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ORIGINAL ARTICLE OPEN ACCESS

Barriers to Healthcare for People With a Learning Disability From Ethnic Minorities: Perspectives of Self-Advocates and Carers

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ABSTRACT

Background: People with a learning disability from ethnic minorities experience barriers in their access to healthcare services and poorer health outcomes. This study aimed to explore the factors that contribute to these barriers and to better understand how they can be reduced.

Methods: Twenty 'experts by experience' took part in experience-based co-design workshops to ascertain how lived experiences related to findings from a co-designed scoping review. Audio recordings were transcribed and analysed using framework analysis.

Findings: Self-advocates and carers experienced discrimination within a range of healthcare settings; however, recognising and understanding the source was difficult. Many people reported a lack of reasonable adjustments or support services that considered their ethnic identities. Participants also experienced isolation and stigma within their own family and community networks. Access to healthcare was adversely affected by COVID-19. Many people were unaware of the Learning Disability Register and there was insufficient support when transitioning between healthcare services.

Conclusions: Services can be improved by effective communication, continuity of care and an enhanced understanding of the experiences of learning disability across different ethnic groups. Understanding an individual's needs and preferences from the first point of contact is important for the allocation of resources.

1 | Background

Ethnicity is a subjective identity shaped by factors such as shared history, origins, language and cultural traditions (Raleigh and Holmes 2021). In this study, 'ethnic minorities' refers to individuals in the United Kingdom who do not identify as White British. Approximately 1.5 million people in the United Kingdom are estimated to have a learning disability (Mencap 2019). While data on the prevalence of learning disabilities within ethnic minorities in the United Kingdom are limited, it was predicted that by 2030, 25% of new entrants to adult social care for individuals with a learning disability would be from ethnic minorities. Additionally, it is suggested that people from ethnic minorities may experience more severe forms of learning disability (Emerson 2012).

Summary

- People with a learning disability from ethnic minorities have problems using healthcare services.

- We call these problems *barriers* because they stop people from getting help. This means their health gets worse.

- We had three meetings with people from ethnic minorities with a learning disability and carers. We asked them to tell us what barriers they have when using healthcare services.

- People were treated unfairly in healthcare. It was difficult to know if this was because of their disability or ethnicity. They were also treated differently by their families and communities.

- Healthcare workers should learn how people from different ethnic groups experience learning disabilities to give better care.

People from ethnic minorities often report negative healthcare experiences (Ojo-Aromokudu et al. 2023) and poorer health outcomes (Kapadia et al. 2022). When ethnicity and learning disability intersect, individuals face additional layers of disadvantage. Research in the United Kingdom highlights that the combination of these two marginalised identities often leads to dual or multiple forms of discrimination. This intersection has drawn attention to the multi-layered nature of discrimination and disadvantage faced by people with a learning disability from ethnic minorities, prompting their identification as priority groups for improved healthcare support in learning disability policies (Department of Health 2009; Foundation for People with Learning Disabilities 2012).

Previous literature highlights the need to explore identity intersections to understand experiences and inequalities (Crenshaw 1990). This is crucial for addressing direct and indirect discrimination and for ensuring reasonable adjustments, as mandated by the Equality Act (2010). People from ethnic minorities with a learning disability face challenges accessing healthcare, leading to the underuse of routine and preventative services (Scott and Havercamp 2014; Bershadsky et al. 2014). Barriers include inadequate language accommodations, as well as a lack of cultural and religious sensitivity (Bonell et al. 2011; Heer, Rose, and Larkin 2016; Robertson et al. 2019).

Additionally, ethnic minority individuals in the United Kingdom, irrespective of the severity of their learning disability, experience a lower median age at death (University of Bristol 2021). People of Black, Black British, Caribbean or African ethnicity face the highest risk of dying at a younger age compared to the White population (White et al. 2022). Evidence shows that ethnic minorities with a learning disability were more severely impacted by COVID-19 (Burke and Ong 2021), highlighting the need for active efforts to address these inequality gaps.

This study was conducted as part of a wider project to review policy and data about people with a learning disability from ethnic minorities in the United Kingdom, including a scoping review (Umpleby et al. 2023) and systematic review (Roberts et al. 2024). Experience-based co-design (EBCD) workshops sought to explore the factors influencing barriers to healthcare for people with a learning disability from ethnic minorities and to better understand how these can be reduced.

2 | Research Questions

The workshops aimed to address the following questions:

1. What are the barriers to accessing healthcare services for people from ethnic minorities with a learning disability?

2. What factors influence these barriers?

3. How can services be improved to meet the needs of people with a learning disability from ethnic minorities?

3 | Methods

This research was funded by the NHS Race and Health Observatory. Ethical approval was obtained from the University of Central Lancashire's Ethics Committee in August 2022.

3.1 | Study Design

Study materials were co-designed with Learning Disability England (LDE), the Race Equality Foundation (REF) and a working group of ten individuals with lived experience, including four self-advocates, three family members and three supporters, seven of whom were from ethnic minorities. This group met monthly over 9 months, influencing the project design and workshop content. The research team consisted of two academic GPs (N.C.M., U.C.) and four researchers (K.U., C.R., N.D., C.H.). The Principal Investigator (U.C.) is from an ethnic minority, and one co-author (A.E.) is a self-advocate.

Three EBCD workshops were held in October–November 2022, either virtually or in accessible venues in London and Leeds. EBCD is a well-established approach that seeks to build close and equal collaboration among people affected by a particular challenge as 'experts by experience', thus developing meaningful solutions by centring service user experiences (Donetto et al. 2015). Core themes were generated from a scoping review (Umpleby et al. 2023) and discussions with the working group based on relevant findings and identified gaps. The six themes discussed in the workshops were: (1) discrimination, (2) community and family networks, (3) COVID-19, (4) digital access, (5) transitional care, and (6) the Learning Disability Register.

3.2 | Recruitment

A range of public advertising methods were employed for opportunistic recruitment, including targeted advertising through LDE and REF networks' mailing lists and social media platforms. Thus, ensuring outreach to a broad spectrum of

ethnic minority communities and organisations focused on learning disabilities and caregiving. Participants chose how to provide consent for the workshops, including written, electronic (Microsoft e-form) or verbally by phone. All participants provided consent by themselves. Participants were offered a voluntary shopping voucher for the value of £20/hour. Travel costs were reimbursed.

3.3 | Participant Selection

Participants were eligible if they were from one of the following groups:

- People from ethnic minorities with a learning disability.
- Carers of people from ethnic minorities with a learning disability.
- Support staff of the above.

Participants were excluded if they were under the age of 14 or if they were living outside of the United Kingdom.

3.4 | EBCD Workshops

Each workshop began with an accessible presentation of core themes. Participants were split into two groups led by LDE or REF facilitators. The facilitators are experienced in balancing contributions and built good working relationships with all participants before the workshops. Strategies were employed to mitigate power imbalances between self-advocates and carers, including mutually agreed ground rules and accessible content which was co-designed by the working group. Each group collectively decided the themes they would focus on based on those important to them (commonly discrimination and community and family networks), although discussions were facilitated for all themes. K.U. and N.C.M. took field notes and recorded conversations using encrypted recorders.

3.5 | Qualitative Analysis

The workshop transcriptions were analysed using framework analysis (Ritchie and Spencer 1994). K.U. transcribed and coded the data for core themes. N.C.M. and C.R. independently reviewed the transcripts, generating subthemes inductively. Interpretations and field notes were discussed with the wider team and working group.

4 | Results

4.1 | Participant Characteristics

Twenty individuals contributed to the workshops, consisting of 13 self-advocates, 5 family carers and 2 support workers. Participants were presented with a voluntary open-ended demographic form. While information on disability severity was not collected, a range of levels of learning disability were observed.

Eleven self-advocates provided demographic information (Table 1). Ages ranged from 32 to 65 years, and seven were male. Nine were of Black ethnicity, one was of a mixed ethnic background and the other was Chinese. Five described their religion as Christian/Catholic and four were agnostic.

Four carers provided demographic information (Table 2). Ages ranged from 44 to 50 years, and three were female. There were two mothers, one father and one sibling. Two were from a Pakistani background, one was Indian and one was British Asian. Three were Muslim.

4.2 | Qualitative Analysis

Core themes and subthemes are summarised in Table 3.

4.3 | Discrimination

Carers observed a lack of reasonable adjustments and a failure to recognise and accommodate individual needs. Self-advocates spoke of system barriers for continuity of care and discrimination outside of healthcare services.

4.4 | Substandard and Unresponsive Care

Carers reported inadequate reasonable adjustments, such as poor communication methods and inflexible appointment times. Self-advocates highlighted the frequent use of 'jargon' in written and verbal communication. One carer recounted her son's first annual health check (a yearly health review with a

TABLE 1 | Self-advocate demographic information.

Self-advocate identification number	Demographic details
P1	Female, mixed ethnic background, not religious
P2	Male, 48, Black African, Christian
P3	Male, 65, Black Caribbean, Christian
P4	Male, 32, Black African, Christian
P5	Female, 49, Black British, Catholic
P6	Male, Black (no further information)
P7	Female, 49, Zambian/British/Yorkshire, not religious
P8	Female, 35, Black British, not religious
P9	Male, 55, Chinese, not religious
P10	Male, 49, Black Caribbean, not religious
P11	Male, 49, Black British, Christian
P12	Did not disclose demographic information
P13	Did not disclose demographic information

TABLE 2 | Carer demographic information.

Carer identification number	Demographic details of carer	Demographic details of the people they care for
C1	Female, Indian; carer of her son	Male, 15, White and Asian, no religion
C2	Female, 44, Pakistani, Muslim; carer of her daughter	Female, 7, Pakistani, Muslim
C3	Female, 60, Pakistani British, Muslim; carer of her two brothers	Male, 52, Pakistani British, Muslim
		Male, 46, Pakistani British, Muslim
C4	Male, 50, British Asian, Muslim; carer of two daughters	Female, 29, British Asian, Muslim
		Female, 26, British Asian, Muslim
C5	Did not disclose demographic information	Did not disclose demographic information

TABLE 3 | Core themes and subthemes.

Core theme	Subthemes
1. Discrimination	1a. Substandard and unresponsive care
	1b. Importance of care continuity and system barriers
	1c. Discrimination outside of healthcare settings
2. Community and Family Networks	2a. Disconnection with a changing world
	2b. Isolation and stigma
	2c. Barriers to community engagement
3. COVID-19	3a. Reduced access to services
	3b. Loneliness and uncertainty
	3c. Barriers to vaccination
4. Digital Access	4a. Digital exclusion
	4b. Choice and control
5. Transitional Care	5a. Lack of information and support
	5b. Disconnect between services
	5c. Fear of the future
6. Learning Disability Register	6a. Awareness of the learning disability register
	6b. Reluctance of being recognised with a learning disability

doctor or nurse in general practice) as an example, citing no easy-read materials, no flexibility for appointments outside school hours and insufficient time to address his health needs.

C1 There's supposed to be adjustments and the guidelines suggest that GPs should have extra time for all of these appointments as well. There was absolutely none of this and it took literally 10 minutes to do his blood pressure, height, weight, and the general nodding of heads saying 'consultants are dealing with this so we don't need to talk about it'. So yeah, not impressive.

Some carers felt they faced ethnic discrimination in healthcare, citing rude or derogatory communication, denial of treatments or being asked to pay for services expected to be free.

Discrimination was also reported with professionals from ethnic minority backgrounds.

C3 Many times you get the impression when you go to the doctors, they think 'oh gosh, here's an Asian woman and she'll just want medication which is expensive' so they try and fob you off, instead of listening to your condition.

C2 You can't assume that they're going to be nice to you just because you're a South Asian. You can get discrimination from them as well. I've been discriminated against by Indian clinicians who don't like Pakistanis. It's really important to understand these things. So, there's discrimination within the community as well.

It was highlighted by one carer that there are ways of being or being perceived that can mitigate discrimination, such as being 'embedded into the British way of life'.

> C1 From my point of view it's not something that has been a real issue for my family because in terms of language and culture, we're very much embedded into the British way of life...In terms of religious beliefs, I don't think that has ever really impacted on us with our access to services, but I know for a lot of other families it does.

Effective communication was considered pivotal for the delivery of person-centred care. This included understanding an individual's needs and preferences from the first point of contact and allocation of resources, such as use of an interpreter.

> P7 Why can't people do some homework. To find out what is out there for people, to understand they might need a language interpreter, they might use Makaton instead of British Sign Language, they might use Braille.

Examples of good practice were also discussed; however, these experiences were infrequent or singular experiences.

> C1 I think I've only ever had one person...that introduced themselves and say how would you like to be addressed? Because I do get irritated when I just get called mum. Obviously, I am mum, but I also have a name. And then the conversation went 'how would you like me to communicate with you? How would you like me to communicate with your son?' and that straight away was all the barriers suddenly came down and everybody was relaxed. We negotiated how the conversation was going to carry on, what communication was required, and it was a great appointment. I just feel like even if people were able to take a little of this on board, it would make parents, carers, people with a learning disability at ease.

4.5 | Importance of Care Continuity and System Barriers

Unlike carers, self-advocates struggled to recognise discrimination or its cause (disability or ethnicity). Both groups agreed that healthcare experiences improved with consistent, familiar staff, while discontinuity led to repeated explanations and travel to different locations.

> P3 They are nice to me [doctors] but now I see different people.

> P8 The doctor's surgeries are all joined up so you can be sent to a different medical centre...The GPs don't know who I am when I go and see them.

> P9 I see a different doctor...the doctors move around from centre to centre...it would probably be better if I saw the same doctor.

Barriers to GP appointments were also reported. A self-advocate was referred to walk-in services, while a carer was repeatedly directed to a pharmacist, which felt impersonal and lacked privacy. Carers also had to seek healthcare advice from third-party organisations.

> P9 When I went to the doctor...they say to go to the walk-in centre. It is far from mine...The walk-in centre is probably 1 hour from me.

> C3 Doctors now, when you ring to make appointments or ask for information, they say you have to get advice from the chemist. When you go to the chemist and ask for advice, they're not very sympathetic. They'll talk to you over the counter and won't take you to one side for your personal issues. I think this is inappropriate and the pharmacists are quick to sell you their products so it can be expensive.

4.6 | Discrimination Outside of Healthcare Settings

Self-advocates provided examples of discrimination outside of healthcare settings. For example, barriers to using public transport, which impacted their ability to attend appointments.

> P12 Sometimes I have trouble with taxis not turning up or they're being rude and not taking the wheelchair.

> P13 Yes, I've had issues with people not letting me on the bus [in wheelchair].

One self-advocate also expressed concerns about financial exploitation from strangers. However, people reported experiencing less discrimination when living in multicultural communities.

> P3 I don't trust people if I go out at night...they could take my money... I made sure now that I don't give them my payment.

> P2 When I lived in (different area), there were not many ethnic minority people. There was discrimination...No problems [here] with racism. There are more ethnic minority people here.

4.7 | Community and Family Networks

Self-advocates valued support from family networks and self-advocacy groups. However, they noted that services sensitive to their ethnic identities were not always available. Carers also expressed that they lacked support from their wider family and ethnic communities, resulting in feelings of isolation.

4.8 | Disconnection With a Changing World

Having a family member or carer present for appointments provided emotional support and aided communication. However,

maintaining consistent support was challenging in the context of changes occurring in the lives of their family and communities.

> P2 Our landlord decided to sell the house and we had to move. We'd been living there for 7 years. For me it was a good experience, but now there is only me now.

> P3 Family help me but everybody's busy now.

> P6 Living with friends, before it was easy, now it's different because they're not in my service anymore. It's not the same anymore...everyone's everywhere.

Regular contact with a support worker or self-advocacy group was particularly useful for people who did not have frequent family support.

> P2 My support worker helps me the most...because I don't see my mum all the time... I meet people in another group for people with learning disabilities. Yes, I have met a lot of people going to this.

> P6 Staff help me book appointments... If I want help, I try to take somebody with me.

One self-advocate voiced that it would be helpful to have staff of the same gender supporting them during appointments.

4.9 | Isolation and Stigma

Carers reported that their experiences of community and family networks did not typically align with the findings from the scoping review. Specifically, they noted that they did not have the traditional extended family network that was portrayed about 'South Asian' people.

> C3 If you go to the professionals and ask for support, they again stereotype you and [they] think you have family who should help.

Carers described a sense of isolation, not only within their immediate family but also in their ethnic communities, where learning disability was still considered a taboo.

> C1 Especially, say when my son was born, a lot of people that I did know kind of backed off a little bit, there was almost a kind of fear factor, that she has this child with a disability, I think it was down to this kind of lack of knowledge but I think there is still a real fear factor and a taboo when it comes to disability in South Asian households.

Two mothers shared how they encouraged their children to participate in community activities to enhance integration and acceptance. They created social networks outside of the mainstream, consisting of friendships formed in school, youth clubs and support groups. Their children felt more 'comfortable' socialising with friends with disabilities outside their ethnic communities.

> C2 I don't know, it just feels more comfortable there, sometimes we just don't feel like we fit in the mainstream.

> C1 [My son] tends to hang out with friends from his school or youth club, whereas I would have ordinarily been hanging out with cousins, everybody is a cousin when you're South Asian. I've certainly noticed a difference in the kind of the community that he hangs around with than what I would anticipate my other children would be hanging around with.

4.10 | Barriers to Community Engagement

One participant, who cares for her two brothers, stressed that it was important for her brothers to engage in religious activities to build relationships within their ethnic community. However, this carer highlighted the barriers relating to the ethnic backgrounds of support staff.

> C3 When you look at my brothers and their culture, there isn't many people with the same culture and workers who will culturally and Islamically think and behave in that order. For instance, on a Friday it is on his care plan to take him to the mosque...But then if you have a Christian White male taking my brothers. I mean they're not prevented. But I'd like them to be physically performing the prayers and join in, so there's barriers there.

Additionally, this carer highlighted that there was a lack of support and self-advocacy groups inclusive of ethnic minorities, which limited opportunities for social engagement.

> C3 Sometimes in an evening my brothers did go to [local support group] but it's all around pubs and stuff. So my brothers can't drink, so why not have a community group that is more based around your ethnicity and culture so you could do activities with like-minded people. I've looked, but there's none of this around. I've even tried setting it up with [local support group] but it's not easy. There's only so much I can do, I can't change the world can I?

Self-advocacy groups and employment were identified as two important ways to meet new people and to socialise.

> P12 I go to [group] on Tuesdays and Fridays and we do different activities.

> P8 If you go to a social group, you might meet new people there. Or, if you work with them, you might meet people through work.

4.11 | COVID-19

Difficulties with access were exacerbated during the COVID-19 pandemic. For some carers, gaining help from care services was

challenging and only achieved during times of crisis, and with perseverance. In addition, the abrupt and prolonged reduced access to services resulted in loneliness and uncertainty.

4.12 | Reduced Access to Services

Self-advocates and carers expressed heightened difficulties in accessing timely support. Carers highlighted that these struggles existed before the pandemic, and they merely intensified following social restrictions.

> P8 I don't like going to the doctors at all. Since COVID it is completely worse. It's worse trying to get a doctor's appointment and a prescription.

Family carers who relied on external care agencies also spoke of the detrimental impact when care was halted. One family carer described this as the 'toughest time of our lives'.

> C3 Both of these young men, on their care plan, have 1-1...So as an individual, I can't possibly provide their needs throughout the day because it is too much...I could cope only for 6 weeks and I'd become really down. I'd be constantly on the phone saying you're gonna have to come and take them because I can't do this. So I kept pushing and pushing and pushing. I don't know how long eventually it took for someone to take them out for an hour just to break the day up for them. But it was like me having to constantly be on the phone to see where I could get support.

Alongside reduced physical support, some carers also reported a lack of information about COVID-19. One carer reported that they did not receive adequate information about how to care for someone medically vulnerable if they contracted COVID-19. This carer was able to obtain training from a third-party organisation.

4.13 | Loneliness and Uncertainty

Self-advocates felt 'forgotten', 'ignored', and 'isolated' due to restrictions. They described feeling overwhelmed and scared during the pandemic, with a 'fear of leaving the house'. Family carers noted the emotional toll as their loved ones struggled to understand the disruption to their activities; one carer mentioned her son felt he was being 'punished' for not being able to participate in his usual routines. Family carers also faced loneliness in decision-making, bearing the burden of making important health choices amid uncertainty, highlighting the need for individualised, culturally sensitive support.

4.14 | Barriers to Vaccination

Self-advocates generally agreed that a 'fear of needles' and a 'fear it will make them sick' were barriers to vaccination. Carers reported complacency, misinformation and mistrust. In one

instance, this sense of complacency stemmed from a lack of information about the potentially serious consequences of COVID-19. Religious beliefs may also influence vaccination decision-making, as one carer referred to the 'will of God', yet this did not appear to have been explored by healthcare professionals.

> C3 The media played a role in this because the wrong information was out there. I mean still, the majority of my family say no, don't take the vaccine cos it will still be more detrimental to your health. And I'm thinking it's the will of God, if it's gonna be it will be.

4.15 | Digital Access

Digital access involves technology-supported interactions between healthcare providers and users. While self-advocates had adapted to digital healthcare, they still needed support. Carers and self-advocates noted a lack of accessible online healthcare information and emphasised that digital engagement should be a personal, needs-inclusive choice.

4.16 | Digital Exclusion

Self-advocates acknowledged that before COVID-19, there was not as much of a requirement to engage with healthcare services digitally. While they found it difficult to navigate, self-advocates had generally become accustomed to using digital technology, though much of this guidance and support was provided by local support groups. However, some self-advocates still consistently relied on support with digital access.

> P5 People with learning disability don't have competency with computers.

> C3 My brothers wouldn't be able to access computers because they don't have that understanding. It's me that has to do all of that.

Both self-advocates and carers reported issues with the accessibility of online health advice, due to a 'minefield of information' and a lack of digital easy-read content.

> C1 Currently my son has alopecia that he's struggling with and again there was no information available for him. I went on the NHS website and it's all lots of language that he doesn't understand, there were no pictures to explain to him. The whole process is not set up to support somebody who just needs that visual information.

4.17 | Choice and Control

Self-advocates and carers voiced the importance of personal 'choice' in seeing medical professionals in person or remotely. They noted remote consultations can be helpful, such as for

those without support to attend appointments, but preferred in-person visits for discussions about medication or physical symptoms. Self-advocates stressed the value of 'personal contact'.

4.18 | Transitional Care

Carers spoke of a lack of information and support during periods of transition (hand-over) in their healthcare, which resulted in fear for the future. There was also a perceived disconnect between healthcare services.

4.19 | Lack of Information and Support

Carers discussed the difficulties of not being able to access information pertaining to transition from child to adult services. One carer reported that multiple services were unable to provide information, including their GP, the children's team and the local authority.

C1 For me, it's almost like a blank space in our lives. So, my son is 15 and whenever we mention the word transition, we hit a brick wall. Either there's a lack of information available or simply nobody talks about it. We've just got to find a way through it and muddle through somehow.

One carer who had experienced this transition reported that more supportive and efficient healthcare was delivered by child services. Following the transition to adult services, they noted longer waiting times and reduced compassion. This lack of information and support was also experienced when transitioning from school to adult daycare services.

C3 With transitioning, there's no support in between. Going from school into day services. When my brother left school it was like a big gap in deciding which service to have, going to visit and stuff. So this was a learning curve for me and when I did get there, this was a time when I did everything myself and got no support.

Two carers had personal ties to healthcare. They both acknowledged that despite 'living in the world of medics', they still did not understand the system and stressed the importance of knowledge.

4.20 | Disconnect Between Services

Participants also noted a lack of effective communication between services, which in some instances resulted in substandard care, and information having to be repeatedly relayed by carers.

C2 For me one of the key things is communication... There's still so much disconnect...It's crazy that we're living in this day and age with this technology and they're

still not communicating well. So you have to repeat everything and everybody needs a separate record on the patient. It's just ridiculous the amount of time I have to spend going over the same thing again and again.

This ineffective communication was also experienced within care settings. One carer spoke of their experience of hospital passports not being adhered to when moving between hospital wards.

C3 One of my brothers had pneumonia and he had his hospital passport. I found that when he moved from one ward to another, it said he needed one to one [care] or he'd abscond and move out of bed when he felt a bit better. When I pointed this out to the nurse in charge, she said you should have told me this earlier...Hello, it's in his care plan, he's come in with it, why have you not read it? Why do I need to relay everything?

Carers reported positive experiences of care when clinicians had an enhanced understanding of learning disability.

C1 My son had to go to hospital to have his teeth looked at and he was really anxious about that. But thankfully, the dental hospital, although they didn't have a learning disability nurse, they clearly had had some training. Because they were talking to him, they were reassuring him, they had pictures where they were able to show him this is the person who is looking after you, this is what they're going to do. I think if that was replicated in all other health settings it would make my son's life so much easier.

4.21 | Fear of the Future

Carers of adults were doubtful of positive experiences of care in the future while carers of children were 'apprehensive' about the transition into adult settings.

C1 The sad thing is I hear such horror stories about people who have transitioned to adult services and have had a complete nightmare in healthcare that it worries me even more and it makes me very apprehensive about what's going to happen when we get to that stage...My son may be transitioning into adulthood, but actually on a cognitive level he's not there, he's still very much a child. So, it's about getting that reassurance that when I do go and see health professionals in an adult setting, they have the knowledge, experience and willingness to understand and work at his level.

C2 I don't really have a lot of experience because [child] is only turning 8. But I do worry about it. I hear about other people's experiences. In the Down's syndrome community, some of the children that are older and just left school, they talk about the challenges they've had so it does worry me.

Carers expressed that their experiences of healthcare services could be improved if they were able to access support from learning disability nurses. Despite their perceived value, carers reported a lack of contact with learning disability nurses, which were likened to 'mythical creatures'.

> C1 Also another thing is learning disability nurses. I'm 15 years into my journey with my son and I'm yet to meet one. That, I find really disappointing, because we keep hearing that there's a big drive to get learning disability nurses in hospital settings and even in primary care.

> C2 It goes back to the learning disability nurses again, what are they? [Laughs].

4.22 | Learning Disability Register

All general practices in England keep a list of people with a learning disability, which should trigger additional support (e.g., longer appointment times, invitation to annual health checks). Self-advocates and carers generally had very little awareness of the Learning Disability Register.

4.23 | Awareness of the Learning Disability Register

Participants were mostly unaware of the Learning Disability Register and expressed that they had received limited information from healthcare professionals.

> P9 I'm not sure if I'm on...nobody has spoken to me about it.

> C3 I haven't been told if my brothers' names are on the Learning Disability Register, nobody has mentioned it to me. They get the annual health check, that's for sure, so they must be on the register.

Some participants felt it was important to raise awareness of the Learning Disability Register and its operation. A self-advocate and support worker were unsure how people are added or if it's a personal choice. A carer noted that better communication about the register in her ethnic community would be helpful.

> C3 If it was explained, especially to my community, then people would understand that it is a priority...it would be good if people were told about this information and check if their loved ones are on it.

In some instances, this lack of awareness translated to annual health checks. Some self-advocates were unsure if they had received a health check or when they should receive one.

> P8 I'm not quite sure [if I've had an annual health check], but I need to see a doctor.

> P13 I've had a health check once but I should have another one at one point but it has been really hard to see doctors.

4.24 | Reluctance of Being Recognised With a Learning Disability

Self-advocates expressed a fear of being treated differently. A carer also added that for some people, there is 'a reluctance in many cases to even accept that their family member has a disability'.

> P1 Sometimes some doctors...you have to be careful. Some people are not treated fairly so they are worried about being on the list.

> P5 Are we going to be treated fairly?

5 | Discussion

5.1 | Healthcare Barriers

The experiences of self-advocates and carers highlight barriers to inclusive care. Many challenges, such as inadequate reasonable adjustments and transitional care, are common across all people with a learning disability (Tuffrey-Wijne et al. 2014; Brown et al. 2019). However, for those from ethnic minorities, communication barriers are especially pronounced, including a lack of interpreting and translation services and accessible digital resources (e.g., multilingual support or visual aids). Racism and stigma further complicate access; self-advocates often found it difficult to distinguish whether discrimination stemmed from ethnicity or disability, while carers more readily identified racism. Many self-advocates and carers were also unaware of the Learning Disability Register and expressed concerns about being labelled within their ethnic communities and healthcare services. These combined factors create compounded disadvantages.

5.2 | Factors Influencing Healthcare Barriers

The central role of community and family networks, which has been highlighted in existing literature, is outdated and stereotypical (Umpleby et al. 2023). Carers in this study reported minimal support from their wider family, relating to experiences of stigma and isolation. The COVID-19 pandemic further served to exacerbate feelings of loneliness and uncertainty, along with ongoing concerns regarding disruptions in continuity of care, transitions within and across healthcare services and access to services which are inclusive for people from ethnic minorities. Hatton et al. (2024) report ongoing problems with healthcare access for people with a learning disability since COVID-19; however, their participants were predominantly White British.

5.3 | How Can Services Be Improved?

There are no clear guidelines on the cultural considerations and information needed for individuals when added to the Learning Disability Register. Mencap's 2022 'easy-read' resources aimed to raise awareness, but this study suggests their circulation and

impact may be insufficient. NHS England should implement targeted awareness campaigns to explain the register's purpose and promote annual health checks. Health and social care organisations have a statutory duty to ensure equality in service access. The 2023 NICE consultation recommends collecting data on ethnic minority individuals receiving annual health checks, to guide targeted solutions and improve access.

Integrated Care Boards should invest in anti-racist and culturally appropriate community support, such as creating ethnic minority liaison roles and expanding the number of learning disability nurses to better represent and serve diverse populations. They should also partner with community organisations to offer learning disability services that take account of faith and foster self-advocacy groups, ensuring these services are accessible and relevant to local cultural contexts.

Future service improvements should incorporate inclusive approaches involving self-advocacy and carer projects led by individuals from ethnic minorities. For instance, the 'Changing Our Lives' (2024) serves as a model for effectively engaging these communities in shaping services.

5.4 | Comparison With Existing Literature

Since *Valuing People Now* (Department of Health 2009) there has been no national learning disability policy explicitly addressing ethnicity, despite evidence from policy analyses, including our report, highlighting its importance (Umpleby et al. 2023). While NHS initiatives have sought to reduce health inequalities, demographic shifts and the impact of COVID-19 emphasise the need to explore current healthcare experiences.

This study builds on earlier research, such as that reviewed by Robertson et al. (2019), which identified barriers like poor communication, limited cultural competence and lack of awareness of services. It also provides a more nuanced view on how discrimination is perceived. Self-advocates frequently found it challenging to discern whether discrimination was rooted in ethnicity, disability or both, illustrating the complex intersections of these identities.

Our study suggests a gap remains between policies like the Equality Act (2010) and their implementation, underscoring the need for better understanding of the drivers of discrimination and disadvantage and how competence training is implemented, and enforcement of reasonable adjustments is delivered. Additionally, the lack of awareness about the Learning Disability Register further limits its benefits for ethnic minority groups.

5.5 | Strengths and Limitations

Co-production fostered collaboration and participation, with the working group identifying research gaps (e.g., COVID-19 and digital access) later explored in the workshops. Participatory approaches like EBCD address power imbalances, while identifying problems and generating solutions in a cyclical

process. Including self-advocates and carers added valuable perspectives, though workshops lacked scope to fully explore how self-advocates conceptualise discrimination, such as racism.

Despite efforts to foster inclusion, the study faced limitations in capturing the perspectives of highly marginalised groups. Non-English speakers and those unaffiliated with self-advocacy groups were not recruited, potentially excluding individuals unknown to services. All carers were from Asian backgrounds, limiting representation of other ethnic groups, and there were no participants from Jewish, asylum seeker or Traveller communities.

5.6 | Directions for Future Research

Improved data and exploratory research are essential for understanding how barriers and inequalities affect people with a learning disability across ethnic groups, especially the role of racism in care disparities. This necessitates improving the accuracy and completeness of ethnicity data at the same time as addressing the failings of learning disability registers and other recording of disability in health data sets to ensure consistency across healthcare services. Expanding data sets, such as the Learning Disability Register, the Health and Care of People with Learning Disabilities data set and the Learning Disabilities Mortality Review (LeDeR), alongside participatory and qualitative research, will provide deeper insights into the factors contributing to inequalities and support targeted interventions and effective policies. Gaps remain on the impact of COVID-19 and digital healthcare.

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