



University of  
Central Lancashire  
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NHS  
RACE & HEALTH  
OBSERVATORY

# PART B

## We deserve better: Ethnic minorities with a learning disability and access to healthcare – an exploration of lived experiences

July 2023



Manchester  
Metropolitan  
University



Learning Disability England



# Contents

Acknowledgements	<b>3</b>
Abbreviations	<b>7</b>
Approach to terminology	<b>8</b>
Introduction	<b>9</b>
Methodological approach	<b>10</b>
Findings	<b>15</b>
Conclusion	<b>39</b>
Recommendations	<b>42</b>
References	<b>43</b>

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## The working group

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A working group was formed consisting of people with lived experience who worked closely with the academic team. Members of this group had previous experience of working with the Race Equality Foundation (REF), Learning Disability England (LDE) and Pathways Associates. Both REF and LDE provided support as necessary, including the provision of training and information in an accessible format. The working group consisted of ten people with lived experience as an ethnic minority self-advocate, family member or supporter. The group was co-chaired by Sam Clark (LDE, Chief Executive) and Aisha Edwards (Lewisham Parliament Representative).

The group met monthly to inform different aspects of the project, including:

- Scoping the review criteria and search terms, sharing their priorities for investigation and reviewing the first phase findings
- Contributing to defining the focus of the policy review
- Designing workshop plans, including making the sessions inclusive and welcoming for all people
- Reviewing and improving the public workshop information and participant consent forms to improve accessibility
- Supporting the promotion of the workshops
- Providing insight on themes emerging from the workshops

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### **Siraaj Nadat**

*“My name is Siraaj Nadat, Senior Quality of Life Facilitator at rights-based organisation Changing Our Lives. Through our work around social justice I have been heavily involved in tackling the health inequalities faced by people with a learning disability and autistic people. Using this knowledge, I was able to valuably contribute to the working group. At Changing Our Lives, we focus our work in and alongside minority ethnic communities, and through this and my own lived experience of being a disabled man from a minority ethnic community I am not only passionate to talk about the health inequalities that these communities face but to see change happen.”*

### **Mary Akinbiyi**

*“My name is Mary a retired retail manager. I am mother/ carer to my handsome son. My son suffers from brain injury, epileptic seizures, speech impairment and a learning disability. I generally have passion for people with a learning disability. I am an advocate because I know they need help to amplify their voices and support to live the life, they are entitled to.”*

### **Aisha Edwards**

*“I am Aisha Edwards and I work as a People Parliament Representative for Lewisham Speaking Up and I enjoy it.”*

### **Kizzy Felstead**

*“I am an autistic adult and mother to two autistic children. I have a background as a social worker and then teacher and have also taught English as a second Language to a variety of ethnic minority groups and have also taught children from Gypsy, Roma, Traveller communities. Whilst studying for an MSc, I also work as a trainer, delivering a variety of topics around autism and learning disability to people working in social care, Justice and Health systems. I am passionate about equity and making a difference to the lives of seldom heard from communities which is why I am working with this project.”*

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*Lee is a representative and advocate for All Wales People First (the united voice of self-advocacy groups and people with a learning disability in Wales). Lee has a passion for speaking up for people with a learning disability.*

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# Abbreviations

**EBCD** Experience based co-design

**GP** General Practitioner

**LDE** Learning Disability England

**LeDeR** Learning from Lives and Deaths – people with a learning disability and autistic people

**MMU** Manchester Metropolitan University

**NHS** National Health Service

**REF** Race Equality Foundation

**UCLan** University of Central Lancashire

# Approach to terminology

The NHS Race and Health Observatory has developed five principles that can be followed when talking about race and ethnicity (NHS Race and Health Observatory, 2021). Throughout this report, an active effort has been made to adhere to these principles:

- Where possible, we have been **specific** about the ethnic backgrounds of people that we are referring to.
- We have avoided the use of **acronyms or initialisms** such as ‘BME’ or ‘BAME’.
- We have only used collective terminology where it was necessary and guided by **context**. For example, when analysing data from external data sources with pre-defined ethnicity groupings, or where we are referring to the findings of pre-existing literature.
- We have been **transparent** about the language that we use throughout this report.
- We understand that acceptable terminology changes over time. As such, we will remain **adaptable** to changing our terminology in future work.

Where we are not referring to people from specific ethnic backgrounds, we will use the term **ethnic minority**. When we are talking about people from an ethnic minority background, we are referring to all ethnic groups except ‘White British’. Ethnic minority also includes white ethnic minority groupings such as Gypsy, Roma and Irish Traveller groups.

Though the terms **‘learning disability’** and ‘intellectual disability’ are often used interchangeably, from here on we will use the term ‘learning disability’. When we talk about the people with a learning disability who have contributed to this project, we use the term **‘self-advocate’**.



# Introduction

**This report presents the findings and recommendations derived from experience-based co-design workshops which explored how people's lived experiences related to the academic findings generated from the scoping review. This research was conducted by academics from the University of Central Lancashire and was facilitated by the Race Equality Foundation and Learning Disability England.**

The lived experiences of self-advocates and carers shed light on the barriers and issues preventing inclusive, responsive care for people with a learning disability from ethnic minority backgrounds. Taken together, these experiences reflect systemic discrimination on the grounds of a person's disability, their ethnicity and other characteristics such as gender and socioeconomic status.

The intersection of ethnicity and disability is a complex concept. These findings reflect the experiences that were most pertinent to participants and are not exclusively related to discrimination on the basis of a person's ethnicity and their culture. Due to the intersectional nature of discrimination, experiences of racism were difficult for participants to recognise. However, sub-themes are presented below that more exclusively focus on the barriers to inclusive healthcare specific to people from ethnic minority backgrounds. These are: substandard and unresponsive care, isolation and stigma, barriers to community engagement, barriers to vaccination and reluctance of being recognised with a learning disability.

# Methodological approach

Workshops were conducted which sought to explore the complex factors which contribute to the disparities in health care experienced by those with a learning disability from ethnic minority backgrounds, to better understand how such inequalities can be reduced. An experience based co-design (EBCD) approach was used for the workshops. This well-established approach enables a wide range of people to contribute to the formulation of a solution to a problem and builds collaboration with people affected by a particular challenge as 'experts by experience' (Donetto et al., 2015). It involves close and equal collaboration among all the groups of people who have a stake in the system or process which is to be improved. This approach aims to make meaningful changes to services by centring service users and health and social care staff experiences and collaborating with these stakeholders to develop solutions to the issues they raise.

## **Inclusion criteria for EBCD workshops:**

- People from ethnic minorities with a learning disability.
- Carers of people from ethnic minorities with a learning disability.
- People who work for organisations that provide support to people from ethnic minorities with a learning disability and/or their carers.

## **Exclusion criteria for EBCD workshops:**

- Children under the age of 14.
- No written or verbal consent (parental/legal guardian permission required for children 14-17).
- Living outside the UK.

## Recruitment

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A range of public advertising methods were employed to opportunistically recruit participants for three EBCD workshops, which took place between October and November 2022. This included advertising through the existing networks that Learning Disability England and the Race Equality Foundation have, which encompass the diversity of ethnic minority communities as well as organisations working across the learning disability spectrum and with carers. This was combined with working with other national partners who operate faith networks. Representatives from Learning Disability England and the Race Equality Foundation acted as the first points of contact.

## EBCD workshop design

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Participants were given the choice of joining a physical or virtual workshop. To ease the barriers to attendance, one workshop was held in London and one in Leeds. Venues secured were accessible to public transport as well accessible in themselves for people with access needs.

The findings of the scoping review were taken to a group of 'experts by experience', which consisted of carers and self-advocates. Specifically, eight themes were generated from the scoping review and from further discussion with the working group. These were presented to participants to ascertain how lived experiences relate to academic findings and to consider ways in which care could be improved. The themes were produced in an easy-read format in partnership with Learning Disability England and the Race Equality Foundation (see Appendix 4).

The eight themes were:

- Discrimination
- Community and family networks
- COVID-19
- Digital access
- Transitional care between adult settings
- Transitional care from child to adult services

## Methodological approach

- The learning disability register
- The LeDeR programme

In relation to the themes outlined above, the objectives were to address the following questions:

1. What are the barriers to accessing health and care services?
2. What are self-advocates' and carers' positive and negative experiences of care?
3. How can services be improved so that they can be more responsive to the needs of self-advocates and their carers?

## Working Group involvement

The working group contributed to the development and delivery of the workshops by providing advice and ideas. The group met monthly to inform different aspects of the workshops by:

- Designing the workshop plans including how to make the sessions inclusive and welcoming for a wide range of people
- Reviewing and improving the public workshop information and participant consent forms ahead of them being shared widely to improve their accessibility
- Supporting the promotion of the workshops
- Generating additional themes to those identified through the literature review for discussion in the workshops

## Workshop participation

A total of twenty individuals contributed to the project, which consisted of 13 self-advocates, five family carers and two support workers. We spoke to these 'experts by experience' between October and December 2022. The main way in which people participated was by attending semi-structured workshops. In total, three workshops were conducted: one in London (Lewisham), one in Leeds and

## Methodological approach

an online workshop. People who could not attend the workshops provided their thoughts about the themes directly with the research team.

We collected some voluntary demographic information about the people who contributed to the research, to provide context and understand if experiences were varied based upon a person's background. The anonymised demographic information of participants is outlined below in Tables 1 and 2, for self-advocates and carers, respectively.

**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 (did not wish to provide further demographic 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 with a learning disability that they care for
<b>C1</b>	Female, Indian; carer of her son	Male, 15, White and Asian, no religion
<b>C2</b>	Female, 44, Pakistani, Muslim; carer of her daughter	Female, 7, Pakistani, Muslim
<b>C3</b>	Female, 60, Pakistani British, Muslim; carer of her two brothers	Male, 52, Pakistani British, Muslim
		Male, 46, Pakistani British, Muslim
<b>C4</b>	Male, 50, British Asian, Muslim; carer of children	Female, 29, British Asian, Muslim
		Female, 26, British Asian, Muslim
<b>C5</b>	Carer (did not disclose further demographic information)	Did not disclose demographic information

# Findings

The qualitative analysis presented below provides an insight into some of the fundamental barriers to inclusive and responsive health care which are experienced by self-advocates and carers. We have collated the data generated from across the workshops to inform subthemes for each of the following eight core themes and the analysis for this report is limited to these themes. We first provide an overview of each core theme, as well as present supporting evidence for each subtheme from the qualitative data. We have combined the two transition themes due to overlapping sub-themes.

## Discrimination

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### Carer

*“I don’t know, but it doesn’t feel right. If it doesn’t feel right, it’s not right.”*

It was evident from experiences that people were discriminated against due to their disability. People reported a lack of reasonable adjustments and a failure to recognise and accommodate individual needs. However, some participants also provided personal experiences of health and care services where they acknowledged that they may have been treated differently due to their ethnic and cultural background, such as being prompted to pay for services which were expected to be free. Discerning the underlying reason(s) for the perceived discrimination (whether it is related to their disability, ethnicity or gender for example) can be difficult to ascertain for the person experiencing it. As such, participants found it easier to recognise and understand discrimination due to their disability rather than experiences of racism.

It was clear that discrimination within health and care services is still problematic, and family carers expressed the constant requirement to defy this systemic discrimination, and advocate for better care for their loved ones, as exhausting. Self-advocates spoke of experiences of discrimination outside of health and care services, including instances of financial exploitation and issues with transport. Three subthemes explore issues associated with substandard and unresponsive care, the importance of continuity of care, and discrimination outside of health and care settings.

### Substandard and unresponsive care

Self-advocates and carers provided examples of discrimination in health and care services which, ultimately, impacted their access and experiences of care. Experiences that were shared could be regarded as discrimination on the grounds of their disability. For example, some participants acknowledged that reasonable adjustments were not employed to accommodate individual needs. Not being responsive to people's needs inadvertently resulted in substandard care and treatment. Examples of inadequate reasonable adjustments included unsuitable methods of communication and inflexibility with appointment times. Self-advocates reported instances of written and verbal communication that was deemed to be unsuitable due to the use of "jargon".

One carer's experience of her son's first annual health check epitomises the inadequate reasonable adjustments outlined above. Specifically, this carer expressed that there was no easy-read information pertaining to the health check, no flexibility to offer an appointment outside of school hours and an inadequate appointment duration that lacked consideration of existing health issues.

#### 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."*

In addition to discrimination on the grounds of a learning disability, some participants also provided personal experiences of health and care where they felt that they may have been discriminated against due to their ethnic and cultural background. Examples of reported discrimination included feeling like they were being spoken to in a distasteful or derogatory way, being denied access to treatment that was deemed to be beneficial or being prompted to pay for services/treatments which were expected to be free. However, one carer "wanted to raise awareness" that discrimination within healthcare can be experienced "within the ['South Asian'] community" too, and that discriminators can also be from an ethnic minority background themselves.

#### 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."*



## Findings

**C3**

*“But to be told when you ring the doctor’s surgery that you need to get consultation from the chemist, and the chemist looks at you and thinks ‘oh God, this is another Asian person’ and not even considering to take you to one side. So yes, it is discrimination and looking at you and thinking you might be wanting too much because you’re Asian.”*

**C2**

*“But can you believe how different my experience is from everybody else?... It’s just so obvious sometimes isn’t it, but I didn’t think it was obvious when it first happened. Isn’t that strange? I always give people the benefit of the doubt when I experience these things and discrimination and racism because I still experience it a lot.”*

**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.”*

**C2**

*“[My daughter] has an ophthalmologist at the hospital and then she’ll go into primary care and get her glasses because she doesn’t have them dispensed from the hospital. I discussed this with the Down’s Syndrome friendship group that we have and I told them when I went in during COVID, I can’t believe how difficult an experience I had with [the optician]. They asked why and I said, well you guys always go in and say you don’t need to pay for glasses. But every single time I go in with [my daughter]...he always tells me there’s a charge for the specs every single time. They haven’t had the same sort of experience and I’m the only non-white person in that group. After the third or fourth time I thought, really, is it just me. Am I overthinking this or is it really happening? But to me when I went in during covid I felt like it was really happening and I thought why is he always doing that to me and not to anybody else in the group.”*

Some participants acknowledged that they may not often be discriminated against on the basis of their cultural background due to 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. I speak other languages but I’m fluent In English so there’s no language barrier there. 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.”*

## Findings

Some carers reported instances of prejudice, where healthcare professionals assumed that they could not speak English due to their race.

### C1

*“I think it's the assumptions that are made, rightly or wrongly. Because there will be people who will turn up at an appointment and don't have the knowledge and may not have the language skills. But sometimes it's that underlying assumption when you walk in and they look at you and go crikey, I need to explain this in slow language or whatever, you kind of go noooo, just give me a chance first let me speak, and they hear you have a good grasp of English. But it puts a real damper on the whole starting point and it makes you think it will be a really tough appointment. I've experienced this a few times.”*

### C2

*“First impressions. I don't know what age we're stuck in [where they live], but people see me and immediately make judgements. I'm not like that with people and I expect the same in return. But can you believe in the past year I've had two experiences where people think I can't speak English, it's unbelievable isn't it. This is the kind of challenge you're faced with. So if people have this impression of you, obviously the discussion that continues from there is going to be different than if they were having this conversation with a white person for example.”*

## Importance of care continuity

### Carer

***“Sometimes primary care is not sure what secondary care is doing, who might not know what the community paediatrician is doing, who then might not know what the school nurse has said. You find yourself constantly repeating, repeating.”***

Self-advocates generally expressed that they were treated fairly in healthcare settings, however, the experience was better when seeing consistent and familiar staff. For example, one self-advocate spoke of the importance of being able to consistently see their pharmacist, who they “trust[ed]”.

### P3

*“They are nice to me [doctors] but now I see different people”.*

### P2

*“They are very friendly at my doctors. They smile at you. That makes me feel happy. I know the name of one of the receptionists (smiles)”.*

## Findings

### P3

*"I feel happy if they tell me I have done good. It's good to get to the doctor for check-up and the foot doctor for toenails to get them cut if they get too big".*

### P8

*"The one person I trust at the pharmacy is leaving".*

Carers and self-advocates reported barriers in primary care which ultimately led to worse access and experiences of care. An important barrier was not being able to consult the same named GP or healthcare professional. This resulted in patients having to repeat information to different primary care professionals, and in some instances, required the patient to travel to different GP practices. One carer, who described having a "supportive" GP, questioned who people turn to for support when they "do not have this connection with their GP?".

### 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."*

### P8

*"The doctor's surgeries are all joined up so you can be sent to a different medical centre."*

### P8

*"The GPs don't know who I am when I go and see them."*

Barriers around accessing GP appointments were also reported. In some instances, instead of being able to consult a GP directly, people were signposted to other primary care services. For example, one self-advocate described being referred to walk-in services to address their health needs, whilst one carer was consistently informed to first seek advice from the pharmacy in relation to her brother's health needs. The carer expressed that visiting a pharmacist was an impersonal experience which lacked privacy.

### 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."*

## Findings

### 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. So, I’m not happy with the way things are going with consulting with the doctors. You have to have a consultation with the chemist first and then they’ll refer you back to the doctors before the doctors will even have a look. For me, everything fails there.”*

This lack of “confidence” and access to GP appointments ultimately led to some people self-diagnosing and self-medicating with health issues that they deemed to be minor. Carers also expressed that they had to become resourceful by obtaining health care advice and support from third party organisations, in the absence of support from primary care professionals.

For instance, one carer reported how they sought support from a third-party organisation following a failure by the GP to review their child’s medication that was prescribed after a traumatic surgery. This third-party medical professional advocated for the child to be prescribed a more suitable medication, which the carer described as life changing.

A different carer described how they self-referred their loved one to a conference where a specialist nurse was in attendance. This interaction with the specialist nurse taught them how to best manage this health condition, following previous unresponsive help from health care professionals.

## Discrimination outside of health and care settings

Self-advocates provided examples of discrimination and unfair treatment that they received outside of health and care settings. For example, in one workshop, self-advocates spoke of discrimination experienced when using transport, which impacted their ability to socialise with friends and family and attend healthcare appointments. The consensus of the group was that transport staff should receive training to ensure that they are operating and communicating in an inclusive way to minimise discrimination.

### P12

*“Sometimes the bus does not turn up and waiting for long times. 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 my wheelchair].”*

## Findings

In addition, one self-advocate also expressed concerns about financial exploitation from strangers. However, people reported experiencing lower levels of discrimination 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. It's important to keep safe."*

### P2

*"When I lived (in a different area), there were not many ethnic minority people. There was discrimination. I reported this to my care manager...No problems [here] with racism. There are more ethnic minority people here".*

## Community and family networks

The second theme refers to community and family networks (see Appendix 4 for accessible version). It was evident from the experiences of self-advocates that support from community and family networks was pivotal for general health and wellbeing. Support from self-advocacy groups was particularly important for people who lacked frequent family support; however sometimes culturally appropriate services were unavailable. Carers also expressed that they lacked support from their wider family and within their communities, which resulted in feelings of isolation. Below, we present three sub-themes of community and family networks, which relate to disconnection with a changing world, isolation and stigma, and barriers to community engagement.

### Disconnection with a changing world

Self-advocates considered community and family networks to be important for general wellbeing and helping to use healthcare services. Having a family member or carer present for healthcare appointments was important for providing emotional support and being able to communicate when healthcare professionals failed to do so in an appropriate manner. However, accessing consistent support from these networks was often challenging in the context of a busy and changing world.

### P1

*"I go to appointments by myself and nobody goes with me...my mum used to take me to all my appointments but now she's not there I have to go by myself. I can't ask my brother because he's busy and he works from home".*

### P3

*"Family help me but everybody's busy now".*

## Findings

### P6

*“Living with friends (in supported living), 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”.*

### P2

*“Before when I lived in a different area to this area, 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”*

Regular contact with a learning disability 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. When she wants to give me something I will see her, but most of the time it’s my support worker”.*

### P6

*“Staff (support workers) help me book appointments [at GP] ...Going to the dentist is not too bad. If I want help, I try to take somebody with me”.*

### P3

*“I can phone my key worker for help if I don’t understand information”.*

### P2

*“I meet people in another group for people with learning disabilities. Yes, I have met a lot of people going to this”.*

However, one self-advocate expressed that they lacked support from family and support workers. This was particularly troublesome when attending healthcare appointments, and this participant voiced that it would be valuable to have a member of staff of the same gender supporting them through their appointment.

## Isolation and stigma

Carers, who described their ethnicity as Pakistani, Indian and Asian (see Table 2), reported that their personal experiences did not typically align with the community and family network findings generated from the scoping review. Specifically, the carers expressed that they did not have the traditional extended family network that was portrayed about ‘South Asian’ people. These carers did not receive support for their caregiving duties from family members and highlighted their limited support network. As such, from their perspective, this view of ‘South Asian’ families depicted by the research is outdated and stereotypical.

## Findings

### C2

*"I think it's completely different for some people now because we don't have that traditional extended family image that was always portrayed about South Asians. I don't know how you feel about it [C1], but it is not like that. I don't know, to give you an example, trying to get respite is so difficult for me if it is not within my nuclear family. I have got extended family, I have got parents, a lot of my husband's family are here but it's just not like that in terms of support."*

### C1

*"I completely agree with [C2] on that. I have been very much on my own with my son and my other boys. I do have my parents, but they live quite far away and they are my only source of respite. They do come and support when I need it, but other than that I wouldn't say we have a huge network that's waiting for me to cry out for support. It really isn't there."*

One carer, who has cared for her brothers with a learning disability for 27 years, also felt that this stereotype was held by health and care workers.

### C3

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

Due to this limited network and support, the carers described a sense of isolation, not only within their immediate family, but also their communities. For example, the carers expressed that learning disability was still somewhat considered a "taboo" within their communities, which impacted the ability for the people who they cared for to integrate within their community.

### 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. That can cause isolation for people."*

Two mothers who participated in the same workshop discussed how they encouraged their children to attend community activities and events, such as visiting places of worship and weddings. In the mothers' opinions, showing that their children were part of the community helped to alleviate some of these issues surrounding integration and acceptance.

### C1

*"I did feel quite isolated when my son was quite young. But over the years because I have not shied away from [my son's] disability and I've never hidden it, you know he's there everywhere we go he gets dragged along whether we like it or not, so he does go to Indian weddings and functions"*

## Findings

*and whatnot, so over the years people have grown to accept that he is there, he is visible, he is a part of the community. But I still feel quite isolated from the wider [South Asian] community.”*

However, these carers established their own networks for their children that were outside of the “mainstream”. The mothers reported that their children’s social networks were mainly comprised of friendships acquired through school, youth clubs and support groups. They expressed that their children felt more “comfortable” socialising with friends with a disability outside of their communities, possibly due to these feelings of stigma associated with learning disability within their community.

### 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 kind of the community that he hangs around with than what I would anticipate my other children would be hanging around with.”*

## Barriers to community engagement

One participant, who cares for her two brothers, stressed that it was important for her brothers to engage in cultural and religious activities. This was also deemed to have the added benefit of building “support” within the community. However, this was challenging in the context of culturally inappropriate services. Specifically, this carer highlighted the barrier of engaging in religious activities when services do not provide workers of a similar cultural background.

### 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. My father used to take them but I also want the community to see and support and make those circles of support. 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.”*

Moreover, this carer highlighted that there was a lack of culturally appropriate support and self-advocacy groups for her brothers to attend, which limited their opportunities for social activities and engagement.



## Findings

### 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 [a learning disability charity] but it’s not easy. There’s only so much I can do, I can’t change the world can I? I can only do whatever is in my capacity.”*

Self-advocacy groups and work were identified as two important ways for self-advocates to meet new people and to socialise.

### P12

*“I go to [local self-advocacy group] on Tuesday and Friday and we do different activities. We do meetings, we do drama, we go to nightclubs ”*

### 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.”*

However, a potential barrier to attending self-advocacy groups was the time of the day in which activities took place. In one workshop, the self-advocates asserted that their local self-advocacy group finished at 9 pm, which may prevent people from attending. The self-advocates expressed that they would prefer attending activities that took place during the day as they did not feel comfortable being out during the evening. A self-advocate from a different workshop also expressed that he disliked going out during the evening due to previous experiences of financial exploitation.

### P12

*“I don’t like going out during the night-time. I like going out during the day.”*

### 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. It’s important to keep safe.”*

## COVID-19

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The third theme refers to COVID-19 and the subsequent effect of the pandemic on access and experiences of health and care services (see Appendix 4 for accessible version). It was noticeable from self-advocates’ and carers’ experiences, that difficulties with access were exacerbated during the pandemic. For some carers, gaining help and information from services was

## Findings

a constant battle and only achieved during severe times of crisis, and due to their own perseverance. In addition, self-advocates spoke of the loneliness and uncertainty caused by the abrupt and prolonged reduced access to support networks. We have generated three subthemes which explore reduced access to services, loneliness and uncertainty, and barriers to vaccination.

### Reduced access to services

Problems with accessing help were exacerbated due to the pandemic. Self-advocates and carers expressed heightened difficulties in accessing timely support from health and care services.

#### 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."*

These difficulties in accessing help also extended to external care agencies. The family carers who relied on external care agencies to provide support, spoke of the detrimental impact on themselves and their loved ones once this support was halted due to the pandemic. They described the emotional and physical impacts of having this additional load to bear, whilst maintaining their already busy lives. One family carer described this as the "toughest time of our lives", as they went from having support in place to nothing.

#### C3

*"Both of these young men, on their care plan, have 1-1. That is what is written for them. So as an individual, I can't possibly provide their needs throughout the day because it is too much."*

This lack of support resulted in the family carers having to consistently request help. It is important to note, however, that these struggles existed for carers prior to the pandemic, and they merely intensified following restrictions.

#### C3

*"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 from health and care services during the pandemic, some carers also reported a lack of information about COVID-19.

## Findings

### C3

*“The only information I’d got [about COVID-19] was through a letter or whatever information I could glean from TV on the news.”*

One carer reported that this lack of information extended to detecting “soft signs” and how to care for someone medically vulnerable if they contracted COVID-19. In the absence of government guidance, this carer was able to obtain training regarding the recognition of COVID-19 symptoms from a third-party organisation.

### C3

*“When they did become ill and have COVID, it was like what do I do now? How do I support them? I mean even to the basic facts of not knowing how to check their breathing, it was later on that I understood and got training from [local support group] about how to check the oximeter.”*

### C3

*“It’s about not knowing what to do... All the news was saying was stay at home, keep yourself protected but nothing about what changes to look for. So things were getting worse and worse because I didn’t know if his breathing was getting worse and I needed to get him to hospital. That’s why most of the people were getting so ill and ended up being in hospital.”*

## Loneliness and uncertainty

Family carers also spoke of the subsequent negative effects of restrictions and reduced access to services on their loved ones, who struggled to adjust to remaining indoors and understand why their usual activities were disrupted. In one instance, a carer reported how her son felt “discriminated” against as he believed he was being punished by not being able to engage in his usual activities prior to the pandemic.

The restrictions caused self-advocates to feel “forgotten”, “ignored” and “isolated”, given that it was difficult for people to see their friends and family. Self-advocates also described feeling overwhelmed and scared during the pandemic and had “a fear of leaving the house due to COVID”. However, one self-advocate voiced that this was not limited to people with a learning disability, and that all vulnerable people had been negatively affected by the pandemic.

This sense of loneliness was also described in relation to decision-making for family carers, e.g., sole family carers being faced with the burden of making important health decisions on behalf of their loved ones (like vaccines) in the context of the uncertainty experienced during the pandemic. This emphasised the difficulties faced by family carers, and the importance of providing individualised, culturally sensitive support for healthcare related decisions.

## Barriers to vaccination

Given the existing literature surrounding vaccine hesitancy, we also explored why some people from ethnic minorities may have been unwilling to receive the COVID-19 vaccine. The explanations that participants provided to explain vaccine hesitancy were manifold. Reported barriers to vaccination included complacency, mistrust and fear. One carer spoke of how their experiences of bereavement during the pandemic prompted them and their loved ones to become vaccinated.

### C3

*“I said no I’m not gonna go and my brothers are not gonna have the vaccine. But it was when I lost my mother-in-law and my husband was close to death that I thought \*expletive\*, excuse my language, I need to protect my brothers and myself.”*

Among self-advocates, the general consensus was that a fear “of needles” and a fear “it will make them sick” may prevent people from receiving a vaccine. However, carers reported a wider range of barriers to vaccination, such as complacency and mistrust. In one instance, this sense of complacency and not immediately recognising the need for the vaccination stemmed from a lack of information about the potentially serious consequences of the virus.

### C3

*“When COVID had just started, I was thinking no [I’m not going to receive the vaccine], if it’s just washing our hands and wearing a mask and stuff. Again, it was about will my brothers keep a mask on and if they’d take to it. So I mean, it all trial and error. I said no I’m not gonna go and my brothers are not gonna have the vaccine.”*

Some carers also spoke of their prior unwillingness to receive the vaccination due to issues around misinformation, mistrust and the media.

### 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.”*

## Transitional Care

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Due to overlapping sub-themes, for the fourth theme, the findings were integrated from both transitional care between services and transitional care from child to adult services (see Appendix 4A and 4C for accessible versions).

## Findings

Carers spoke of their experiences of health and care services, and in particular, a lack of support and information during periods of transition. This lack of information had resulted in the carers of younger children fearing the transition to adult services, particularly from a health care perspective. A noticeable barrier which emerged from the two independent transition themes focused on the importance, and lack of, communication between healthcare services. Thus, the three sub-themes that are outlined below focus on a lack of information and support, disconnect between services and a fear of the future.

### Lack of information and support

A consistent theme from people's experiences was a lack of information and support about most aspects of health and care services. This lack of information was particularly troubling for the carers whose loved ones would be transitioning from child to adult settings. Carers spoke of the barrier of not being able to access information pertaining to the transition to adult settings. One carer reported that a multitude of services were unable to provide this 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 whose loved one had transitioned to adult settings reported that more supportive and efficient health care was delivered whilst under child services. In particular, they noted much longer waiting times for treatments since being seen under adult settings and a lack of compassion.

This lack of information and support was not limited to health care settings. One carer spoke of the "big gap" when their loved one was transitioning from school to day 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. And not knowing which group was going to be taken for him. 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 who participated in the project had personal ties to health care. They both acknowledged that despite "living in the world of medics", they still did not understand the system, and stressed the importance of knowledge.

## Disconnect between services

People also spoke of a disconnect and lack of effective communication between services, which in some instances, resulted in substandard care, and information having to be consistently relayed by the patient.

### C2

*“For me one of the key things is communication, and that can be said for everything. There’s still so much disconnect, between, not just all the services that our children use, but even in health care, there’s a disconnect between primary, acute and community health care. 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 with people.”*

This disconnect between services was apparent from one carer’s experiences of their loved one being discharged from hospital. Specifically, they reported that no support was put in place, and they struggled to receive support from primary and secondary care services. Ultimately, this carer stressed that they were left to manage by themselves.

However, 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. Subsequently, the carer had to re-write the information contained within the hospital passport and the carer arranged for their usual Personal Assistants to support their loved one whilst in hospital.

### 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 1 to 1 and he’d abscond and move out of bed when he felt a bit better. When I pointed this out to the clerk, the nurse in charge, she said you should have told me this earlier, I could have put someone in place. 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 when I’m really tired? You don’t get your loved one to hospital until it’s a dire need and you’ve obviously worked hard enough to try and sort things out so that they don’t need to go to hospital.”*

Effective communication was considered to be important among participants, and self-advocates reported positive experiences when referred to services which were nearby and when care plans were clearly communicated.

### P3

*“I used to travel far for my eye test, but now I go to a better one which is closer.”*

### P2

*“They have given me information about my eye problem at the hospital. They give me information on how I can ask for help and where to get help in the future.”*

## Fear of the future

Ultimately, this lack of effective communication and knowledge resulted in carers fearing for the future. Carers whose loved ones had already transitioned into adult services were doubtful of positive experiences of care in the future. Furthermore, carers of younger children acknowledged that they were “apprehensive” about this 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. This is kind of my experiences of this with my son.”*

### C2

*“I don’t really have a lot of experience because [my 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.”*

In addition to a lack of knowledge, issues around an understanding and consideration of learning disability and individual differences fuelled one carers’ fear of transitioning into adult healthcare services.

### C1

*“[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.”*

As learning disability nurses have an enhanced understanding of learning disability and are integral during transitional periods, carers expressed that their experiences of health and care services could be improved if they were able to access support from learning disability nurses. One carer reported that this would have been particularly beneficial when her brother was admitted into hospital.

## Findings

### C3

*“If there was a disability nurse with all the surgeries, at least I’d know to access someone like that before they went into that [hospital] system.”*

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].”*

### C3

*“In my experience, there is not enough learning disability nurses.”*

There were also fears about the transition into adulthood from a community and family network perspective. One carer spoke of how she is trying to escape the stereotype within the community that her son will “always stay at home because that’s what Asian families do”.

### C1

*“I think there’s also that assumption that we will keep our children at home forever and a day but actually I don’t want to do that. I have two other children, one younger and one older. I hope that [my son] will somehow find semi-independent or some kind of supported living. So I want to move away from this whole concept of he’ll always stay at home because that’s what Asian families do. I’m trying to break away from that but that’s quite difficult to do as there’s a lot of pressure. I do feel a lot of pressure from external people saying ‘oh he’ll always be home with you, you don’t need to worry’. But I’m thinking maybe he doesn’t want to live at home with me or maybe I don’t want him to be at home with me all the time. So this can be kind of difficult as well.”*

## Learning Disability Register

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The fifth theme refers to the learning disability register. GP practices have a list of their patients known to have a learning disability, which facilitates access to appropriate support (see Appendix 4 for accessible version). For example, being recognised on the learning disability register provides eligibility for annual



## Findings

health checks and priority for flu jabs and vaccines. It was evident from people's experiences, however, that generally there was a lack of awareness of the learning disability register, among both self-advocates and carers. Whilst self-advocates and carers recognised that themselves or their loved ones received annual health checks, they were unaware of the existence of the register. Self-advocates identified potential barriers to wanting to be on the learning disability register and expressed that people may be "scared". Thus, two sub-themes are presented below which relate to awareness of the learning disability register and a reluctance of being added to the learning disability register.

### Awareness of the learning disability register

Participants were generally unaware of the learning disability register and expressed that they had received no communication or information pertaining to it from health care professionals.

#### 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."*

#### P9

*"I'm not sure if I'm on [the learning disability register]...nobody has spoken to me about it."*

Some participants expressed that it would be beneficial to increase awareness of the learning disability register and how it operates. For example, one self-advocate and their support worker commented that they were unsure how people are added to the learning disability register, and if this was a personal choice or whether GP's do it. Additionally, one carer highlighted that communication about the learning disability register within her community would be valuable.

#### 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. Specifically, some self-advocates were unaware of whether they had previously received an annual health check, due to a lack of effective communication from healthcare professionals.

#### 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.”*

## Reluctance of being recognised with a learning disability

Self-advocates and carers also spoke of the barriers of being added to the learning disability register. Self-advocates agreed with a carer’s sentiment that there can be a sense of “reluctance” among people from ethnic minorities wanting to be recognised as having a learning disability. Self-advocates identified two reasons for such reluctance; specifically, a fear of being treated differently in health and care settings, as well as not “wanting outside help” and wanting to be “looked after by their family”. 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?”*

## Digital Access

The sixth theme explores digital access (see Appendix 4 for accessible version). By digital access we mean technology supported interactions between health care providers and patients or carers in different locations and may include the use of a computer or telephone. The COVID-19 pandemic accelerated the provision of digital and remote healthcare. However, little is known about how this shift may have affected the access and experiences of healthcare among people with a learning disability from ethnic minorities. Self-advocates expressed that whilst they have mainly adjusted to using digital technology for health and care purposes, they still require support as it was deemed to be “complex to use”. Additionally, both carers and self-advocates reported a shortage of accessible healthcare information online. Participants stressed that being able to engage with health and care services digitally should be a personal choice, that is inclusive of their needs. Two sub-themes are outlined below which focus on digital exclusion and choice and control.

### Digital exclusion

Self-advocates acknowledged that prior to the pandemic, there was not as much of a requirement to engage with health and care services digitally. Whilst 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 to access online meetings.

#### 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.”*

#### P5

*“People with learning disability don’t have competency with computers.”*

Both self-advocates and carers reported issues with the accessibility of online healthcare information. These issues were two-fold. First, it was described that there is a “minefield” of information online that may not be relevant. Second, people reported that there was a lack of digital easy read content pertaining to health information. Ultimately, participants stressed that more easy read material should be made available that avoids “jargon and medical terms”.

#### 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.”*

#### C3

*“When you google stuff, some information is inappropriate, and it can be a minefield of information that doesn’t always relate to you and it can frighten you.”*

### Choice and control

Both self-advocates and carers voiced that it needs to be a personal “choice” to see a medical professional in person or to engage with health and care services remotely. They acknowledged that in some instances, a remote consultation (telephone or video for example) is advantageous, for example if people lack support when attending healthcare appointments. However, on some occasions, an in-person appointment is preferred, such as regarding medication management or for a GP appointment. There were concerns that digital appointments may impact the co-productive approach between a patient

and a clinician, which may hinder desired outcomes. Self-advocates generally highlighted that they “still want that personal contact” that comes with an in-person appointment.

## The LeDeR programme

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The final theme refers to the ‘Learning from lives and deaths – people with a learning disability and autistic people’ (LeDeR) programme (see Appendix 4 for accessible version). Previously known as The Learning Disability Mortality Review, the programme was established in 2017 to review the deaths of people with a learning disability in England. The aim of these annual reviews is to learn from the deaths of people and minimise ‘avoidable deaths’ by improving the care of people with a learning disability and/or autism. As the workshops were guided by participants and focused on the issues most pertinent to their experiences, discussions about LeDeR were limited to highlighting a lack of knowledge of the programme. Both self-advocates and carers reported that targeted information about LeDeR to raise awareness of the value of the programme would be beneficial.

## How can services be improved?

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### Carer

***“It all starts with good communication.”***

A central overarching theme which emerged from the workshops was individualised and flexible communication. We asked participants how health and care services could be improved so that they can be more responsive to the needs of self-advocates and their carers. Reoccurring sentiments focused on the provision of accessible information, effective communication, a need for clinicians to have an enhanced understanding of learning disability, as well as having standardised approaches across healthcare services, which recognise the diverse experiences of people from ethnic minorities with a learning disability.

A prominent barrier to inclusive and responsive healthcare, that was central to several core themes outlined above, was a lack of effective communication. Effective communication was deemed to be pivotal for the delivery of person-centred care and was particularly important in two ways. Firstly, both carers and self-advocates expressed that it is important for health and care staff to consider an individual’s needs from the first point of contact. Establishing such a discourse and understanding how people want to be addressed helped

## Findings

ease anxiety whilst attending appointments. Having this communication is also important for the allocation of resources, such as the need for an interpreter.

### P1

*“There are good doctors and nurses in my surgery. It makes me feel better when they talk to me...[this] makes me feel less worried.”*

### C1

*“I think I’ve only ever had one person say that to me, 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.”*

### 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.”*

A second aspect of effective communication is to validate the individual at the centre of care and respect their communication needs. A barrier to inclusive healthcare among self-advocates was a failure by clinicians to communicate with people with a learning disability in an appropriate format, as they often used “medical jargon” during appointments. Further to this is respecting the ‘triangle of care’. Whilst carers and supporters play a vital role in supporting the individual, it is important to establish a dialogue with the individual at the centre of the care, and not solely rely on their supporters to provide information.

Carers reported positive experiences of care when the clinicians had an enhanced understanding of learning disability. Such carers voiced that their and their loved one’s experiences of health and care services would be improved if the services that they used had staff with this deeper level of understanding.

### 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 me son’s life so much easier, he wouldn’t feel anxiety, and I, as his carer and the person who’s then got to go through that process*

## Findings

*with him, it would certainly relieve me of the anxiety when going to a different appointment.”*

### C3

*“The learning disability nurse I met... So much pressure comes off your shoulders when someone understands what you’re saying.”*

### P1

*“There are good doctors and nurses in my surgery. It makes me feel better when they talk to me...[this] makes me feel less worried”*

## Additional insight from the working group

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The working group provided additional insight into some of the core themes outlined above and findings from the workshops. Part of this discussion involved how to overcome a lack of awareness about the learning disability register. This feedback is also useful in understanding how to increase awareness of the LeDeR programme.

The working group expressed that education, and “spreading awareness of the advantages of being on the register” is vital in overcoming this reluctance of wanting to be recognised as having a learning disability. However, they stressed that it is important that information is portrayed in an accessible format, such as in easy-read and in an appropriate language, and that the information is delivered by “trusted” figures within the community.

In their opinion, much more than a “leaflet” is required to create awareness in underserved communities. The group spoke of how during the COVID-19 vaccine drive, the NHS worked with community and local groups to disseminate information regarding vaccination. One self-advocate described how this was a beneficial process, and the group concurred that tailoring targeted information within communities would be an inclusive way of creating awareness of the learning disability register.

### Self-advocate

*“The first one I had was in a Mosque. A lot of Iman’s and faith leaders were there to say it was a good thing. There was a lot of hesitancy, but I think going to the communities helped.”*

# Conclusion

**This research has sought to explore the complex factors which contribute to inequalities in healthcare that are experienced by people with a learning disability from ethnic minorities.**

The inclusion of both self-advocates and carers has provided an insight into different perspectives regarding the barriers to healthcare that are experienced by people with a learning disability from ethnic minorities. However, we have been limited by the views that we have been able to capture, as it is likely that people experiencing higher levels of marginalisation may have different experiences of health and care services. For instance, only the views and experiences of carers and self-advocates who were able to speak English took part in the workshops, though effort was made to facilitate access. Similarly, we were unable to access the views of certain communities (Jewish and Roma for example). A further limitation was that we may not have captured the experiences of self-advocates who, in a medical sense, have more profound disability. It is also recognised that, by the nature of our recruitment, most workshop participants had pre-existing involvement with community support networks. Therefore, these findings may not necessarily represent the voices of people with limited or no self-advocacy support.

Participants provided examples of experiences that could be perceived as discrimination based on disability. There are organisational barriers which impact the access and experiences of care, as healthcare services are inherently discriminatory against people who have additional needs. For instance, the reliance on technology supported interactions between healthcare providers and patients creates an instant barrier for people who may not be digitally literate.

Despite the 2010 Equality Act mandating reasonable adjustments should be anticipatory (they should happen before the first point of contact) for people with a learning disability, it was apparent from people's experiences of care that reasonable adjustments were not always implemented. This is particularly important for people with a learning disability from ethnic minority groups, where routine ways of working puts some people off using a service, or makes it pragmatically very difficult or impossible to access services. Ensuring that reasonable adjustments are enforced will help alleviate barriers to health care for all people with a learning disability.

Learning disability liaison nurses are also integral for improving the care of people with a learning disability. However, a running theme throughout the workshops was inadequate access to learning disability liaison nurses, which

## Conclusion

were likened to a “mythical creature”. Learning disability liaison nurses may have a greater role in addressing the needs of people with a learning disability in ethnic minority communities.

Alongside discrimination on the grounds of disability, people can also be discriminated against due to their ethnicity. How ethnicity is understood or expressed is complex and perhaps reflected by the data gathered from the participants, with some choosing not to disclose and others defining ethnicity by their cultural heritage, nationality and or religion and when talking about different communities or themselves, using terms such as ‘Asian’ and ‘South Asian’. Additionally, defining discrimination based on ethnicity, particularly for those with a learning disability, can also be a difficult concept to explain though knowing you are being treated differently/unfairly was not. Overt discrimination within a health and social care setting is unlikely to be experienced but more subtle manifestations harder to pinpoint. Additionally, due to the intersectional nature of discrimination, this can also encompass additional factors, such as age and gender. Therefore, as discrimination is multifaceted, it can be difficult for people to recognise and understand the source of the discrimination that they experience.

### Carer

***“It’s just so obvious sometimes isn’t it, but I didn’t think it was obvious when it [discrimination] first happened. Isn’t that strange? I always give people the benefit of the doubt when I experience these things and discrimination and racism because I still experience it a lot.”***

Many of the findings from this work are in line with the previous literature outlined in the scoping review; which suggests that both self-advocates and their carers experience disparities in healthcare. Reported barriers to responsive and inclusive care included: a lack of effective communication resulting from a failure by clinicians to modify their communication style, a lack of easy read information and a lack of information during periods of transition. In culmination, these consistent experiences led to some carers fearing for the future for their loved ones.

However, our findings around the community and family network theme contrasts with previous literature. For example, Bhardwaj (2017), in a mixed-method study about social network composition, found that ‘South Asian’ (Indian, Pakistani and Bangladeshi) people with a learning disability had more family members in their network than their ‘white’ counterparts. However, the family carers that we spoke to reported that their personal experiences did not typically align with the findings generated from the scoping review. Specifically, the carers expressed that they did not have the traditional extended family network that was portrayed about ‘South Asian’ people and highlighted their limited support networks. In the carer’s opinions, this stereotype was also held by healthcare workers.



## Conclusion

It is evident that the recent changes in health care services adopted during COVID-19 restrictions, transformation as part of the digital innovation and restructuring based on efficiencies has often had detrimental effects for people with a learning disability and more so for those from ethnic minority populations. Access to care is met with additional hurdles with no obvious reasonable adjustments offered. This is compounded by communication difficulties.

Many institutions including the NHS now recognise as part of their Equality, Diversity and Inclusion strategy the importance of recognising the intersectionality disadvantages faced by many in our society and as such have begun to offer training to raise awareness of such issues. However, the quality, consistency and impact of such training, even within the NHS, is limited.

## Recommendations

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### Actions for NHS England:

- All organisations providing health and care for people with a learning disability must meet their statutory requirements of making reasonable adjustments, in line with the Equality Act 2010 to facilitate access to services.
- NHS England and its partners should run an awareness campaign to explain to people with a learning disability and their carers from ethnic minority groups the value of being on the GP learning disability register and attending yearly health checks.

### Actions for integrated care systems and boards:

- Integrated Care Boards should commission culturally appropriate community-based support and self-advocacy groups – these groups should support meaningful patient and public involvement.
- Integrated Care Boards should ensure they have sufficient representative learning disability nurses employed within their geography to support the diversity of their local populations.

### Actions for NIHR and other research bodies:

- Specific research should be commissioned to explore discrimination and the role racism plays in the unequal care outcomes experienced by people from ethnic minority groups with a learning disability.
- Research should be commissioned to understand the ethnicity and geographical distribution of learning disability liaison nurses compared to the communities they serve.

# References

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