 2023).

At present, the Triangle of Care (Hannan et al., 2016) does not talk about incorporating cultural and religious needs when create a partnership between patients, carers and professionals. Having direct contact with the South Asian community may be more beneficial to help professionals engage with their lived experiences (Ross et al., 2020). Professionals can be curious and culturally sensitive when working with Ethnic Minority families and encourage discussions around cultural and religious needs during their appointments to support their learning and gain an understanding of how they and their children would like to be supported. In addition, professionals may choose to seek support from community religious leaders and chaplaincy to further educate themselves on the cultural and religious needs of the South Asian community.

Participants in the current research identified a need for increased ethnic minority professionals in health and social care services. Recently, there has been an increase in diversity within psychology services in the UK (Kanceljak & Calia, 2023), and the NHS 10-year plan has also highlighted a need for more diversity within NHS services (UK Government, 2025).

As of June 2022, 1.3 million people were employed in the NHS (UK Government, 2023). Recent figures indicate 74.5% of the NHS workforce is White and the second highest ethnicity is

South Asian (12.5%) (UK Government, 2023). However, despite the NHS having a high number of South Asian staff, many are facing race inequalities around career progression and leadership. Figures have also shown that 68.7% of professionally qualified staff were white, in comparison to 15.9% of South Asians (UK Government, 2023). Very few have limited opportunities to take up senior level positions where policies are made and implemented, meaning the views of ethnic minorities often go unheard or unconsidered (Palmer et al., 2021; Ross et al., 2020). This has been attributed to systemic discrimination and an unconscious bias towards Ethnic Minority staff where they have been bypassed for career development opportunities (Ross et al., 2020; Adegoke et al., 2025).

This highlights a need for NHS services to encourage career development amongst Ethnic Minorities where they can reach senior level positions (Palmer et al., 2021). This may help influence policy making to incorporate the needs of diverse communities to promote positive change and increase patient satisfaction outcomes (Palmer et al., 2021; Perrigino & Jenkins, 2023). In addition, patient experiences may also improve as staff will be seen as more representative of the community they are supporting (Palmer et al., 2021).

Whilst increased diversity can be beneficial, all professionals regardless of ethnic identity have a duty of care to support the needs of the community. Therefore, the responsibility of providing culturally sensitive care lies within all professionals.

Increased support for PWLD

The Care Act (2014) states that carers should be provided with a range of high-quality provision and appropriate services to support their needs and the individuals they are caring for (DHSC, 2016). Many participants in the research felt PWLD were undervalued, and their needs were not considered in society. Many participants felt that society was not equipped to support the needs of PWLD and highlighted that their adulthood can be different to those without an LD. This was regarding education opportunities, employment and community activities. Some participants felt the opportunities given to PWLD were limited and unequal compared to those without an LD. This highlights that PWLD require more provision within mainstream society to support their development through adulthood.

The recent cuts of £5 billion in disability payments proposed by the UK Government also proposes further health risks to PWLD so it is imperative that they and their families are supported (Ryan, 2025; Mencap, 2025). This can be achieved though professionals developing knowledge of provision in the area for PWLD and carers and signpost accordingly. Professionals can also add this information to carer support packs, as outlined in the Triangle of Care (Hannan et al., 2016) so carers and PWLD are aware of what can be accessed to support their needs.

Trauma informed approaches

Trauma informed approaches have become common in health and social care services to reduce the negative impact of traumatic experiences faced by patients and families (Office for Home Improvement and Disparities, 2022). Samsha (2014) outline six key principles which are fundamental to implementing a trauma informed approach. These are:

- Safety: staff and patients feel physically and psychologically safe in regard to the settings and interactions.
- Trustworthiness and transparency: organisational decisions are made with transparency and incorporate the needs of patients, families and staff.
- Peer support: having peer support from individuals with lived experiences of trauma was key to building trust and safety.
- Collaboration and mutuality: organisations recognise the power differences between professionals and patients and seek to balance this through shared decision making.
- Empowerment, voice and choice: organisations recognise how power can diminish patient choice and aims to strengthen this by acknowledging every individual experience is unique.
- Cultural, historical and gender issues: organisations respond sensitively to cultural stereotypes and biases (e.g. race, disability, ethnicity) and incorporates processes that meet the needs of individuals.

How services respond to trauma impacts the experiences of patients and their families (Samhsa, 2014). Professionals with an aim to help can re-traumatise patients and families if they overlook or misunderstand the impact of the trauma (Samhsa, 2014). Participants' experiences in this research have highlighted many negative experiences when they have accessed support, indicating they may not have receive trauma informed care. Their experiences have consisted of being viewed suspiciously and their cultural needs have not been considered by professionals, which can indicate feeling a lack of safety when accessing services. When interacting with professionals, participants felt there was a power imbalance between themselves and professionals and their views were not considered when discussing the care of their children. They also expressed how they felt uncared for and unconsidered by professionals, who felt lacked awareness on their role as an IC.

These experiences can help us to understand why many South Asian ICs were reluctant to access services. This highlights a need for professionals to implement Trauma informed approaches when working with South Asian families. The PTMF (Johnstone and Boyle, 2018

could be used to explore this, as it could help professionals to listen to and understand the experiences of South Asian ICs on an individual level and seek to prevent further trauma by empathising with their difficulties (Office for Home Improvement and Disparities, 2022). In response to the current research findings, this may also help to break barriers and promote collaboration between professionals and South Asian IC's who may be struggling to liaise with professionals.

Future research considerations

This research project was successful in achieving its aim of exploring the needs and experiences of South Asian ICs. It has highlighted the value of ICs in supporting their familial member through childhood and as they enter adulthood, whilst creating a safe home environment for them. It is hoped that the results from this research can contribute to the current literature within this area and encourage future research to take place. Suggestions for further research are detailed below:

- The sample within this research mainly consisted of parental-carers looking after their son or daughter who had LD. Future research may consider the experiences of other forms of carers, such as young carers, older carers and sibling carers to ascertain their experience of looking after a familial member with an LD.
- Many participants within the research were also born in the UK. Future research may wish to consider the experiences of immigrant parent-carers looking after their son or daughter who had LD to understand their needs and experiences when accessing health and social care services.
- The research took place within South-West Yorkshire. It has been acknowledged that these results may not be generalised to other populations within the UK. Future research may consider the experiences of familial members within different regions of the UK to ascertain their needs and experiences when supporting an adult familial member with an LD.
- Some participants expressed their concerns for the future care of their familial member. Future research could explore the concerns of ICs regarding this and ascertain what support is required to navigate this period.
- The research has highlighted that many participants felt their cultural and religious needs were not considered by health and social care professionals. Many participants also felt their South Asian identity impacted how they were treated by health and social care professionals. Future research could explore the experiences of professionals when working with South Asian families.

- Participants in the current research had limited understanding on what an LD was. The literature review also highlighted that many South Asian parents were unaware than an LD register existed in the UK, which suggests there may be some underrepresentation of South Asian PWLD (NHS-RHO 2023b). Future research may choose to investigate what is contributing to this underrepresentation and what are South Asian families understanding of LD.
- As society evolves, future research could be developed to continue exploring the needs of South Asian ICs and whether these have changed or remained the same to allow adaptations to be made to support the needs of carers.
- The Triangle of Care also appears applicable to LD services to support PWLD and carers. Future research could apply the model and evaluate its effectiveness, particularly with South Asian families.
- Research around the impact of trauma informed care for the South Asian community appears limited. Future research could evaluate the effectiveness of trauma informed approaches within services to understand if this improves the experiences of South Asian families and PWLD when accessing support, and when interacting with professionals.
- Consider implementing and evaluating a carer information programme for South Asian families with children with LD to improve their awareness of LD and what support is available for them and their children.
- Consider methods of supporting carers to build more positivity within their role to support their emotional and physical wellbeing.

Conclusion

As has been discussed, the findings can be understood through the application of various theoretical models, including the Power Threat Meaning Framework (Johnstone and Boyle, 2018), Social Identity Theory (Tajfel and Turner, 1979), PERMA (Seligman), and the grief cycle (Kubler-Ross and Kessler, 2005).

Participants' experiences during the childhood phase highlighted that many were initially unaware of what a learning disability (LD) was and how to manage their child's needs. There was a sense of grief and loss relating to the child and family life they had anticipated. Some participants described hope that medical professionals could cure their child's LD, which later shifted as they realised this was not possible.

When accessing health and social care services, participants reported feeling supported by paediatric services but abandoned when their child entered the transition phase. A lack of accessible information regarding available services and entitlements contributed to feelings of unpreparedness during adulthood/the present day. As a result, many participants described becoming self-sufficient in seeking support and acting as advocates for their children, particularly when their children were unable to advocate for themselves.

The caregiving journey identified within this research highlights a range of hidden experiences across the lifespan. While ICs often appeared to cope outwardly, many described masking significant emotional and physical challenges. Participants reported ongoing caregiving demands without sufficient training, support, or respite, increasing the risk of burnout. These responsibilities were often managed in isolation, with limited support from family, partners, or the wider South Asian community.

Interactions with professionals were frequently characterised by perceived power imbalances. Participants described feeling unheard, undervalued, and uncared for, with some attributing these experiences to their South Asian identity. Cultural and religious needs were often overlooked, raising concerns about stereotyping and discrimination. Many participants felt society did not value their children's needs and highlighted there were limited opportunities for them in mainstream society compared to those without an LD.

Overall, this research has highlighted the needs and experiences of South Asian informal carers supporting their children with a learning disability (LD) across the lifespan. It is important to acknowledge that this may not be the case for all South Asian carers in the UK given the diversity, as has been discussed. For some, the caregiving role can be both physically and emotionally demanding, often undertaken with limited support or preparedness. Many ICs may frequently navigate hidden challenges while striving to meet their children's needs whist at

times feeling abandoned and uncared for by the systems around them. The findings also suggest that some carers and their children may experience a “double discrimination” (NHS-RHO, 2023b, pg. 11) due to their LD and ethnicity.

In light of these experiences, the implications of this research indicate that some South Asian carers require greater support, recognition, and appreciation for their role. Despite the challenges identified, ICs continue to advocate for their children, striving to ensure they are not disadvantaged and that their lives are valued equally within mainstream society. ICs hold important knowledge that can contribute meaningfully to meeting their children’s needs. Therefore, increased support across the caregiving journey including improved access to information, services, support, entitlements and equal opportunities, is essential to promote more equitable opportunities for South Asian families of children with LD. For some, there is a need to recognise and reduce power imbalances between carers and professionals, ensuring that carers’ voices, expertise, and lived experiences are valued within collaborative care.

Final Reflections

I feel privileged that I was able to share a space with six South Asian women who were also carers and listen to their stories. At times, this was difficult to hear because their experiences mirrored some of my own. I like to hope this research has showcased the reality of being a South Asian IC to inform understanding of this role. I also hope that the results from this research can contribute to changes in health and social care services and mainstream society to minimise the inequalities faced by some South Asian ICs and PWLD. ICs will always be needed so I would hope that research continues to highlight the significance they hold in society whilst ensuring they are supported to complete a role which may have been unexpectedly bestowed on them.

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Appendices

Appendix A: Research advertisement

UNIVERSITY OF LEEDS

A CARERS JOURNEY:
A FOCUS ON YOUR NEEDS AND EXPERIENCES.

Hello! My name is Tania Singla, a Trainee Clinical Psychologist at the University of Leeds.

I am looking for participants for my Doctoral research, looking into the needs and experiences of South-Asian carers

WHO CAN TAKE PART?

- People who identify as South-Asian (i.e., Indian, Pakistani, Bangladeshi, Sri Lankan, or mixed)
- Parent providing unpaid care for a child who is aged 18+ with a Learning Disability

WHAT WILL THE STUDY INVOLVE?

- A 45–90-minute interview with myself.
- The interview can be arranged face-to-face or online
- Access to an interpreter can be arranged if required

Your voice and your story are really important, and I want to listen to your experiences.

As a thank you for your participation, you will receive a £15 Giftpay voucher!

If you would like more information or would like to take part, please email me at [redacted]

Appendix B: Interview guide

Demographics

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6
Age						
Gender						
Ethnicity						
Religion						
Place of Birth						
Carer job title						
Number of hours of paid work per week						
Are you receiving carers allowance?						
Relationship to familial member with LD						
Current age of familial member with LD						

Topic Guide

Childhood / First Diagnosis

- At what age was your child diagnosed with a learning disability?
    - Please can you tell me about the process you went through to seek a diagnosis?
    - What this experience was like for you?
    - What were your needs at this point in time?
- Following diagnosis, what were the needs of your child? (e.g. physical, emotional social)
    - What was this like to experience for you as a carer?
- When did you first come into contact with health and social care services?
    - What were your needs at this point in time?
    - How was this experience for you?
    - Did you experience any barriers at this point, e.g. did you feel there was anything which may have stopped you from accessing and/or using health and social care services for support?
    - At this point, is there anything that may have helped you more as a carer?
    - At this point is there anything that may have helped your child more?

Transition

- Between age 16-18, we see children transition from childhood to adulthood. What were the needs of your child at this point in time?
    - How was the transition experience for you as a carer?
    - What needs did you have at this point?
- During the transition period, did you seek support from health and social care services?
    - How was this experience for you?
    - Did you experience any barriers at this point in time?
    - During the transition phase, is there anything that may have helped you more?
    - During the transition phase, is there anything that may have helped your child more?

Adulthood

- As an adult with a learning disability, how would you describe their needs at this point in time?
    - How has this changed overtime, from diagnosis?
- At this point in time, what are your needs as a carer?
- Are you seeking support from health and social care service at this point in time?
    - How has this experience been for you?
    - Have you or are you experiencing any barriers at this point in time from health and social care services.
    - Is there anything that can make things better for you?

Overall

- Is there anything about your needs and experiences as an informal carer that I may have missed which you would like to share?
- Is there anything about your experiences around accessing health and social care services for additional support that you would like to share which we have not discussed today?

Appendix C: Consent form

Faculty of Medicine and Health; School of Medicine

UNIVERSITY OF LEEDS

Participant Informed Consent Form

Informed Consent to take part in:

A Carers Journey: What are the Needs and Experiences of South Asian Informal Parent-Carers for Individuals over aged 18 with a Learning Disability.

I confirm that I have read and understand the information sheet provided, which explains the above research project.	
I confirm that I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw up to 5 days after my interview without giving a reason. In this situation, I understand that I must email the researcher and let them know of my withdrawal from the research.	
I understand that I do not have to answer questions I feel uncomfortable answering.	
I understand that any identifiable information I provide will be anonymized by the researcher and I will be given a false name (pseudonym).	
I agree to my interview being audio recorded for analysis purposes.	
I agree for the use of any anonymised quotes I provide to be included in the final research report.	
I understand that other researchers may use my words (direct quotes) in further publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as consented in this form.	
I understand the purpose of this research is part of a requirement for the Doctorate in Clinical Psychology programme at the University of Leeds.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change during my participation in the project.	

How has informed consent been obtained:

- ❑ Informed consent has been obtained via a verbal recording from the participant.
- ❑ Informed consent has been obtained via the participant's written signature.

Participant Initials	
Participant Signature	
Date	
Name of Lead Researcher	
Lead Researcher Signature	
Date	

Appendix D: Information sheet

Faculty of Medicine and Health; School of Medicine

Application Reference Number - MREC 23-064

UNIVERSITY OF LEEDS

Participant Information Sheet

A Carers Journey: What are the Needs and Experiences of South Asian Informal Parent-Carers for Individuals over aged 18 with a Learning Disability.

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

What is the purpose of the project?

Being an informal carer can be physically and emotionally exhausting, especially as most informal carers fulfil their caring duties alongside full-time employment. Previous research has suggested that not all South Asian informal carers have access to adequate support from health and social care services, and at times, many informal carers can feel let down and unsupported.

Although support has been developed to try to meet the needs of and improve the experiences of informal carers, we still need to understand the experiences and needs of South Asian informal carers to continue to develop the right support. Therefore, this study aims to explore some of those needs and experiences.

Why have I been invited?

You have been invited to participate in this study because:

- You are an **informal carer**. This means you provide unpaid care and support to someone who is disabled, has an illness or long-term condition and they require extra help as they grow older.
- As an informal carer, you identify as South Asian (i.e. Indian, Pakistani, Bangladeshi, Sri Lankan, or mixed).
- You are the parent and the main informal carer for your child who is over aged 18 and has a Learning Disability.

Do I have to take part?

It is up to you to decide whether or not to take part. **If you do decide to take part**, you will be asked to sign a consent form, or record verbal consent prior to you participating. You can withdraw from the study, up to 5 days after taking part, and you do not have to give a reason for withdrawing if you choose to. After 5 days, your data will be anonymised (to support confidentiality) by the researcher and therefore withdrawal will not be possible.

What do I have to do?

You will be asked to participate in a 45–90-minute interview, which will be arranged between me and you at your convenience. The interview can be face-to-face at the University of Leeds, your home, or a location close to you, or the interview can be online via video on MS Teams.

Access to an interpreter can be arranged if required. The interpreter will be selected from an approved list from the University of Leeds. The interpreter will be required to maintain confidentiality and will not have access to your personal information.

What type of information will be asked for?

I will be asking you questions relating to your care needs, how you manage your role as an informal carer, and what your experiences have been when accessing health and social care services for additional support. You can choose not to answer questions you feel uncomfortable with answering.

The information you provide will help to understand the experiences and needs of South Asian informal carer.

What are the possible disadvantages and risks of taking part?

Taking part in this study could feel difficult at times and bring up different emotions. However, you do not have to answer any questions you feel uncomfortable with answering.

What are the possible benefits of taking part?

It is expected this work will add to the existing knowledge within this area and will also help South Asian informal carers to get their voices heard, which may support health and social care professionals to have a better understanding of needs and experiences and implement this into their practice.

Use, dissemination and storage of research data.

The audio recording of your interview during this research will be anonymised and used only for analysis purposes, with some quotes possibly being used in the final report. Only the researcher will have access to interview recordings. Once these have been anonymised, the researcher may share common themes with the research team, however, you will not be identified from the information provided.

The report produced from this study is part of the requirements for the Doctorate in Clinical Psychology training programme at the University of Leeds. The report may also be submitted for formal publication in a relevant journal which can be accessed and used by fellow researchers in the future. Your participation in this study will remain confidential and only anonymised data will be published into the report.

What will happen to my personal information?

All the contact information that we collect about you during the research will be kept strictly confidential and will be stored separately from the research data. The data you provide will be anonymised and you will be referred to as a pseudonym (false name), so that you will not be identified in any reports or publications.

All of your personal data will be stored on the researcher's personal University of Leeds OneDrive account. This account can only be accessed by the researcher. Data will be kept for up to three years following completion of the study as per data and privacy notice (below).

Who is organising/funding the research?

This study has been approved by the University of Leeds Ethics committee and will be funded by the University of Leeds.

Contact for further information.

If you have any questions or would like more information relating to the study, please contact me via email on [redacted]. The details of the research team are below:

Tania Singla Principle Researcher / Trainee Clinical Psychologist University of Leeds [redacted]
Dr Tracey Smith Research Supervisor [redacted]
Dr Kirsty Smith Research Co-Supervisor [redacted]

Thank you for taking the time to read through the information.

Tania Singla, Trainee Clinical Psychologist.

Research Participant Privacy Notice

Purpose of this Notice

This Notice explains how and why the University uses personal data for research; what individual rights are afforded under the Data Protection Act 2018 (DPA) and who to contact with any queries or concerns.

All research projects are different. This information is intended to supplement the specific information you will have been provided with when asked to participate in one of our research projects. The project specify information will provide details on how and why we will process your personal data, who will have access to it, any automated decision-making that affects you and for how long we will retain your personal data.

Why do we process personal data?

As a publicly funded organisation we undertake scientific research which is in the public interest. The DPA requires us to have a legal basis for this processing; we rely upon "the performance of a task carried out in the public interest" as our lawful basis for processing personal data, and on "archiving in the public interest, scientific or historical research purposes, or statistical purposes" as our additional lawful basis for processing special category personal data (that which reveals racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic or biometric data, and data concerning health, sex life or sexual orientation).

How do we follow data protection principles?

- We have lawful bases for processing personal and special category data.
- Data are used fairly and transparently; we will make it clear to individuals what their data will be used for, how it will be handled and what their rights are.
- We only collect and use personal data for our research, for research in the public interest, or to support the work of our organisation.
- We only collect the minimum amount of personal data which we need for our purposes.
- We take steps to ensure that the personal data we hold is accurate.
- We keep your personal data in an identifiable format for the minimum time required.
- We take steps to ensure that your data is held securely.
- We keep a record of our processing activities.

What do we do with personal data?

Research data can be a very valuable resource for improving public services and our understanding of the societies we live in. One way we can get the most benefit from this work is to make the data available, usually when the research has finished, to other researchers. Sometimes these researchers will be based outside the European Union. We will only ever share research data with organisations that can guarantee to store it securely. We will never sell your personal data, and any data shared cannot be used to contact individuals.

The project specific information will include more detail about how your data will be used.

Your rights as a data subject

Because we use personals data to support scientific research on the public interest, individuals participating in research do not have the same rights regarding their personal data as they would in other situations. This means that the following rights are limited for individuals who participate, or have participated in, a research project:

- The right to access the data we hold about you.
- The right to rectify the data we hold about you.
- The right to have the data we hold about you erased.
- The right to restrict how we process your data.
- The right to data portability.
- The right to object to us processing the data we hold about you.

Data security

We have put in place security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way and will notify you and any applicable regulator of a suspected breach where we are legally required to do so.

Retention periods

We will only retain your identifiable personal information for as long as necessary to fulfil the purposes we collected it for; we may then retain your data in anonymised or pseudonymised format.

To determine the appropriate retention period for personal data we consider the amount, nature, and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure, the purposes for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements.

Additional notices and guidance/policies

The University has also published separate policies and guidance which may be applicable to you in addition to other privacy notices:

- Current staff privacy notice
- Current students privacy notice

The Research and Innovation Service website has other relevant policies and guidance.

Communication.

In the first instance please contact the researcher who your initial contact was with. You may also contact the Data Protection Officer for further information (see contact details below).

Please see the Information Commissioner's website for further information on the law.

You have a right to complain to the Information Commissioner's Office (ICO) about the way in which we process your personal data. Please see the ICO's website.

Concerns and contact details.

If you have any concerns with regard to the way your personal data is being processed or have a query with regard to this Notice, please contact our Data Protection Officer (Alice Temple: A.C.Temple@leeds.ac.uk).

Our general postal address is University of Leeds, Leeds LS2 9JT, UK.

Our postal address for data protection issues is University of Leeds Secretariat, Room 11.72 EC Stoner Building, Leeds, LS2 9JT.

Our telephone number is +44 (0)113 2431751.

Our data controller registration number provided by the Information Commissioner's Office is Z553814X.

This notice was last updated on 20 February 2019.

Appendix E: Debrief form

Faculty of Medicine and Health; School of Medicine

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Participant Debrief Form

A Carers Journey: What are the Needs and Experiences of South Asian Informal Parent-Carers for Individuals over aged 18 with a Learning Disability.

The purpose of this research was to explore the needs and experiences of South Asian informal carers for familial members over aged 18 with a Learning Disability.

All participants were required to participate in an interview which explored their care needs, how they navigated their role as an informal carer and their experiences when accessing health and social care services for additional support.

The overall objective of the research was to help South Asian informal carers to share their experiences of being an informal carer and to get their voices heard. The results of the study hope to support health and social care professionals to have a better understanding of the needs and experiences of South Asian informal carers and implement these findings into their practice.

The nature of this study was not easy, and I would like to thank you for your participation and for sharing your story. Should you need any further support following your participation in this study, I have provided some support resources which you can access and may find beneficial.

You are reminded that you have up to 5 days to contact myself [redacted] if you wish to withdraw yourself from this research. If you have any further questions about the research, please do not hesitate to contact myself.

Thank you again for your participation!

Local Support Resources

Organisation	Location	About Us	Contact Information
Carers Leeds Working together to support carers Charity number: 1058706	Leeds	Carers Leeds provides supports, advice, and information to unpaid carers in Leeds. Carers Leeds operate an advice line for information or advice about your caring situation. Common enquiries include: • Finances and benefits. • Access to services, respite, and holidays. • Equipment and support for the cared for individual. • Opportunities for social contact.	Carers Advice Line: • Telephone: 0113 380 4300. • Email: advice@carersleeds.org.uk • Monday - Thursday: 9am - 5pm. • Friday: 9am - 4:30pm. General Enquiries: • Telephone: 0113 246 8338. • Monday-Thursday: 9am-5pm. • Friday: 9am-4:30pm. Drop in: • The Headrow, Leeds, LS1 6PT. • Monday to Friday: 10am - 4pm. Website: • https://www.carersleeds.org.uk/
carers' resource you care for them, we care for you Charity number: 1049278.	Bradford Harrogate Selby Craven	Carers Resource provide information, advice and support to unpaid carers to enable them to cope. Carers Resources offer a range of services including: • Planning and coping. • Money and benefits.	Telephone: • 0808 5015939. Website: • https://www.carersresource.org/

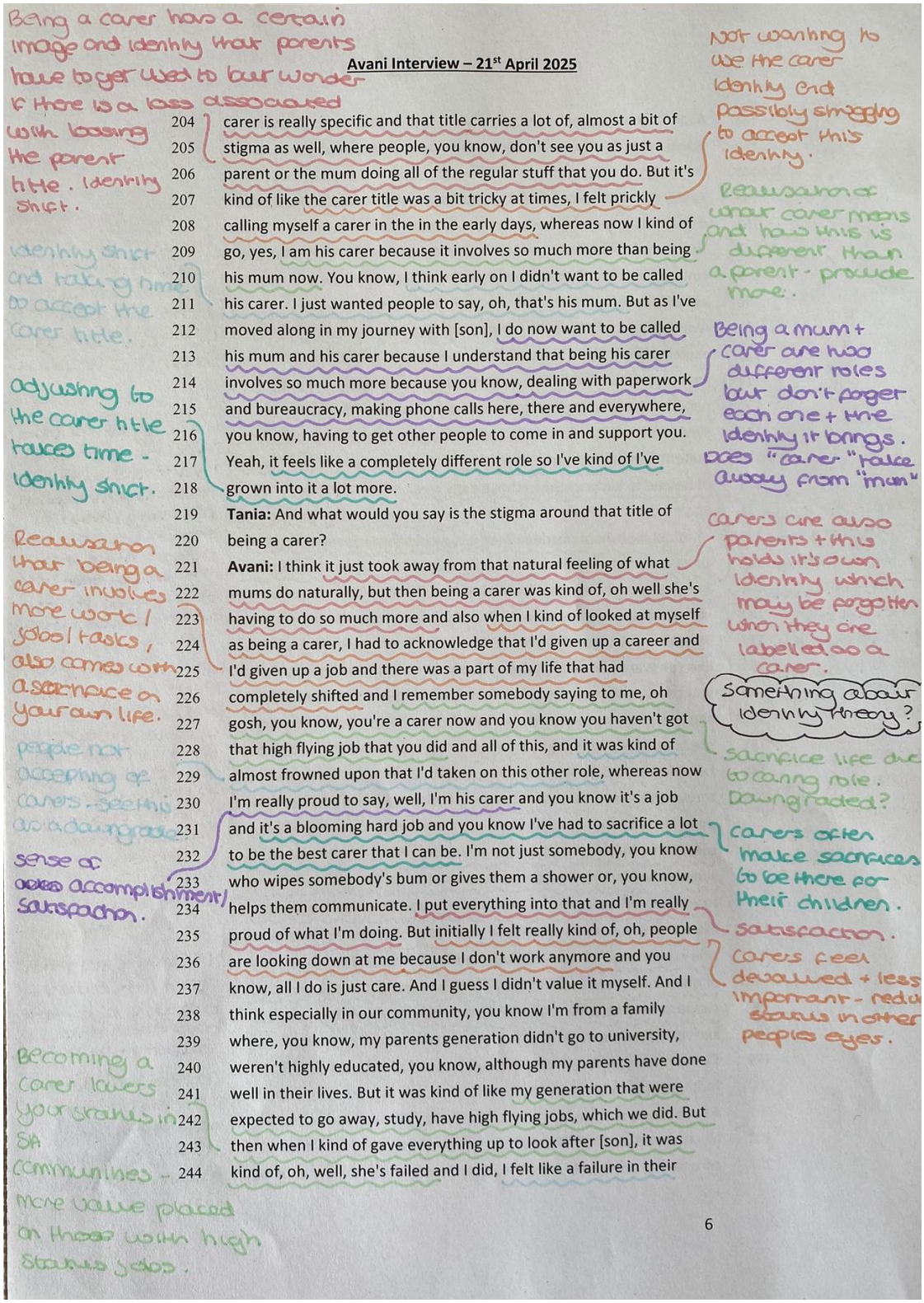
		• Support groups and events. • Employment and education. • Carers time off. • Young carers and family support.	
Charity number: 1097608	Kirklees	Carers Count are a charity supporting unpaid carers over aged 18 within Kirklees. Carers Count offer the following services: • Support groups and activities for unpaid carers. • Benefits advice. • Meditation sessions and wellbeing support. • Understanding your rights as a carer. • Respite services.	Opening Times: • Monday-Friday: 9am-5pm. Address: • Carers Count, Lower Ground Floor, Brian Jackson House, New North Parade, Huddersfield, HD1 5JP. Phone: • 0300 012 0231. Email: • info@carerscount.org.uk Website: • https://carerscount.org.uk/
	Wakefield	Wakefield Carers provide advice, information, and support to unpaid carers within the region. Wakefield Carers offer the following services:	Opening times: • Monday-Wednesday: 9am – 5pm. • Thursday: 9am - 7pm. • Friday: 9am – 5pm. Address:

Charity number: 1053295		• Carer support groups. • Care home support. • Support with applying for carers grant. • Carers hospital discharge support.	• 25 King Street, Wakefield, West Yorkshire, WF1 2SR. Telephone: • 01924 305544 Email: • info@carerswakefield.org.uk Website: • https://www.carerswakefield.org.uk/
Charity number: 1109413	Calderdale	Unique Ways are a parent-carer led organisation who support children aged 0-25 with disabilities and their families. Unique Ways can provide the following services: • Courses and training. • Information and signposting. • 1-1 family support. • Monthly coffee mornings and afternoon tea sessions. • Max cards – these provide discounts on family days out to over 300 locations in the Yorkshire region.	Address: • Unique Ways, Hanson Lane Enterprise Centre, Hanson Lane, Halifax, HX1 5PG. Telephone: • 01422 343 090 Email: • hi@uniqueways.org.uk Website: • https://www.uniqueways.org.uk/

LEEP1 Charity number: 07252221	Leeds	Leedp1 support people with a Larning Disability to self-advocate. Leep1 can provide the following services: • Becoming independent. • Volunteering opportunities. • Develop social, health, life and employment skills. • Social events for people with Learning Disabilities. • Café Leep – a friendly community space for people with Learning Disabilities to meet and enjoy a meal.	Opening hours: • Monday – Friday: 9am-3pm. • Closed Bank Holidays. Address: • LEEP1, Unity Business Centre, 26 Roundhay Road, Leeds, LS7 1AB. Telephone: • Leep1 office: 0113 243 9477 • Cafe Leep: 0113 243 6791 Email: • manager@leep1.co.uk Website: • https://leep1.co.uk/
Forum Central	Leeds	Forum Central have a network dedicated to people with Learning Disabilities. They work with and for people with a Learning Disability in Leeds. Members are supported to improve services, and opportunities for people with Learning Disabilities in Leeds.	Opening hours: • Monday – Friday: 9am-4pm Address: • Suite C24, Joseph's Well, Hanover Walk, Leeds, LS3 1AB. Telephone: • 0113 242 1321 Email: • dominique.burley@forumcentral.org.uk • hello@forumcentral.org.uk

			Website: • https://forumcentral.org.uk/learning-disability/
Voluntary Action Leeds	Leeds	Voluntary Action Leeds are an organisation supporting other charities and networks in Leeds. Their aim is to strengthen groups, organisations and movements to achieve positive change.	Address: • Stringer House, 34 Lupton St, Hunslet, Leeds LS10 2QW. Telephone: • 0113 297 7920 Email: • info@val.org.uk Website: • https://doinggoodleeds.org.uk/voluntary-action-leeds-2/

Appendix F: Example of exploratory noting



Being a carer has a certain image and identity that parents have to get used to but wonder if there is a loss associated with losing the parent title. Identity shift.

Identity shift and taking time to accept the carer title.

Adjusting to the carer title takes time - identity shift.

Reassurance that being a carer involves more work / jobs / tasks, also comes with a sacrifice on your own life.

people not accepting of carers - see this as a downgrade

sense of accomplishment / satisfaction.

Becoming a carer lowers your status in SA communities - more value placed on those with high status jobs.

Avani Interview – 21st April 2025

204 carer is really specific and that title carries a lot of, almost a bit of
205 stigma as well, where people, you know, don't see you as just a
206 parent or the mum doing all of the regular stuff that you do. But it's
207 kind of like the carer title was a bit tricky at times, I felt prickly
208 calling myself a carer in the in the early days, whereas now I kind of
209 go, yes, I am his carer because it involves so much more than being
210 his mum now. You know, I think early on I didn't want to be called
211 his carer. I just wanted people to say, oh, that's his mum. But as I've
212 moved along in my journey with [son], I do now want to be called
213 his mum and his carer because I understand that being his carer
214 involves so much more because you know, dealing with paperwork
215 and bureaucracy, making phone calls here, there and everywhere,
216 you know, having to get other people to come in and support you.
217 Yeah, it feels like a completely different role so I've kind of I've
218 grown into it a lot more.
219 **Tania:** And what would you say is the stigma around that title of
220 being a carer?
221 **Avani:** I think it just took away from that natural feeling of what
222 mums do naturally, but then being a carer was kind of, oh well she's
223 having to do so much more and also when I kind of looked at myself
224 as being a carer, I had to acknowledge that I'd given up a career and
225 I'd given up a job and there was a part of my life that had
226 completely shifted and I remember somebody saying to me, oh
227 gosh, you know, you're a carer now and you know you haven't got
228 that high flying job that you did and all of this, and it was kind of
229 almost frowned upon that I'd taken on this other role, whereas now
230 I'm really proud to say, well, I'm his carer and you know it's a job
231 and it's a blooming hard job and you know I've had to sacrifice a lot
232 to be the best carer that I can be. I'm not just somebody, you know
233 who wipes somebody's bum or gives them a shower or, you know,
234 helps them communicate. I put everything into that and I'm really
235 proud of what I'm doing. But initially I felt really kind of, oh, people
236 are looking down at me because I don't work anymore and you
237 know, all I do is just care. And I guess I didn't value it myself. And I
238 think especially in our community, you know I'm from a family
239 where, you know, my parents generation didn't go to university,
240 weren't highly educated, you know, although my parents have done
241 well in their lives. But it was kind of like my generation that were
242 expected to go away, study, have high flying jobs, which we did. But
243 then when I kind of gave everything up to look after [son], it was
244 kind of, oh, well, she's failed and I did, I felt like a failure in their

Not wanting to use the carer identity and possibly struggling to accept this identity.

Reassurance of what carer means and how this is different than a parent - provide more.

Being a mum + carer are two different roles but don't forget each one + the identity it brings. Does "carer" take away from "mum"

Carers are also parents + this holds it's own identity which may be forgotten when they are labelled as a carer.

Something about identity theory?

Sacrifice life due to caring role. Downgraded?

Carers often make sacrifices to be there for their children.

Satisfaction.

Carers feel devalued + less important - redu status in other peoples eyes.

6

Appendix G: Example of experiential statements

Being a carer involves more responsibility than the identity of a parent.

Avani Interview – 21st April 2025

carer is really specific and that title carries a lot of, almost a bit of stigma as well, where people, you know, don't see you as just a parent or the mum doing all of the regular stuff that you do. But it's kind of like the carer title was a bit tricky at times, I felt prickly calling myself a carer in the in the early days, whereas now I kind of go, yes, I am his carer because it involves so much more than being his mum now. You know, I think early on I didn't want to be called his carer. I just wanted people to say, oh, that's his mum. But as I've moved along in my journey with [son], I do now want to be called his mum and his carer because I understand that being his carer involves so much more because you know, dealing with paperwork and bureaucracy, making phone calls here, there and everywhere, you know, having to get other people to come in and support you. Yeah, it feels like a completely different role so I've kind of I've grown into it a lot more.

Tania: And what would you say is the stigma around that title of being a carer?

Avani: I think it just took away from that natural feeling of what mums do naturally, but then being a carer was kind of, oh well she's having to do so much more and also when I kind of looked at myself as being a carer, I had to acknowledge that I'd given up a career and I'd given up a job and there was a part of my life that had completely shifted and I remember somebody saying to me, oh gosh, you know, you're a carer now and you know you haven't got that high flying job that you did and all of this, and it was kind of almost frowned upon that I'd taken on this other role, whereas now I'm really proud to say, well, I'm his carer and you know it's a job and it's a blooming hard job and you know I've had to sacrifice a lot to be the best carer that I can be. I'm not just somebody, you know who wipes somebody's bum or gives them a shower or, you know, helps them communicate. I put everything into that and I'm really proud of what I'm doing. But initially I felt really kind of, oh, people are looking down at me because I don't work anymore and you know, all I do is just care. And I guess I didn't value it myself. And I think especially in our community, you know I'm from a family where, you know, my parents generation didn't go to university, weren't highly educated, you know, although my parents have done well in their lives. But it was kind of like my generation that were expected to go away, study, have high flying jobs, which we did. But then when I kind of gave everything up to look after [son], it was kind of, oh, well, she's failed and I did, I felt like a failure in their

adjusting to the carer identity.

adjusting to carer label/ identity.

carer involves more responsibility than parent identity.

realising being a carer involves more work/ responsibility.

learning to adjust to being a carer.

carers having to do more.

identity shift from mum to carer.

sacrificing aspects of your life to be a carer.

feeling proud of her role as a carer.

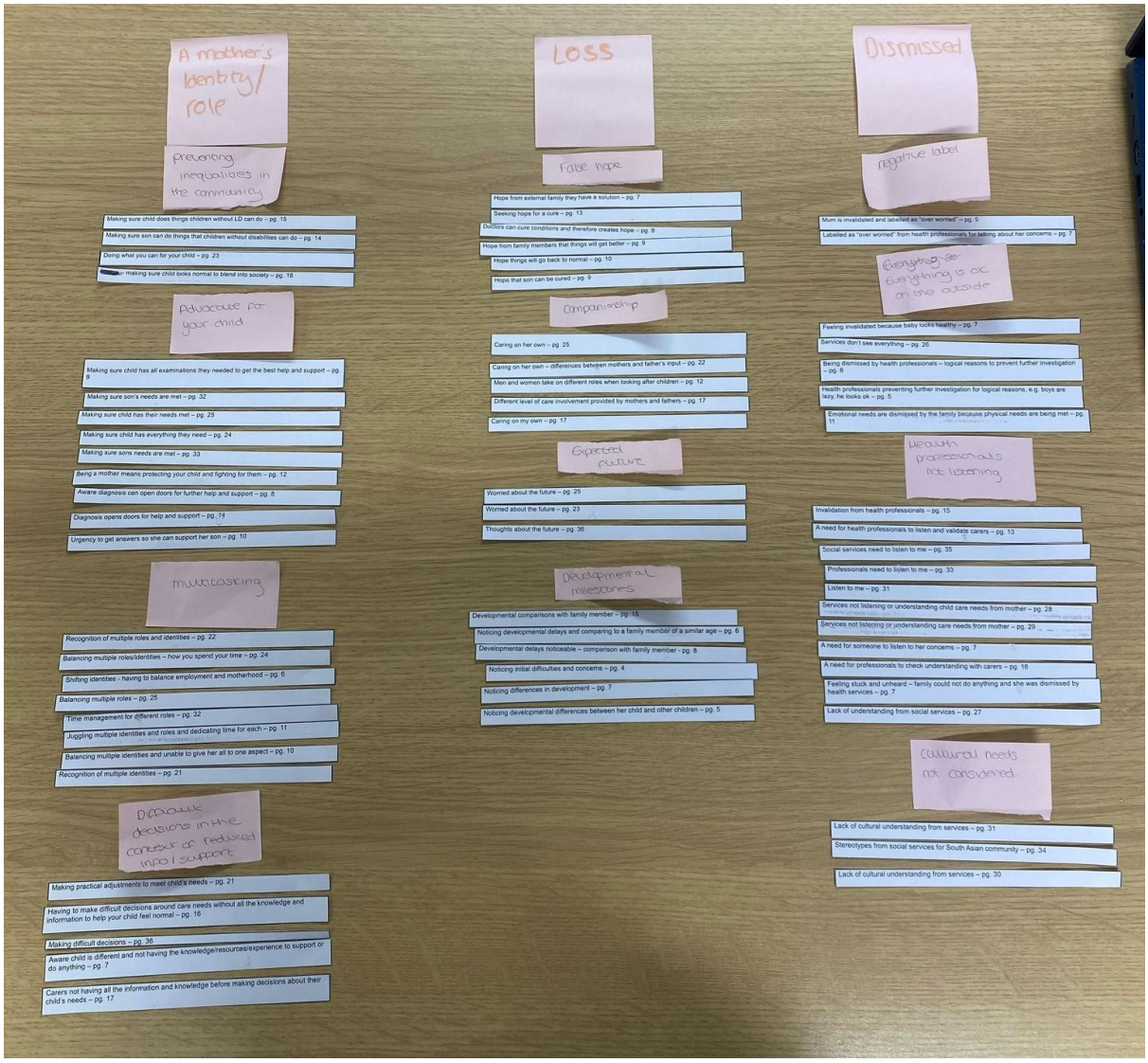
making sacrifices when becoming a carer.

feeling proud as a carer.

a carer identity devalues you in society.

feeling the carer identity devalues you in SA community.

Appendix H: Example of developing the Personal Experiential Themes (PETs)



Appendix I: Example of developing the Group Experiential Themes (GETs)

Group Themes	**Individual Themes**
Disempowered	Not involved (decision making with professionals) / professionals know everything
	Powerless against the system (professionals side with each other) and carers are unprotected
	Invalidated (opinions) – ignored, dismissed
	Carers feeling unappreciated / unimportant
	Medical negligence / inadequate healthcare
	Overlooked as a South Asian – not noticed/considered
	Cultural needs are not considered / accepted by professionals / judgement
	Suspicious – how you are looked at as a South Asian – exaggerated problems
	Assumptions of family support from professionals / general assumptions of SA
Hidden Experiences	Emotional isolation – coping / managing emotions on your own
	Balancing multiple needs of the child / overworked / burnout
	Not given a break from caring / no life outside of caring
	Carers are committed (around sacrificing your life to be a carer and being reliable / overreliance
	Carers can mask – put on a front
	Being self-educated, understand the system, do more research
	Teaching children to become adults
	Carers are empowered – ready to fight and stand up for your child, protect. Fight for access, prevent inequalities

Appendix J: Ethical approval

MREC 23-064 - Study Approval Confirmation

M

Medicine and Health Univ Ethics Review

Reply | Reply all | Forward

To: Tania Singla

Tue 17/09/2024 11:17

Cc: Kirsty Hughes; Smith Tracey [redacted] Tracey Smith

Dear Tania

MREC 23-064 – A Carers Journey: What are the Needs and Experiences of South-Asian Informal Parent-Carers for Individuals over aged 18 with a Learning Disability?

NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.

We are pleased to inform you that your research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the documentation received at date of this email.

Please retain this email as evidence of approval in your study file.

Please notify the committee if you intend to make any amendments to the research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see https://secretariat.leeds.ac.uk/research-ethics/how-to-apply-for-research-ethics-amendment/ or contact the Research Ethics & Governance Administrator for further information [redacted] if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes
Sou Chung
On behalf of Dr Klaus Witte, CHAIR, SoMREC