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ORIGINAL ARTICLE

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Culturally adaptive healthcare for people with a learning disability from an ethnic minority background: A qualitative synthesis

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Abstract

Background: People with a learning disability face health inequality. Those from ethnic minority backgrounds with a learning disability face 'double discrimination' as members of two marginalised groups.

Methods: This codesigned review consolidated the evidence on the healthcare experiences of individuals and their carers from ethnic minority backgrounds with a learning disability. Three electronic databases were searched for UK studies from January 1990 to June 2022. Qualitative data from 28 studies were analysed using thematic framework analysis.

Findings: There was an overarching theme of 'culture, choice and conflicts of control', which related to the variable preferences for involvement in healthcare decisions. Cultural and individual factors impacted upon experience, with themes relating to 'misunderstanding and mistrust', 'discrimination and stigma', 'isolation', 'feelings of shame and blame', 'burdens of care' and 'carer wellbeing'. Factors associated with healthcare-seeking and care provision are described in the themes 'triangles of care', 'community networks' and 'adaptive communication'.

Conclusions: People from ethnic minority backgrounds with learning disability experience complex barriers which influence their healthcare experiences. Recognising and understanding discrimination can be difficult for people with a learning disability. Carers face challenges which influence their own wellbeing. Services need to be responsive to individual cultural contexts, while addressing potential conflicts of control.

KEYWORDS

ethnic minority, health inequalities, intellectual disability, learning disability, systematic review

Accessible summary

- People with a learning disability from ethnic minority backgrounds experience problems using healthcare services and poorer health.

- This review compared findings from 28 UK studies which explored the healthcare experiences of people with a learning disability from ethnic minority backgrounds, and their carers.
- Patients and carers had different preferences in how they wanted to be involved in their healthcare, which were often unmet by healthcare services.
- Services should be responsive to the needs of individuals from different ethnic minority backgrounds with a learning disability, and their carers.

1 | INTRODUCTION

Ethnicity is a complex concept defined by shared history, origins, language and cultural traditions. It is a subjective identity based on how individuals define themselves (Raleigh & Holmes, 2021). This review uses the term 'ethnic minority backgrounds' to refer to people living in the United Kingdom who are from ethnic minority communities and do not identify themselves as White British. Historically, the voices of individuals from ethnic minority backgrounds, particularly those with a learning disability, have remained concealed within disability research. Consequently, there is limited understanding of their experiences and needs.

People from ethnic minority backgrounds with a learning disability are more likely to experience poorer health (Emerson & Hatton, 2013; Hackett et al., 2020; Robertson et al., 2019), racial discrimination and socioeconomic deprivation (Turner, 2011). They face specific barriers with communication, health literacy and lack of cultural competence and awareness within services (Ali et al., 2013; Robertson et al., 2019). This disparity is further evidenced within the 2020 'Learning from lives and deaths' report, which found that 42% of White British people with a learning disability died aged 65 or over, compared with just 7% of people from Asian British (Indian, Pakistani, and Bangladeshi heritage) and 5% of Black ethnic groups.

Estimated prevalence of learning disability in the United Kingdom has increased from 985,000 in 2008 (Emerson & Hatton, 2008) to 1.5 million in 2020 (Mencap, 2019). It would be reasonable to assert that the number of individuals with a learning disability from an ethnic minority background has increased. However, precise counts in the United Kingdom remain elusive due to the absence of centralised data collection systems; this, coupled with the umbrella term 'disability', contributes to the lack of clear data (data availability; Public Health England, 2016). Predictions were that 25% of new entrants to adult social care for people with a learning disability would be from ethnic minority backgrounds by 2023 (Emerson et al., 2012). Therefore, understanding these barriers and how they relate to the experiences of individuals with a learning disability from an ethnic minority background is critical.

2 | AIMS

This review aimed to provide an in-depth analysis of qualitative studies on experiences relating to healthcare (defined as any services which provide support, treatment or assessment for a person's physical or mental health, including primary, secondary, community, and residential care settings), identified through a scoping review on barriers to healthcare for people from an ethnic minority background with a learning disability, and their carers (Umpleby et al., 2023).

3 | METHODS

3.1 | Reflection from the authors

In research about individuals from marginalised groups, the privilege of an outside researcher cannot be ignored. The authors have experience working with adults with a learning disability, including those from ethnic minority backgrounds though the lead authors are not from ethnic minority backgrounds. One author (U.C.) is a professor and GP from an ethnic minority background, with many years of expertise in supporting patients from ethnic minority communities. Cultural nuances and the ability to truly empathise with the experiences of individuals with a learning disability from ethnic minority backgrounds are all aspects that the authors have confronted when synthesising this review. The methods and interpretation of findings have been guided by a project working group consisting of 10 people with lived experience, as a self-advocate, family member, or carer, all from ethnic minority backgrounds.

3.2 | Study identification and selection

This review was conducted in accordance with PRISMA reporting guidelines (Page et al., 2021). A systematic search was completed in June 2022 to identify records published between 1990 and 2022 using electronic databases—APA PsycINFO, MEDLINE with Full Text and CINAHL Ultimate (Prospero registration ID: CRD42022347318). An example of search terms is provided in Supporting Information S1: Appendix 1. The

TABLE 1 Inclusion and exclusion criteria.

Inclusion criteria	
i. Population	People from an ethnic minority background with a learning disability and/or their carers
ii. Interventions	Healthcare services
iii. Outcomes of interest	Experiences of care
iv. Setting	All care settings in the United Kingdom
v. Study designs	All qualitative designs
vi. Dates of publication	January 1990 to June 2022
Exclusion criteria	
i. Language	Languages other than English
ii. Full text unavailable	Incomplete articles or conference/meeting abstracts
iii. Publication date	Before 1990
iv. Inadequate sample size	Sample less than 5 participants from an ethnic minority background
v. Other populations	Conditions where learning disability cannot be assumed (e.g., cerebral palsy) where results were not disaggregated. Findings on professional experiences only
vi. Nonoriginal studies	Reviews, letters, commentaries, editorials

search was adapted from a review by Robertson et al. (2019) to include the latest list of ethnicities compiled by the Office for National Statistics, along with additional healthcare terms identified by the project working group. All qualitative studies from UK-based healthcare settings were included if they included a minimum of five participants from an ethnic minority background, and/or their carers (Table 1). All studies were screened by a minimum of two researchers (K.U., N.D., C.R., N.C.M. and U.C.).

3.3 | Quality appraisal

Two researchers (C.R. and N.D.) independently evaluated and rated records, assessing quality using the Joanna Briggs Institute (2017) checklist for qualitative research. No studies were excluded due to poor quality.

3.4 | Methodological approach

Combined with in-depth reflexive thematic analysis (Braun & Clarke, 2006), the analytical method within this review is guided by phenomenological constructivist principles, which aim to explore the participant's lived experiences while understanding the construction of personal meanings attached to their interactions with healthcare services.

3.5 | Data analysis

An initial coding framework was established based on findings from the previous scoping review (Umpleby et al., 2023) and further adapted following consultation with the working group and themes generated from three experience-based codesign workshops (Table 2).

All studies were independently coded according to the initial coding framework by three researchers (C.R., N.D. and N.C.M.). All qualitative data and emergent themes were reviewed multiple times to familiarise and immerse the researchers to gain a deeper understanding of the data. The framework was iteratively adapted according to the analysis findings and reflective discussions with the wider research team and working group.

TABLE 2 Initial coding framework.

Discrimination
Substandard and unresponsive care
Importance of care continuity
Disconnection from a changing world
Isolation and stigma
Barriers to community engagement
Choice and control
Digital exclusion
Lack of information and support with transitional care
Disconnect between services
Fear of the future
COVID-19 and access to services
Awareness of the learning disability register
Reluctance of being recognised with a learning disability

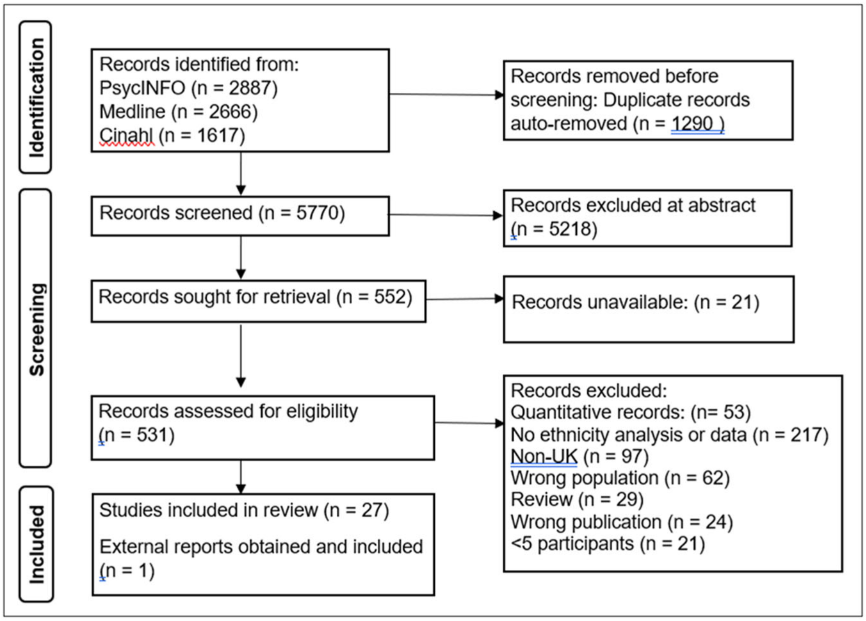


FIGURE 1 Flowchart of study screening and inclusion. [Color figure can be viewed at wileyonlinelibrary.com]

4 | RESULTS

The electronic database search yielded a total of 7170 records. After eliminating 1400 duplicate entries, 5770 records underwent title and abstract screening. Five hundred and thirty-one articles progressed to full-text assessment, including one study retrieved externally by author's recommendation. A total of 28 articles were included in the review (Figure 1).

4.1 | Study characteristics

All included studies are summarised in Supporting Information S1: Appendix 2 according to healthcare setting, study focus, study design, sample characteristics, and key findings.

Three studies (11%) included the experiences of individuals with a learning disability alongside their carers/families. Eighteen studies (64%) looked at the views of carers and families (Supporting Information S1: Appendix 3). Most studies (*n* = 23, 82%) included participants from South Asian (Indian, Pakistani and Bangladeshi) communities (Supporting Information S1: Appendix 4). Eighteen studies (64%) focussed specifically on an ethnic minority background; including 12 South Asian, one Jewish, one Chinese, one African and one Kurdish/Cypriot community. Nine (32%) included white populations alongside an ethnic minority background.

5 | FINDINGS

5.1 | Summary of themes

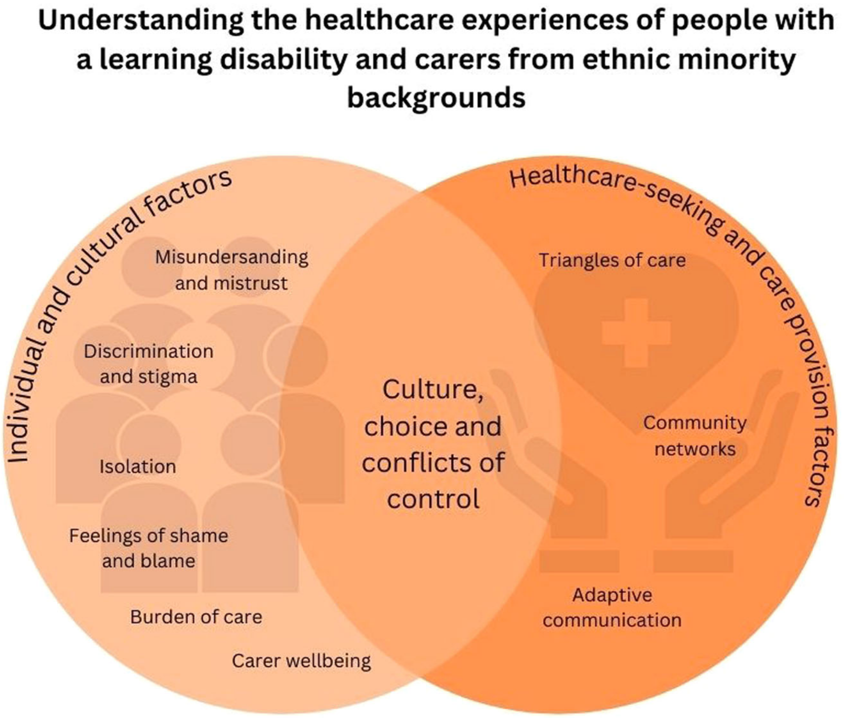
There was an overarching theme of 'culture, choice and conflicts of control', which related to the variable preferences for the involvement of individuals, and their carers, in healthcare decisions. Individuals with a learning disability and their carers experienced cultural and individual factors which impacted their experience, with themes relating to 'misunderstanding and mistrust', 'discrimination and stigma' and 'isolation', both within healthcare settings and their communities. Carers described 'feelings of shame and blame', 'burdens of care' and issues relating to 'carer wellbeing'. Factors associated with healthcare-seeking and care provision are described in the themes 'triangles of care', 'community networks' and 'adaptive communication' which were identified as important for addressing feelings of disempowerment. See Figure 2 for an overview of themes.

5.2 | Culture, choice and conflicts of control

This theme centres around autonomy and the power struggles that individuals with a learning disability and their carers face. Many studies described the importance of recognising cultural context, particularly when offering choices around healthcare decisions. Caton et al. (2007) found that services that provided culturally adaptive care were perceived to be better, specifically among the Pakistani community. Services that worked in partnership with individual families, accounting for their ethnicity, led to better engagement.

In their study of inpatients at specialist psychiatric hospitals, Chinn et al. (2010) found that conflicts of control were due to hierarchical systems, with unit staff viewed by patients as 'powerful figures'. Patients felt ignored and excluded from critical discussions, which led to patients feeling devalued and disempowered. Patients had control over their immediate environments, such as room decoration and diet; however, conflict arose surrounding medical decisions, such as medication. For example, one participant stated:

FIGURE 2 Overview of themes. [Color figure can be viewed at wileyonlinelibrary.com]



> *No, no-one's been listening to my opinion at the moment. As far as I'm concerned, it's been going out of one ear and the other.* (Emilia – person with a learning disability) (Chinn et al., 2010, p. 56)

Russ et al. (2020) drew attention to conflicts which may arise when individuals question healthcare decisions. The authors suggest this harms the relationship between the individual and the professional. The authors note that individuals from minority groups may not have the confidence to speak up as they believe this may impact the care they receive, with evidence pointing to carers' cultural and belief systems contributing to the conflict.

Munroe et al. (2016) explored the experiences of immigrant mothers of autistic children with a learning disability. The authors suggest potential conflicts relating to the participants' traditional beliefs, particularly within the context of the African mothers navigating their child's diagnoses. Key findings from the study indicate that mothers experience dissonance when medical diagnoses of autism or learning disability do not align with their traditional beliefs (disabled children viewed as 'possessed' or 'naughty').

> *Holding these sets of conflicting beliefs appeared to create a sense of cultural dissonance for the mothers, leading them to re-evaluate their previous beliefs and assumptions and to find ways of integrating these sets of apparently conflicting information.* (Munroe et al., 2016, p. 812)

> *Mabinti alternated between describing her African culture very positively and very negatively. Although she appeared to wish to remain connected to her African culture and maintained some of her prior belief system, she described feeling alienated from the community in Africa.* (Munroe et al., 2016, p. 813)

5.3 | Individual and cultural factors

5.3.1 | Misunderstanding and mistrust

In their study of 11 Pakistani carers utilising physiotherapy services, Croot (2012) evidenced misunderstanding and mistrust surrounding the provision of care. Several carers expressed that they felt unsupported, with participants stating that professionals had been dishonest about their child's diagnosis. The authors highlighted that carers considered the potential benefits and risks of treatment themselves as they did not trust professional opinions. Hatton et al. (2009) suggest that this mistrust extends to research, which could contribute to the paucity of research involving people from ethnic minority backgrounds.

Kramer-Roy (2012) suggested that carers failed to see the value of health services due to their lack of consultation about treatment plans. Although Larkin et al. (2018) found that individuals were positive about services, this was based on their relationships with support workers and not the service itself. In their study of 29 adults, three participants placed emphasis on independence being introduced as an 'external threat' (p. 201). Participants mistrusted the ability of services to provide stable, consistent care:

> *I used to have my support on Monday afternoon—this one Monday, the support worker never turned up. I had*

> *no call, no—eh – nothing to say that she weren't coming, so I went two to three months with no support.* (Person with a learning disability) (Larkin et al., 2018, p. 201)

Akbar and Woods (2020) found that culture and religion play a role in the acceptance and understanding of learning disability, with caregivers' understanding of disability as a barrier to accessing support. In some cases, families only deemed physical disabilities worthy of attention, whereas others viewed learning disability as the will of God.

> *Oh I am a special person, Allah chose me to give me a special kid. Anybody can raise up a bright kid.* (Qosar – mother) (Akbar & Woods, 2020, p. 670)

Tensions surrounding cultural values held by South Asian families are evident in Heer et al.'s (2016) study of formal carers of South Asian people with a learning disability. Their findings suggest that cultural tensions have a detrimental impact on interactions and connections. Service providers were viewed as 'oppositional' (p. 112), resulting in mistrust. It was recognised that this mistrust could be attributed to the loss of control carers face:

> *There is a massive loss of control, you know professionals step in and do things in the individual's best interests.* (Sukhdeep – service provider) (Heer et al., 2016, p. 112)

McCarthy et al. (2020) and Durling et al. (2018) noted that South Asian participant's views of acceptance of people with a learning disability in communities were due to a lack of knowledge or understanding:

> '*…people don't know what learning disability is*' (Carer) (McCarthy et al., 2020, p. 203)

> *In Bangladesh, if you're poor or have any disabilities it's regarded as a normal part of life.* (Brother) (Durling et al., 2018, p. 1137)

Interestingly, both studies noted that although there is greater awareness of individuals with a learning disability in the United Kingdom, this does not translate into acceptance:

> *In our community, no one wants to talk about it…it's really difficult. It's sort of frowned upon when I say my niece has learning disabilities, people say 'oh really, I'm so sorry to hear that.* (Carer) (McCarthy et al., 2020, p. 203)

5.3.2 | Discrimination and stigma

Sixteen studies discussed the impact of discrimination and stigma. Azmi et al. (1997) interviewed 21 adults and adolescents with a learning disability from South Asian communities. Both racism and ableism from individuals outside of their communities were described, sometimes from healthcare professionals.

> *They throw eggs… they don't like Asian people… say racist remarks and swear at you… it makes me want to go back to India.* (Person with a learning disability) (Azmi et al., 1997, p. 260)

> Yes, they're horrible to me. They call me Paki. [Interviewer: Who calls you Paki?] (name of care-worker) did at the day centre. (Person with a learning disability) (Azmi et al., 1997, p. 260)

Several papers highlight the impact of stigma about learning disability from within ethnic minority communities. Akbar and Woods (2020) conducted interviews with 10 Pakistani heritage caregivers of children with a learning disability and special educational needs. Caregivers described difficulty accepting their child's diagnosis, which was fuelled by stigma about disability within their community.

> *Mohed, Qosar and Nighat report that some family members do not believe the child has a disability: 'You're making it up' (Mohed); 'he's not very clever, that's not a condition' (Nighat); 'Allah has blessed you with a son and you're not grateful, you're getting him diagnosed with a learning difficulty'.* (Qosar, parent) (Akbar & Woods, 2020, p. 668)

This made carers want to hide their children's disability, keeping their diagnosis a secret for fear of stigma.

> *When Saira's daughter was first diagnosed, she wished to keep her at home close to her and had not shared the diagnosis; she did not wish to tell her family in Pakistan because she believed it would be an added source of stress for her because they would catastrophise. Zalaikha hides the diagnosis out of fear for her son being stigmatised.* (Akbar & Woods, 2020, p. 669)

Munroe et al. (2016) explored the 'unbearable' role of cultural beliefs as a catalyst for stigma, with participants describing a 'dichotomy between visible and hidden disabilities'. Mothers describe how in their African culture, individuals with 'hidden' disabilities can be perceived as 'mad' or even 'possessed'.

> *I took him somewhere and the woman told me he was possessed […] I felt bad about it, that is a really bad word you know, especially saying someone is demonic.* (Ife – mother) (Munroe et al., 2016, p. 812)

Raghavan and Waseem (2007) described the anxiety experienced by families of people with a learning disability as they feel they must 'hide' the person with a learning disability.

> *Most participants wanted to keep such issues concerning their family members within the family structure, with carers taking extra precautions to hide any conditions associated with mental health problems.* (Raghavan & Waseem, 2007, p. 28)

5.3.3 | Isolation

Unsurprisingly, the effects of stigma lead to feelings of isolation.

> *I was very isolated. I didn't think our community was understanding of it. And I didn't get any support or anything from any of our faith organisations or anything…* (Carer) (McCarthy et al., 2020, p. 203)

Carers' responsibilities create an ongoing struggle to sustain relationships, and they often find themselves disconnected with limited engagement with their ethnic community (Hubert, 2006).

> *When she was young I thought when she gets older I will have more help, but … it is really a struggle and I think this is the time when carers like me need help because they are getting older … I think my life stopped 20 years ago … It is really, really difficult and my life is nothing. It is just gone…There is no me anymore.* (Mother from India) (Hubert, 2006, p. 263)

The reluctance to discuss learning disability was particularly challenging for some South Asian mothers (Heer et al., 2015). One participant stated:

> *don't go around telling people that [your child has a learning disability], you have to get her married at some point.* (Sanjit – mother) (Heer et al., 2015, p. 233)

Participants with a learning disability discuss feelings of loneliness arising from social isolation. Larkin et al. (2018) and Malik et al. (2017) suggest that primary services were service users' main point of contact. Establishing social connections with staff was deeply valued, yet the fear of losing these connections as they moved towards independence was a complex process to navigate:

> *I'll cook them [i.e. support workers, if they visit] a meal; I'll cook them a curry. Really, I don't want to be on my own, that's what I'm trying to say.* (Harinder – person with a learning disability) (Larkin et al., 2018, p. 201)

5.3.4 | Feelings of shame and blame

The intertwining issues surrounding misunderstanding, mistrust, discrimination, stigma, and isolation have significant implications for family carers. These all add to feelings of shame and blame experienced by carers, creating layers of additional challenges.

Munroe et al. (2016) described carers blaming themselves for their child's learning disability:

> *The implication that the mothers were to blame appeared to be at the root of many judgements and made these particularly difficult to bear, impacting upon their identities.* (Munroe et al., 2016, p. 809)

Sham and Mei (1996) explain that even if individuals have support from the immediate family, in Chinese communities there is still the notion that parents are to blame for the learning disability. Craig and Scambler (2006) describe a parent's shame in the context of tube feeding. One participant discussed the notion that a thin child suggests neglect and inadequate care, which leads to shaming of the parents.

> *In my culture, if a child is skin and bone…never mind about what he doesn't want, you feed him. And that is what would be forced on me.* (Garry's mother) (Craig & Scambler, 2006, p. 1122)

Shame and blame are experienced privately too; one mother in Munroe et al. (2016) described feelings of inadequacy due to their partner's comments and felt it was necessary to have a 'normal' child to prove they could be a 'good mother'.

5.3.5 | Burden of care

Several studies discuss the challenges surrounding carer responsibilities, with several studies equating caregiving responsibilities to a 'twenty-four hour job' (Heer et al., 2015). Carers often put their careers on hold due to the nonstop demands of caring for an individual with a learning disability (Heer et al., 2015; Kramer-Roy, 2012; Sandhu et al., 2016). The impact of this can result in carers finding it increasingly hard to manage self-care alongside the care of their child (Hubert, 2006).

> *It is very difficult to have a child who's got special needs, because ummm, they need 24 h attention … they need your input all the time, I'm exhausted.* (Fumni – mother) (Munroe et al., 2016, p. 807)

> *I have to look after her 24 h a day; I can never leave her on her own at home at all.* (MISD3, Carer) (Hatton et al., 2009 p. 67)

Heer et al. (2016) found that carers are often reluctant to seek help until they reach a crisis point.

> *…a reluctance to seek help resulting in families delaying contact with services until situations reached crisis point and could no longer be contained within the family.* (Heer et al., 2016, p. 112)

Several studies discuss marriage to address the burden of care, with carers, particularly from the South Asian community, using this to mitigate the strain on the families. McCarthy et al. (2020) studied forced marriage and suggested that in some cases there is pressure from within the community to arrange a marriage to ensure the person with a learning disability will have support as their family carers age. Durling et al. (2018) state that it was common within Bangladeshi communities to arrange a marriage as it was considered part of the 'cycle of life' (p. 1139). In some cases, it was viewed as necessary to ensure that the person with a learning disability had a safe future:

> *Everyone was really pleased … if was a relief because then they knew he was going to be looked after later in life.* (*FM4 – brother*) (Durling et al., 2018, p. 1137)

5.3.6 | Carer wellbeing

As discussed previously, Hubert (2006) states that carers often struggle to attend to their own health and wellbeing. Similarly, Ali et al. (2013) and Sandhu et al. (2016) found that carers often neglected their own health needs and revealed that they were more likely to suffer from conditions such as depression.

> '*She had to take care of her, and then she had a kidney stone and they had to remove her kidney*'. (Family 1 – sister) '*…and then we became unwell too, we got diabetes, cholesterol, everything, we have everything too*'. (Family 2 – father) (Sandhu et al., 2016, p. 376)

Hubert (2006) stressed that 60% of participants did not receive respite care. In some cases, parents relied on their other adult children to assist in caregiving. One elderly parent refused respite care for fear her poor health would be revealed and her child would be removed from her care:

> *Because it is just the two of us here. I have no company, he's the only help I have here … Sometimes when I [fall] he will make me a cup of tea and things like that. So I can't send him away. They don't understand, they want to know why I didn't take the respite.* (Mother) (Hubert, 2006, p. 262)

Both Ali et al. (2013) and Hubert (2006) conclude that carers often do not receive the assistance they need due to services not recognising the needs of the carer. Hatton et al. (2009) noted that carers had a better quality of life and better physical health when they received support from services.

5.4 | Healthcare-seeking and care factors

5.4.1 | Triangles of care

Triangles of care refer to the involvement of patients, carers, and professionals in healthcare decisions. Several papers, including Hatton et al. (2009), discussed the importance of carers being listened to by professionals. Carers from an ethnic minority background often felt left out of decision-making processes due to a feeling of inferiority and viewing the professional as an expert. In Ali et al. (2013), carers criticised professionals for failing to include them in clinical decisions.

> *We were sort of piggy in the middle kind of thing, going from him, speaking to his mum, and speaking to social services and trying to find out information from the hospital. It was very difficult to find out information from the hospital… And we are asking questions and they are very secretive, um, I understand the confidentiality aspects of it, but somebody needs to know what's happening.* (C7; paid carer) (Ali et al., 2013, p. 6)

Hatton et al. (2009) noted that carers from ethnic minority backgrounds encountered a disproportionate number of negative experiences with services. Examples such as poor continuity, poor community engagement and distance of services from home all contribute to the breakdown of triangles of care (Chinn et al., 2010; Hatton et al., 2009).

5.4.2 | Adaptive communication

Several studies highlighted the importance of adaptive communication to improve healthcare experiences. Croot, Grant, et al. (2012) emphasise the importance of attentive listening which facilitates meaningful engagement and ensures care is individualised to respect belief systems. Ali et al. (2013) documented examples of good practice which demonstrated good communication skills, describing how this established mutual respect, and how this was facilitated by reasonable adjustments (such as longer appointment times).

> *It was the first time that a doctor had ever spoken directly to [person with a learning disability]…he actually just addressed her only and then only looked at me for support….I just thought he was absolutely amazing, he was so respectful to her and that was really good.* (C2; mother) (Ali et al., 2013, p. 8)

Isolation resulting from language barriers was described by Sandhu et al. (2016) in their study of five Turkish migrant families.

The authors reflect that families described difficulties communicating with services, leading to people feeling ‘anxious when health workers visited’. Communication barriers perpetuated misunderstanding and mistrust, such as the fear that services would take children away.

> *[Questions] like does he hit me, how does he treat me, they were just talking about negatives and risk. I just thought they were going to take him away from me.* (Family 2 – mother) (Sandhu et al., 2016, p. 377)

Nonetheless, providing accessible communication is not limited to language, especially for individuals with a learning disability. Throughout this review, we encountered issues relating to adaptive communication, such as unavailability of easy-to-read materials, representing a key barrier to accessing healthcare.

5.4.3 | Community networks

Community and family networks were highlighted as an important source of support by the project working group and workshops which informed the coding framework for this review. The studies in this review demonstrate the key role of family carers, however, many people lacked wider family support.

Kramer-Roy (2012) detailed how children with a learning disability were often deliberately excluded from community networks, increasing the burden on families carers strived to offer their children a strong sense of belonging at home. The study gave parents the motivation to be more proactive in seeking contact with and supporting other Pakistani parents with disabled children and in challenging negative attitudes in their community.

Hatton et al. (2009) described the importance of close community and family networks in supporting the person with a learning disability and their family carers, though noted that family carers varied in their relationships with local communities, often due to negative perceptions of their acceptance within local communities.

> *[Daughter with intellectual disabilities] has aunts who love her very much…T goes to my aunt's house every Saturday or Sunday and they take her out. That's because they get direct payments.* (Carer) (Hatton et al., 2009, p. 68)

6 | DISCUSSION

Health inequalities arise from a complex interaction of factors such as income, education and housing, with wider social determinants such as social support networks, cultural beliefs, and societal norms influencing behaviours and healthcare-seeking patterns (Marmot, 2020). This review has demonstrated that the experiences of different ethnic minorities are a key consideration when caring for individuals from an ethnic minority background with a learning disability.

Societal and cultural expectations are complex and specific to each individual and their ethnic community. Centrally, people with a learning disability from ethnic minority backgrounds, and their carers, experience conflicts of control around culture and choice when navigating healthcare services. Being able to exercise choice and participate in healthcare decision-making is a foundational principle of person-centred care. It is evident from this review that individuals and their carers encounter inadequacies with culturally adaptive care, leading to the devaluation of their agency.

Racism, in the form of direct and indirect racial discrimination, harassment, and discrimination (Equality Act, 2010) negatively impacts healthcare experiences and opportunities of people with a learning disability from an ethnic minority background and their families. However, although many examples of racism were described in the papers reviewed, discussions of ‘racism’ and what it means in the lives of people with a learning disability were rare.

We were struck by the focus in the literature on cultural influences on experience for people with a learning disability from ethnic minority backgrounds and their carers. It is important to emphasise that a multitude of sociopolitical and systematic factors influence healthcare experiences, particularly for individuals from marginalised groups, including people with a learning disability from ethnic minority backgrounds and their carers (Umpleby et al., 2023). Systemic failures to address unmet needs must be scrutinised to address unequal healthcare experiences and outcomes.

Socioeconomic disadvantage is an important example of a sociopolitical factor that can impact the availability of services, stress and level of need amongst people from ethnic minority backgrounds (Hatton et al., 1998). However, reflections and experiences relating to socioeconomic disadvantage were not commonly described in the literature. This suggests more research is needed looking at how socioeconomic status, human and social capital (e.g., Hatton et al., 2009) impact the experiences of people with a learning disability from an ethnic minority background and their carers.

7 | RECOMMENDATIONS FOR SERVICES AND FUTURE RESEARCH

Healthcare professionals should seek to build trust through adaptive communication and community networks. Healthcare professionals should seek to understand and explore sources of conflict, such as those described in this review, which impact patient experiences. Carers' involvement in healthcare decisions and support for carers with burdens of care and wellbeing should be explored.

Future research should support the involvement of individuals with a learning disability from ethnic minority backgrounds, including people lacking capacity, and underrepresented ethnic groups (e.g., traveller communities). Codesign and participatory methods should be used to develop strategies to improve care.

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DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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Additional supporting information can be found online in the Supporting Information section at the end of this article.

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