

Small Margins

Working with people with a learning disability and autistic people from minority ethnic communities

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Changing Our Lives is a rights-based organisation. We work in partnership with disabled people and people with lived experience of mental health difficulties to find solutions to social injustice and health inequalities.

All of our work is rooted in the belief that no one is too disabled and that no one's mental health is too complex to lead an 'ordinary life'.

Our approach rests firmly on the social model of disability. As such, we don't believe people's lives should be limited or defined by labels or diagnoses, and we are committed to reframing how society views mental health and disability.

Our vision is of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights, resulting in them being in control of their own lives as equal citizens.

Changing Our Lives' philosophy is underpinned by a commitment to anti-racist practice. Anti-racism is all about taking action to challenge and change racist policies, behaviours and beliefs. In order to make this commitment a reality, we target our resources to benefit communities that experience social injustice and health inequalities on multiple levels.

Acknowledgements

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Small Margins

During Autumn – Winter 2022, Changing Our Lives partnered with Manchester Metropolitan University on a project called Small Margins. This project worked with people with a learning disability, autistic people and their families from minority ethnic communities (South Asian, African Caribbean, Black African and dual heritage) who either lived in their own home (supported living), lived in residential care, or were moving out of inpatient hospital settings. We also included people who lived within the family home as data suggests that proportionally less people from minority ethnic communities live in residential care or supported living when compared with white people.¹

The Small Margins project sought to identify:

- issues relating to ethnicity that affect people's day to day lives in relation to the support they receive, gaps in support and knowledge and the impact individuals and their families see this has on their lives
- future learning

We hope this information will be used by people who commission services, organisations who provide support for adults with a learning disability and autistic people, race related organisations, people with a learning disability, autistic people and their families, and the Care Quality Commission.

We have chosen to use the term 'minority ethnic communities' in this report as this is the phrase we use when we describe our work on a large scale. However, our preference and the preference of people we work with is to recognise the local community we are working with, for example the British Punjabi community. We recognise that no language is ideal and seldom reflects the communities we work with, for example, many communities we work with are not minority in their local area and any label naturally papers over the diversity of experiences and cultures within groups of people.

This is an extension of the original 200 Lives research project, which Changing Our Lives worked on alongside Manchester Metropolitan University, London School of Economics and National Development Team for Inclusion. This research project was funded by the National Institute for Health and Care Research.²

1 NHS Digital (2021) *Adult Social Care Activity and Finance Report, England - 2020–21* <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2020-21>

2 NDTI (2022) *Resources from 200 Lives project: Evaluating supported living and residential care for adults with learning disabilities* <https://www.ndti.org.uk/resources/research-project/resources-from-200-lives-project-evaluating-supported-living-and-residential-care-for-adults-with-learning-disabilities>

Stage one

For stage one of this project, a desktop exercise was performed to gather evidence and good practice from 3 strands of our existing and previous work. These areas were:

Quality of Life Reviews

Quality of Life Reviews are a person centred way of checking how services ensure people with a learning disability and autistic people can lead ordinary lives. Each review is measured against a set of standards that have been produced by people with a learning disability and autistic people. Paid individuals with a learning disability work in the review team.³

Colour Between the Lines

Drawing on oral history approaches and funded by the Heritage Lottery, Colour Between the Lines charted the individual development and successes of 7 disabled individuals from minority ethnic communities who, in spite of societal prejudices and discrimination towards race and disability, have established successful and thriving lives. The project emerged from an awareness of the relative invisibility of disabled people from minority ethnic communities in society and in oral histories, and the need to challenge these gaps in the narrative. As the individuals involved with this project sit at the intersection between disability discrimination and racism, they were able to provide a unique vantage point on the role ethnicity plays in disability and self-advocacy movements.⁴

Equal Treatment

Equal Treatment is an anti-racist training programme funded by NHS England. Changing Our Lives led on 1 of 3 strands of the work with a focus on strengthening self-advocacy. Hosted by Learning Disability England and in partnership with the Race Equality Foundation it encourages people with a learning disability within self-advocacy organisations as well as their management structures, to develop their practice in order to address the stark inequalities faced by people with a learning disability from minority ethnic communities, and to overcome barriers and taboos in relation to understanding and speaking up about racism.⁵ The project is part of wider work the Race Equality Foundation is leading on that is finding the evidence and examples of what will help stop racism or unequal treatment.

3 Changing Our Lives (2017) *Quality of Life Standards & Toolkit* <https://changingourlives.org/wp-content/uploads/2022/09/QOLStandardsandToolkitFeb2017.pdf>

4 Changing Our Lives (2022) *Colour Between the Lines* <https://changingourlives.org/wp-content/uploads/2022/09/Colour-Between-the-Lines-100-high.pdf>

5 Changing Our Lives (2023) *Anti-racism projects* <https://changingourlives.org/our-work/anti-racism-projects/>



Stage two

Stage two involved us speaking with 18 people, including individuals and family members, either one-to-one or in small workshop settings. This included people we knew from previous and existing Changing Our Lives work.

Some of these individuals were chosen from our Future Planning programme, where we work with people with a learning disability and autistic people in locked hospitals across the country. The average length of time that these individuals have spent in hospital is around five years, with some having been in hospital for up to 45 years. Our work in locked hospitals involves person centred planning, rights based advocacy, facilitation and challenging professionals with the ultimate aim of supporting people to move out of hospital into their own home. This can be a very lengthy process. While the ultimate aim is to help people leave hospital, we also work to bring about change in people's quality of life within their existing care and support.⁶

⁶ Changing Our Lives (2023) *Working with individuals* <https://changingourlives.org/our-work/working-with-individuals/>

Who we worked with

Disability

- 7 people with a learning disability, 2 of whom have the label of profound and multiple learning disability
- 4 autistic people
- 3 autistic people with a learning disability
- 4 people who are family members of the people listed above

Gender

- 7 men
- 11 women

Ethnicity

- 4 Black Caribbean people
- 7 South Asian people
- 3 Black African people
- 3 dual heritage people

Where people live

- 1 person living in a residential care home
- 7 people living in their own home with support, of whom 4 have lived in locked hospital settings. 3 of these people have moved into their own home in the last 5 months after living in hospital for between 8 and 45 years.
- 6 people living in the family home

We had conversations with these 18 people to record and understand their lived experience and knowledge of issues that affect their lives relating specifically to ethnicity and the impact this has.

One workshop in Birmingham was attended by people and families from the South Asian community. Another workshop was facilitated in London in partnership with the Disability Advice Service Lambeth, in Brixton. This was attended by people and families from Black Caribbean, dual heritage and Black African communities. We used the workshops to discuss the evidence we had already gathered up to that point, and also to ask individuals for their knowledge and experience.

Areas of learning

Across stage one and stage two of the project we compiled areas of learning that are relevant to the commissioning and delivery of services and individual supports.

Stage one

In stage one, the desktop review of our previous work, we picked areas of learning from 3 strands of our work:

- Quality of Life Reviews
- Colour Between the Lines
- Equal Treatment

Intersectionality

Identity is complex; no one is just disabled. Disabled individuals also have an ethnicity, gender, sexuality and economic background, as well as having other factors which impact on identity such as religion. These aspects of identity are lived simultaneously and this is known as intersectionality. However despite increased awareness of the complexity of identity, when speaking with people with a learning disability, disability is often still seen first and as people's main defining characteristic. Equally because of the way services are configured, disability is still uppermost in the minds of people commissioning and providing services, often to the detriment of other aspects of identity.

Visible and invisible disability

Disabled people we have worked with over the years experienced far less racism if their disability was visible. They told us that people saw them as disabled people first and foremost and as a result experienced discrimination and prejudice linked to disability.

In the 2022 in the Colour Between the Lines publication Monique and Samee reflected on experiences of more experiences of disability discrimination than racism:

"I've seen more discrimination because of my disability than the colour of my skin because people just see the chair and they assume I can't speak or they're afraid to speak to me. When this happens people aren't horrible, it's the silence that hurts the most. I'm very proud of my culture and its traditions. They assume I'm paralysed, that I can't move my legs but I can. They need to turn it around and focus on my abilities and not my disability."

Monique

"I haven't experienced much racism. People tend to look at me and see the chair first and think he won't be able to do things and he won't be able to communicate. When they hear me speak and see me do things, they are shocked. They can see how passionate I am."

Samee

However, generally where the disability may be less visible, for example autism, we have found that individuals experience far more racism. Andrew from Colour Between the Lines experienced more racism as a young Black man as his autism was not visible:

"I mainly experience racism, because people can't see that I'm autistic. I think people make assumptions because I'm a Black man; they think I smoke weed and I might be into drugs...I'm not. There was one time when this guy asked me, 'Where do you come from?' I said 'Birmingham'. He said, 'But where are your parents from?' I said 'Birmingham'. He said, 'But where do your grandparents come from?' I said, 'Birmingham' and then I had enough!"

This experience was echoed in the experience of one autistic woman we spoke to in Stage Two of Small Margins. She told us that at school she experienced a lot of racist bullying until her physical disability and autism were diagnosed at 13 and 15. Then she says that the name-calling moved on to her disability. Once she had a diagnosis of spina bifida people would taunt her about it. She remembers thinking "Oh my god, does this never end?" In her opinion she feels that people tend to focus on either race or disability in their negative opinions of her. "They go for the most obvious thing first and then they move onto the next thing."

Intersectionality and the self-advocacy movement

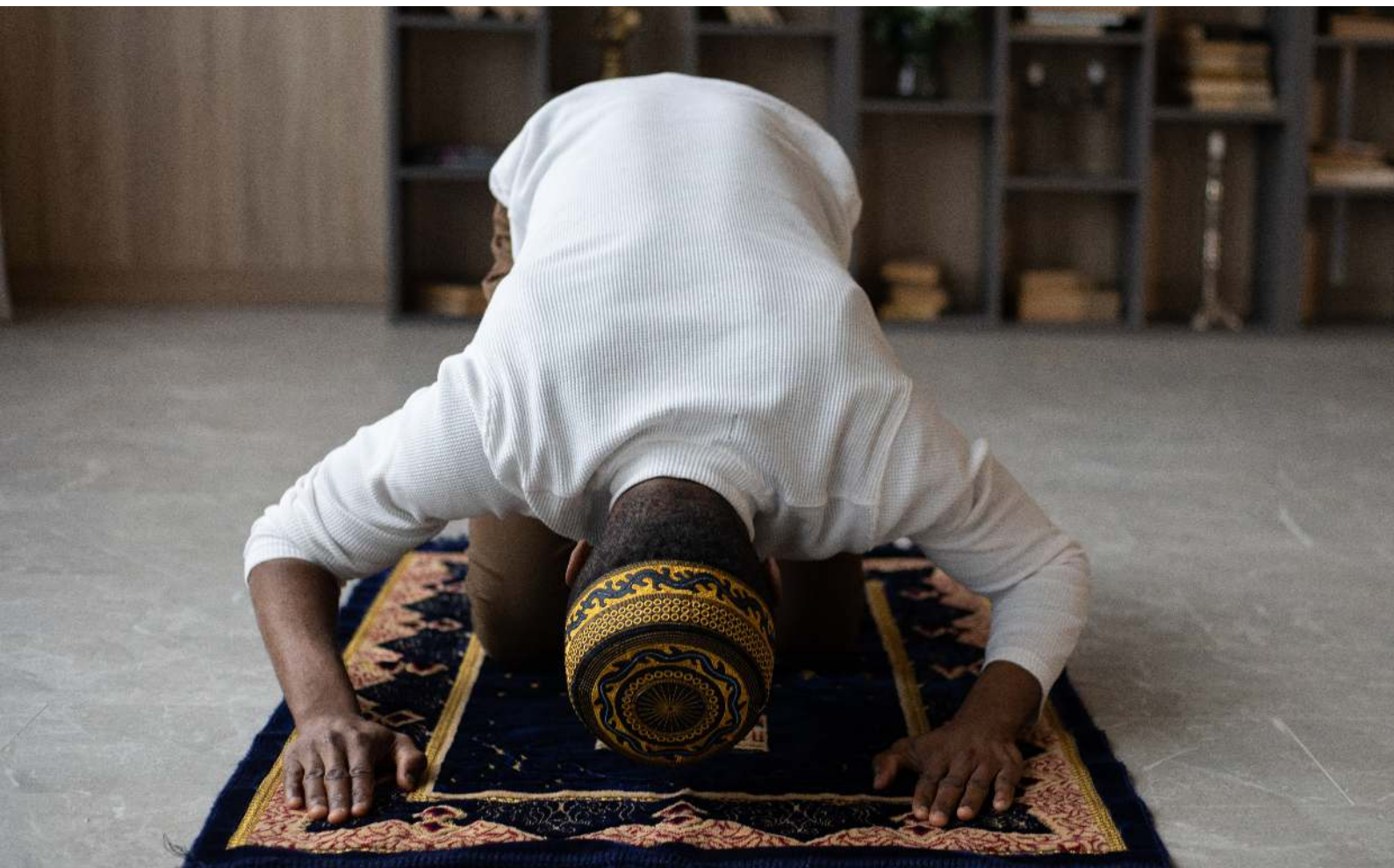
In our interactions with people in the learning disability self-advocacy movement, although great strides have been made over the years by some groups to champion disability rights, there is little if any awareness of racism and ethnicity. Some individuals in the movement have reported to us that if they were to focus on anti-racism, they would be concerned this would take the emphasis away from learning disability.

In Colour Between the Lines, Caprice reflected on the lack of awareness of ethnicity in the disability movement:

"Disabled people always bring it back to disability and think you can understand racism because of the discrimination you have experienced as a disabled person, but it's a whole different experience being disabled and also experiencing racism. In a way being disabled and experiencing racism can make it harder sometimes."

This was echoed in the Equal Treatment training programme delivered to self-advocacy organisations where there was an acknowledgement that the self-advocacy movement for people with a learning disability is a white space. Disabled self-advocates and non-disabled management recognised the enormity of work required to ensure that the self-advocacy movement is both representative at all levels and has a deeper understanding of racism, how this impacts on people lives and how to become anti-racist in their practices.

Self-advocates from minority ethnic communities on the programme were particularly appreciative of the opportunity to talk about racism, often for the first time in their self-advocacy experience.



Challenging myths

Working with people with a learning disability and autistic people in minority ethnic communities, it is important to work in coproduction with people to acknowledge and challenge some of the myths that exist surrounding disability in these communities.

In *Colour Between the Lines*, Monique and Sirraaj spoke about myths in their cultures surrounding disability, which although mainly restricted to older individuals, can be hurtful and need to be resisted:

"It's most likely to be the elderly aunties and uncles where they have said to me, 'Oh, what's wrong with you and why don't you go to the Golden Temple in India and go into the waters to get healed?' I know myself and know what I can and can't do. I enjoy the waters but they will not bring about a cure. Telling people God will heal them gives them false hope. Before I stepped into the disability world I didn't know much about the politics of it. Now I see what a positive impact disability has on people's lives."

Monique

"I've been told 'you will get better' but disability is for life. You can't let disability restrict you; it's part of you."

Sirraaj

Anti-racism

Being 'not racist' is not enough. Anti-racism is not just about hearts and minds. Anti-racism is a life long commitment. Anti-racism is the active work to oppose racism and to produce racial equity – so that racial identity is no longer a factor in determining people's life chances. Being anti-racist means changing systems, policies, behaviours and beliefs.

To be actively anti-racist we need to understand what racism is and what it looks like, the inequalities that exist because of racism, how racism effects people, and understand the part we play - our own beliefs and how we need to change them. If we want to address racism we have to talk about what it means to be white. To take anti-racist action, we need to understand how racism has shaped all of us, particularly by unduly elevating the positions and perspectives of white people.

Race is not a scientific category, but a social construct built on false beliefs, designed to divide and define all members of a racial category. This ideology has been used throughout history to justify racism, and still exists today. However, racial identity is very real. In a racialised society, everyone is assigned a racial identity whether they are aware of it or not. For people from minority ethnic communities this defines a lifelong experience of discrimination and oppression.

For people with a learning disability and autistic people from minority ethnic communities this discrimination and injustice hits much harder, often referred to as double discrimination (at the intersection of disability and race), with much greater disparities in both life chances and life span.

This impacts people's lives in concrete ways. According to The Learning Disabilities Mortality Review 2021, people of Black, Black British, Caribbean or African, mixed ethnic group and Asian or Asian British ethnicity died at a younger age in comparison to those of white ethnicity.⁷ The small sample size of LeDeR makes it difficult to draw conclusions, but this trend has been seen over several LeDeR reviews. It is also notable that white people are overrepresented in LeDeR statistics (91%)⁸ compared with the broader population of the UK (81.7%),⁹ suggesting that more needs to be done to accurately gather data about people with a learning disability from minority ethnic communities.

According to the Race Equality Foundation, people with a learning disability were six times more likely to die from Covid and 40 percent of these deaths were people from Black and Pakistani communities.¹⁰

7 White et al (2022) *LeDeR Report 2021* <https://www.kcl.ac.uk/research/leder>

8 Ibid.

9 UK Government (2022) *Ethnicity Facts and Figures* <https://www.ethnicity-facts-figures.service.gov.uk/>

10 Race Equality Foundation (2021) *Collaboratives on addressing racial inequity in covid recovery: Learning Disability Briefing Paper* <https://raceequalityfoundation.org.uk/wp-content/uploads/2022/09/Collaborative-briefing-learning-disability-FINAL-1.pdf>

A CQC survey of more than 4,000 people aged 65 and over who had used health or social care services showed that older people from ethnic minority backgrounds tended to use services less frequently. 68% said they only used health or social care services about once every 2 to 3 months or once in the last 6 months, compared with 58% of people from White British backgrounds.¹¹

In our Quality of Life work across the years we have come across people with a learning disability and autistic people from minority ethnic communities that aren't aware of their ethnicity and in particular their race, as it has never been something that they have been encouraged to explore or identify with. One individual who had remained for years within services made up of only white people had no awareness he was Black. Equally these individuals and their white friends have rarely had the opportunity to discuss racism and explore anti-racist ways of thinking and living.

None of the individuals we worked with in the Equal Treatment project from self-advocacy organisations had been offered opportunities to take part in conversations around racism prior to our work with them. They were also unaware of any specific work around anti-racism among their support staff.

11 Care Quality Commission (2022) *The state of health care and adult social care in England 2021/22*
https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf



Quality Checking

In the world of 'quality checking' various organisations, some self-advocacy organisations and others that work around a rights based agenda, work in coproduction with people with a learning disability to check the quality of services and supports. In Changing Our Lives we have developed the Quality of Life review which is a person centred way of checking how services ensure people with a learning disability and autistic people can lead ordinary lives. Each review is measured against a set of standards that have been produced by people with a learning disability and autistic people. Paid individuals with a learning disability work in the review team.¹²

Over the past 15 years we have come across the methodologies of self-advocacy organisations who work in the quality checking field. In 2018 we worked with some of these organisations and NHS England on the national quality checking toolkits¹³ and in 2019 we were one of the founding organisations of The Association of Quality Checkers, an umbrella body for quality checking organisations.¹⁴ All of these organisations, including ourselves, are commissioned around people's lives with a learning disability, and disability discrimination and barriers are the main focus of each quality check. To date, we know of no instances in England of a quality check that focused on ethnicity. This means we don't have such a clear picture of the experiences of people with a learning disability from minority ethnic communities within services.

12 Changing Our Lives (2017) *Quality of Life Standards & Toolkit* <https://changingourlives.org/wp-content/uploads/2022/09/QOLStandardsandToolkitFeb2017.pdf>

13 NHS England (2018) *NHS Quality Checker Toolkits* <https://www.england.nhs.uk/publication/nhs-quality-checkers-toolkits/>

14 The Association of Quality Checkers (2023) <http://qualitycheckers.org.uk/home>

Stage two

These are the key findings from our stage two research.

Culturally competent services

Cultural competency is the willingness to learn and appreciate the culture of the individual you are working with, enquire about how the support you offer can be culturally sensitive, and ensure the support you offer is culturally appropriate and celebrates what the individual appreciates about their culture. Being culturally competent will often mean not only working with an individual, but also working with their family and their community. These areas formed part of our conversations with research participants. They are taken from the Care Quality Commission's examples of culturally appropriate care.¹⁵

The learning identified under these cultural competencies comes from the 18 people we spoke to and our work on our Future Planning programme.

People commented on all areas of the cultural competencies, with the exception of 'personal and shared space' and 'shared activities' as these areas did not appear to interest them.

Religious and spiritual practices

For many people, religion is one of the most important defining characteristics of their identity.

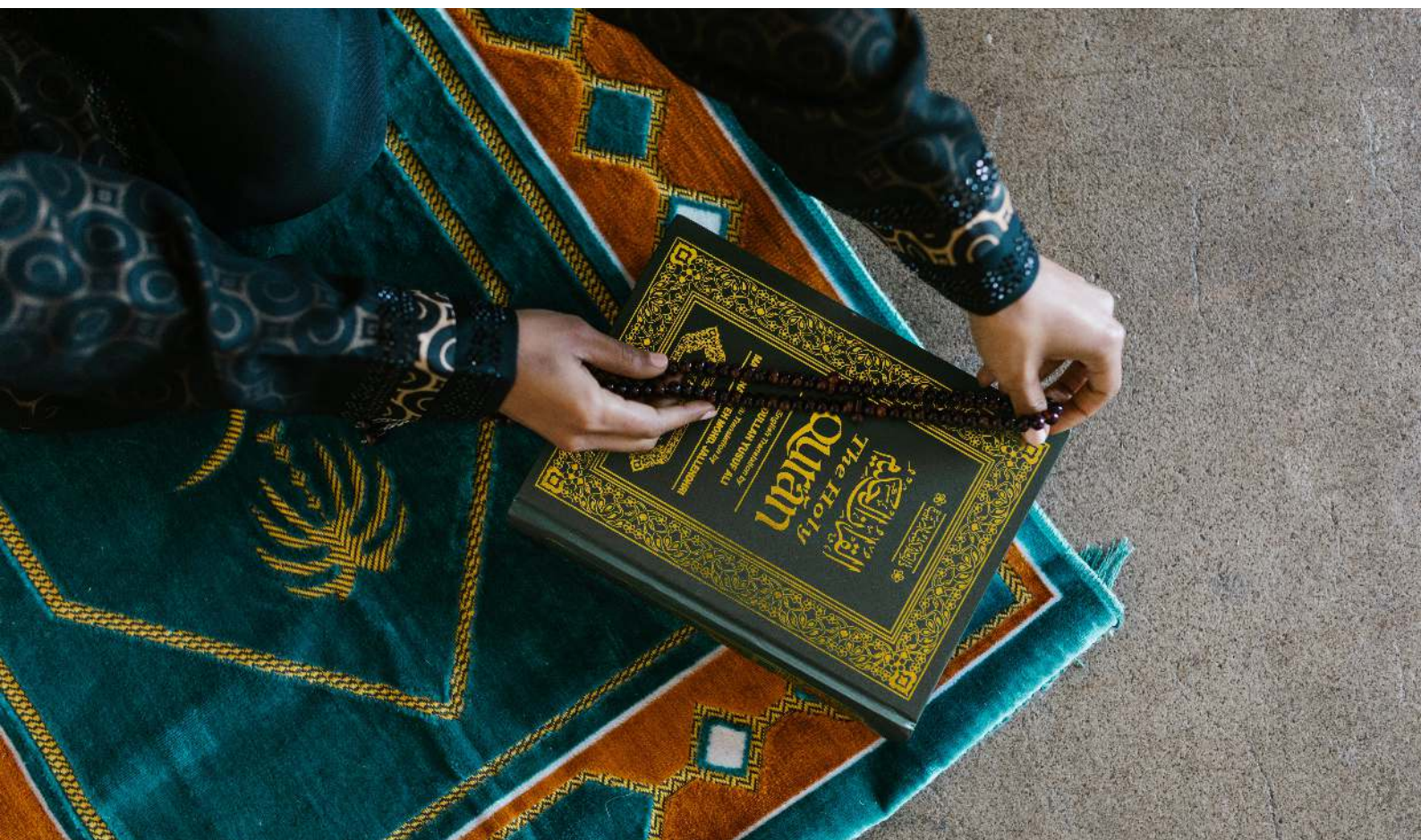
Of the 18 people we spoke with, 13 cited religion and spirituality as playing a part and more often than not an important part of their lives. All of these people have religious beliefs and practices which come with some form of expectation, as they often require support.

"Staff need to be aware of fasting and adapt times when they support around this. For instance staff might need to support me in the evening when I eat during Ramadan."

"I expect staff to know my religious practices, for example I pray 5 times a day. I expect respect from them in relation to this. I need them to respect who I am. I also expect them to have some knowledge. I would also educate them and ask them to be culturally sensitive."

"I go to the prayer room in the main station in Birmingham if I am in town. I've also been to the prayer room in the Trafford Centre. Prayer rooms need to be available and staff need to know where these are when they are out with people. If people pray at home and they share a home, they should not have to just pray in their bedroom. It's a good idea to have carpets in areas where people pray, as it's more comfortable. If people are limited in their prayer, this can mean their cultural identity is lost."

¹⁵ Care Quality Commission (2022) Examples of culturally appropriate care <https://www.cqc.org.uk/guidance-providers/adult-social-care/examples-culturally-appropriate-care>



One person told us she was in foster care from the age of 3 until 20. She was fostered by a white Christian family and says she was not allowed to practice Islam as a child. She says she stopped going to the Mosque when she was fostered and she has never been back.

Another person told us, "Expressing my faith in my own way. In the absence of cultural understanding and difference I have experienced prejudice, racism and discrimination based on the colour of my skin. My personal practices are based on multiple ancient ways and I do not feel that it is fully respected from a cultural perspective which has led to many misconceptions and stereotypes."

In contrast to these negative experiences, another person, B from our Future Planning programme, who has just moved into his own home after years in a locked hospital was brought up within the Christian faith. He was an active member of his Church, spending a lot of time at Church events and with friends from the Church. He knew a lot of people through the Church, and was well liked. B still talks about some of his friends from Church although does not have contact with any of them currently. His faith is still important to him and he was offered weekly Bible reading times within hospital, choosing to take this up half of the time.

B sometimes seeks reassurance around his behaviour, the behaviour of others and the consequences of misbehaviour in terms of the Christian perspective (going to heaven or hell after death) and needs reassurance around this. He also uses particular terms to refer to his relationship with others that are rooted in his faith. It is important to B that people acknowledge the terms he uses, this is written in to his current plans including his person centred plan. His staff team, both at the hospital and his new provider are consistent in reassuring him in these aspects.

Food and drink

Culture, race, and ethnicity are intricately connected to the complex ways that individuals make decisions about food choice. Cooking and eating practices are often not only symbolic but also ways that ethnic identities are preserved in multicultural societies. People from minority ethnic communities often have a strong desire to protect their culture through food practices, especially when their culture is not the dominant culture in that society.

17 of the 18 people we spoke to highlighted the importance of cooking and eating practices in their lives:

"I expect staff to know about Halal meat and how to prepare food, for example preparing Halal and non Halal separately. Also being aware of preparing vegetarian food separately. That's very important."

"People supporting me need to know how we sometimes eat with our fingers and naan bread and sometimes forks or spoons."

Some people spoke of the negative impact of a service not understanding their food preferences and practices:

"I have a restricted diet and I found myself being further restricted around my diet due to lack of choice, understanding of my communication needs, preferences, belief and practice. At one point I was considered as 'non-compliant' and a 'food refuser', and matters nearly escalated into best interest, as I would not eat the food offered on the trolley as there were no options available for me to select from. My needs were not understood."

For the person in the quote above, having their relative involved in the decision-making process allowed vital information to be shared about them, which de-escalated this situation. The information captured was used to implement reasonable adjustments, devise a plan and share information with all staff to create consistency across the staff team.

Another person who is Muslim told us, "There wasn't any belief or religion in the care home. They gave me pork sausage and I used to tell them I can't eat pork sausage, but they kept giving it to me. They didn't understand about my religion. They wouldn't believe me that I can't eat pork."

Some people told us about support staff who share the same heritage as them, cooking with or for them:

E remembered what a good cook her dad was and how he would cook for her before he passed away.

"One of my support workers often cooks Caribbean food for me such as rice and peas, mutton ackee and salt fish and dumplings. I really like her cooking - it is as good as my dad's."

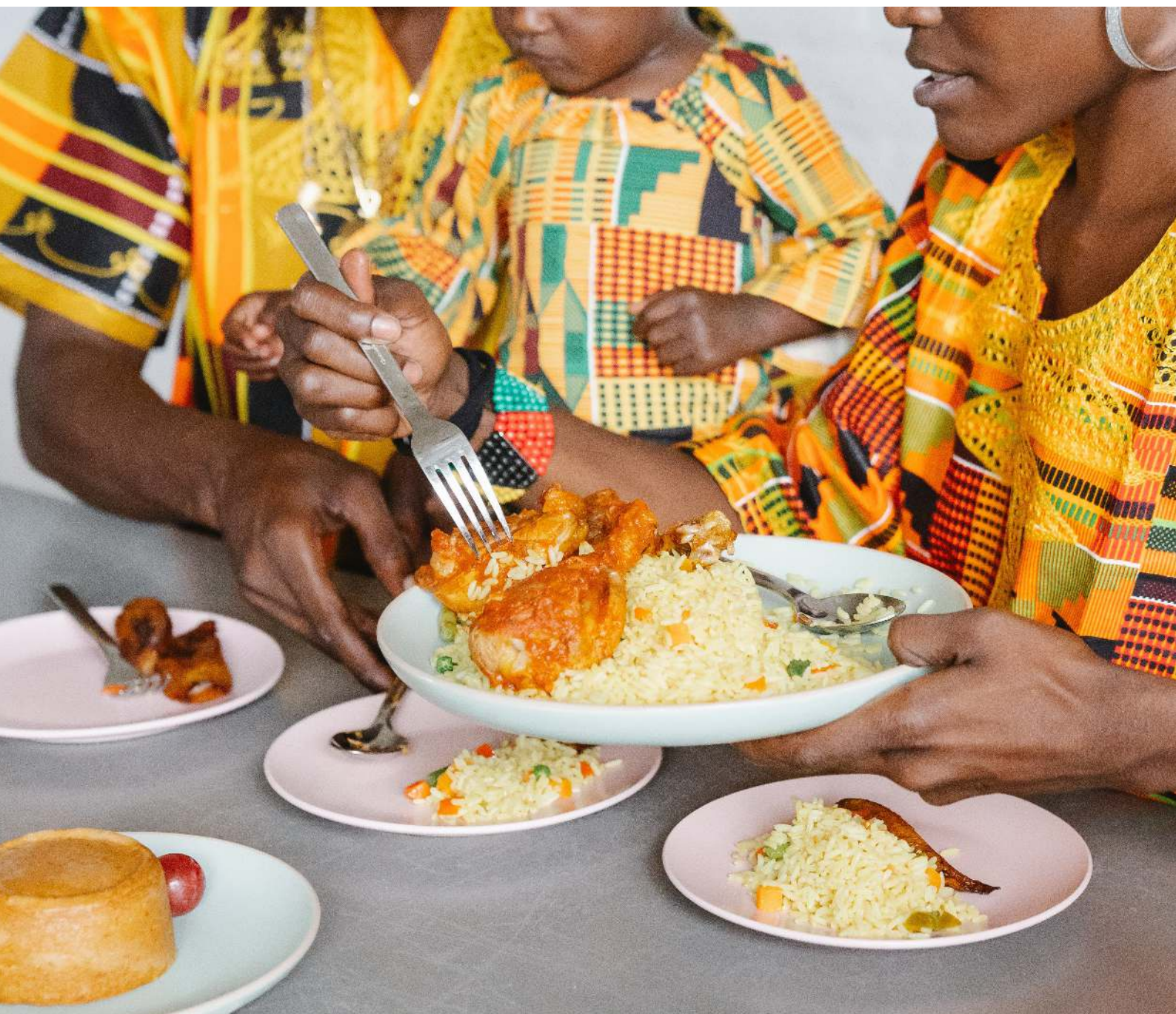
Although people highlighted the importance of cooking and eating practices in their lives, it is important not to make assumptions so that blanket responses are applied to everyone who shares the same ethnicity.

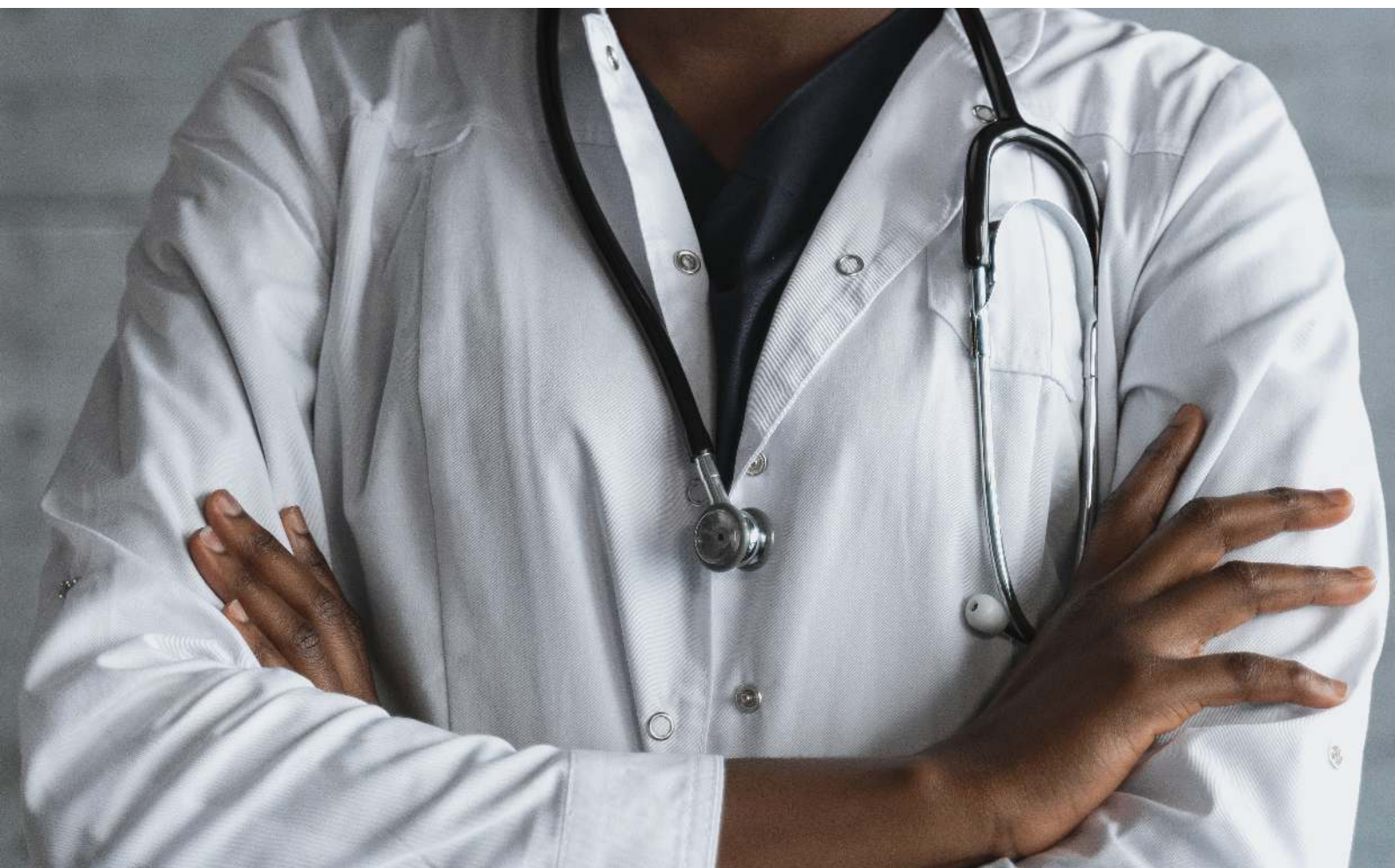
One person, who is of dual heritage, including Portuguese heritage, told us:

"I love a bag of chips the most. I eat different things at home - sometimes Portuguese food. Mum cooks it sometimes, and dad."

"There is the assumption that we are Asian and we eat only Asian food. I love all different types of food. It's like people think we can't have chips and gravy."

"I like Penguin bars, and muffins, but my favourite food is spinach. I also like Christmas dinner and Christmas pudding."





Healthcare

Good health and good healthcare is fundamental to all of us. However, ethnicity and race are drivers of healthcare inequalities, as starkly highlighted in a 2021 overview by The King's Fund:

*"In England, there are health inequalities between ethnic minority and white groups, and between different ethnic minority groups... Access to primary care health services is generally equitable for ethnic minority groups, but this is less consistently so across other health services. However, people from ethnic minority groups are more likely to report being in poorer health and to report poorer experiences of using health services than their white counterparts... Among ethnic minority groups structural racism can reinforce inequalities, for example, in housing, employment and the criminal justice system, which in turn can have a negative impact on health. Evidence shows that racism and discrimination can also have a negative impact on the physical and mental health of people from ethnic minority groups. Covid-19 has shone a light on inequalities and highlighted the urgent need to strengthen action to prevent and manage ill health in deprived and ethnic minority communities. A cross-government strategy for reducing health inequalities (and the wider socio-economic and structural inequalities that drive them) and addressing the diverse health needs of all groups at risk of poor health and high mortality has never been more urgent."*¹⁶

16 The King's Fund (2021) *The health of people from ethnic minority groups in England* <https://www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england>

We found that people's interactions and experiences with the healthcare system were variable, but overall poor in relation to support around their ethnicity, including when there is increased risks of health conditions:

"There is not enough time allocated for long explanations during appointments and sometimes general information is given to me about my health. I have never received anything that is culturally adapted or targeted information that relates specifically to me and the statistics as a Black Caribbean male, or how it might be different across other ethnic groups."

One person, Q felt strongly that there is not enough support and advocacy for Asian people, particularly around healthcare. She believes there should be more and that this should include interpreters. She has spoken up in the past about intermarriage because of family experience and thinks there should be more awareness in her community about the health implications of marrying relatives.

For one person, it was important to be able to draw on help from someone with a similar cultural background, "If I am feeling low and need someone to talk to, it can be good to talk to someone from my own culture."

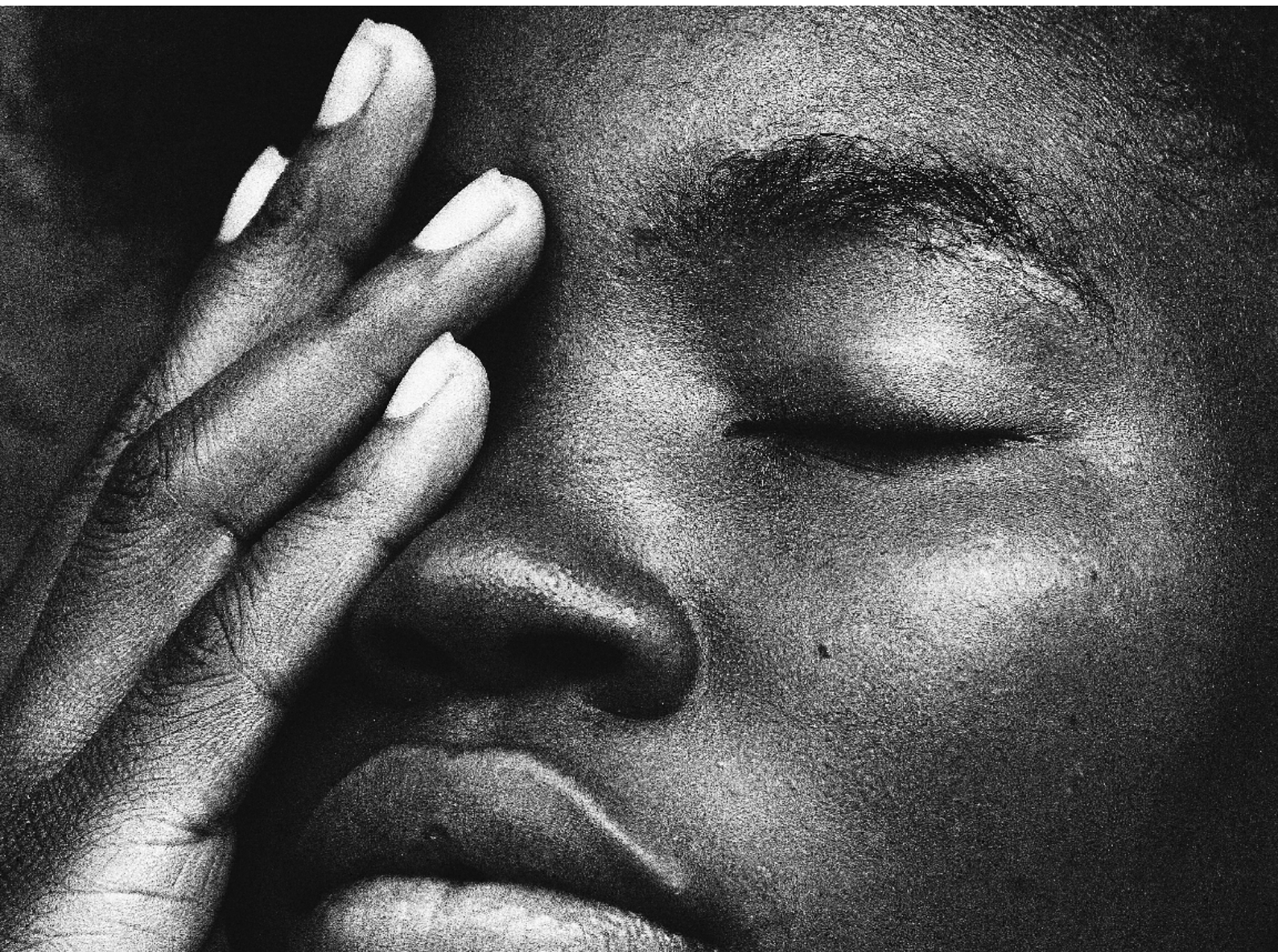
Another person told us that his dad's side of the family have Lupus and he worries about this and about passing it onto his children in the future. Nobody has spoken to him about it and he is not sure how to start the conversation. He would like someone to be with him to explain what this means for him and for the future.



In the year to March 2021, Black people were almost 5 times as likely as white people to be detained under the Mental Health Act.¹⁷

Of the 4 people (3 Black Caribbean/African and 1 South Asian) with years of experience of being stuck in a locked hospital and sectioned under the Mental Health Act, we were told racism played a part in the experiences of the 3 individuals from Black communities.

One person's mother expressed deep concern about the use of medication for her son; however, this was not motivated by her religious or cultural beliefs around what treatments are acceptable or religious interpretations of causes of mental health distress. She felt that stereotypes about Black men have influenced how her son has been viewed and treated over the years, as well as stereotypes about Black women influencing how she, as a mother has been viewed and treated.



17 UK Government (2020) Detentions under the Mental Health Act <https://www.ethnicity-facts-figures.service.gov.uk/health/mental-health/detentions-under-the-mental-health-act/latest>

Another person told us:

"You are always painted as the aggressor. We protect our children but it's seen and received as an attack, which has nothing to do with the tone, language or volume of voice. I know I don't fit their stereotype and can't tell you how frequently professionals tell me they are intrigued to know what my background story is in terms of how I ended up here [in a position of knowledge, therefore challenge to the system]. I don't know what my life is supposed to look like, I am a mum fighting for my child. It's almost like I'm viewed as manipulative because I'm equipped with the knowledge to challenge injustice. People don't want to give me the paperwork I ask for to read things about my son. The holding of that power further compounds things. It's like a predetermined route."

In our Future Planning work, K was demonised, dehumanised and labelled as "dangerous", "unpredictable" and "risky". They were othered by language, fear, and power and it was this racist ideology that contributed to the legitimacy of years of being hidden away and locked in hospital for 45 years

"It's important for my history not to be lost as so much fable and mythology surrounds me. Understanding who we are is maybe one of life's biggest questions. People like me face prejudice and stigma and are unaware of the depth of our culture and history. I have never had an opportunity to make a connection with my life history and cultural heritage to provide me with a sense of belonging."

Taken from K's person centred plan

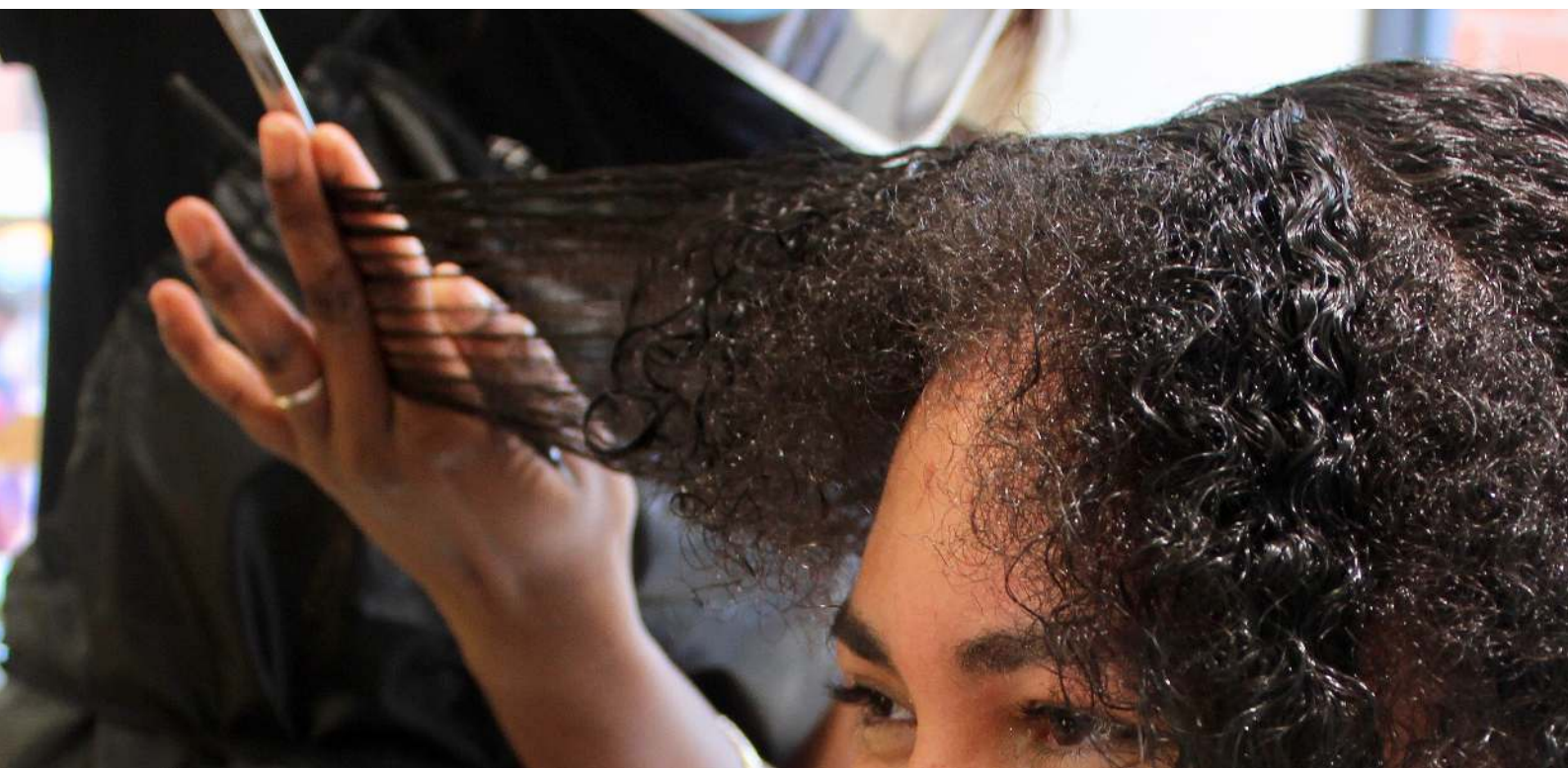
Some of the people involved in the project expressed their own views and ideas on the sorts of things they would like to see introduced to support people with a learning disability and autistic people from minority ethnic communities:

"Good practice to coproduce culturally tailored materials & resources to break down barriers especially in areas of health that disproportionality affects people from minority ethnic communities. This should increase awareness and access of key issues such as institutional, structural, societal privilege that could account for difference."

"Reasonable adjustments need to be culturally specific. For example, in hospitals now when a Muslim person passes away, they play a CD with Arabic words being recited. This is good as people recite these words at home when a person passes. I wonder if this is made available for people with a learning disability too."

"I think there should be more advocates who actually come from the communities they are serving". This individual is heavily involved in self-advocacy, particularly around healthcare.

"GPs need to ensure ethnicity, access requirements and identified needs are recorded, and flags added to the system. GPs and the wider health care system should be able to direct to useful culturally adaptive services in the local area."



Clothes and personal presentation

What people wear is a very individual thing and should be a personal choice. Clothing is a cultural and social identity which is part of a symbol that can explain a person's identity. This can also be said for the way people wear their hair or for practices or customs around clothes and presentation, dictated by religious etiquette.

For people from minority ethnic communities, particularly those individuals from, or including Black African and Black Caribbean backgrounds skin and hair products provide oils, which are essential for maintaining strength and moisture, alongside a skin and haircare routine. Black skin and hair, in particular, struggles in cold weather. Research tells us that Black skin is more prone to the drying effects of winter weather because it loses moisture at a fast rate than other ethnicities. Hair is also more prone to breakage, so it's not uncommon for people to experience dry and itchy scalps and skin conditions like eczema or cracked skin in the winter. These matters were commonly spoken about by people from these communities:

"Skin and hair products provide important oils and moisturiser, particularly when plaiting hair. This is important to hair care as dry hair can lead to breakage if not treated correctly. This should be catered for as basic care, within a care package."

One mixed race person J, told us that her support worker helps her with her hair care and takes her to the salon for her relaxers every couple of months. She helps her with washing and caring for her hair as J says she can't manage her hair, and finds it difficult to reach it properly. Her support worker has a daughter who is mixed-race, so J says that she understood how to help her care for her hair from the beginning and J never had to explain this to her. She says her support worker helps her to apply oil to her hair every few days.

"I have always used the same Afro-Caribbean hair salon, since I was about 16."

J's hairdresser has advised her to wear a silk wrap on her hair for bed but she says she can't tolerate this because she is autistic. J's support worker also helps her with her skincare as her skin gets dry. J says that before, her previous supporters didn't understand how to support her to treat and care for her hair and skin and didn't understand how much attention it needs.

Another person, E told us that she used many hairdressers over the years: some have been specialists in African Caribbean hair, and others haven't, like the one she goes to now. E changes her hair a lot: the style and colour and chooses this completely independently. She buys her hair products from a shop which sells products for African Caribbean hair. She has her eyebrows waxed at the same salon and says she uses cocoa butter and E45 creams on her skin.

Some people talked about how religion intersects with clothes and personal presentation:

"In Islam people should shave or remove with cream their pubic and under arm hair frequently, as it is seen as unclean. Staff need to be respectful of this and speak to the person about how to best support them to do this if this is their practice."

"Support staff need to be aware of how I dress. I don't always wear traditional clothes but I sometimes like to. In fact, I love to as they make me feel great. When I started to wear my pyjama suit and scarf my staff did not know how to fix it, but now they do."

"I work in jeans, T shirts and shirts but I wear the Abaya and cap most of the time when at home as I pray 5 times a day. I always wear the Abaya for worship."



Relationships and community connections

A sense of social connection is one of our fundamental human needs. Relationships and community connections play a key role in supporting our wellbeing, especially when going through difficult periods of our lives. Even just a simple 'Hello' every day can give our wellbeing a huge boost. Developing our relationships with our neighbours builds our sense of community, helps us feel safer and gives us a sense of belonging. Speaking or spending time with others can help us feel less stressed, isolated, or lonely.

Positive and healthy connections with others and learning how to rely on others for support also makes us much more resilient. Increased community connection supports our mental wellbeing, and decreases our rates of anxiety and depression.

Some people were well connected into their communities and others had few or no connections. For all people we spoke to, connections were mainly with family members and other disabled people. Almost all of the people we spoke to, not living in the family home didn't have opportunities to connect into their communities through groups, networks and individuals that reflect their ethnicity. We heard few examples of people being at things like family celebrations and community events, local cultural events and mentoring and leadership programmes.

One person, Q is particularly proud of her mum and dad as she feels they have overcome a lot of difficulties in life. Q and her sibling are both disabled and her mum came to Britain when she was 16. Her foster parents died fairly recently, her foster mum died a year ago and her foster dad just before that. Since then, she has started to rekindle the relationship with her mum. She has recently started visiting her mum:

"When I go to my mum's I pray and do everything that she does. I missed all of that in childhood."
Q describes herself as almost having two sides to her identity: *"When I'm at my mum's I'm [Birth Name] and I do what my mum does, I pray and all that. When I'm at home I'm [Anglicised Name] and I do what I want."*

Q's dad is a taxi driver. When he finishes a job he comes to see her "for a coffee and a fag". She sees quite a lot of her dad.

Q lives in an area where she says there are not many people who go to Mosque or observe Islam. She says that there are some Asian people in her neighbourhood, but there are more Black people. She does have people she knows out and about in the local area who are Asian, but she doesn't go to any organised groups or activities to do with this.

Another person, E is well connected in her community and goes to several different services that are targeted at people with a learning disability. She volunteers with Air Ambulance Service and Scope in their charity shops and she goes to a Weight Watchers group. She does not go to any places that specifically reflect her ethnic background, shared cultural experiences or traditions. E was asked whether she wanted to connect with people with a similar ethnicity to her and she said she would like to look into this with her support worker.

One individual, J was very close with her mum and aunt and said she sees them a lot. She sees her dad several times a week and does see some of his family who live nearby. J says that when she was younger she didn't see much of her dad as her parents had split and it was awkward. Since she moved out of her mum's house and into her own flat she now sees her dad a few times a week, he lives up the road from her. She arranges to see him herself. Others in her dad's family live in Jamaica and America so she says she doesn't see them very often if at all.

J has a couple of friends in her block of flats who, but otherwise J tends to like to do her own thing with her support worker. She doesn't really mix with people or have friends locally who share her ethnicity, although she does keep in touch with some old friends from residential college when she goes back for their 'Women's Group' alumni. J doesn't really do groups or community events as she prefers to do her own thing.

Another individual from our Future Planning work, B has been in hospital on and off for many years and he has lost practically all his connections with networks he was part of in the past. While in hospital, over the last year, he had access to section 17 leave. This was inconsistently offered to him but, he often chose not to go out, particularly since Covid and the lockdowns. However, he did chose on most occasions to go on transition visits to his new house. The team at the hospital didn't explore the sort of places B might like to access that would be of interest to him or reflect anything about his Caribbean background, shared cultural experiences or traditions, or that understand and affirm the Caribbean culture. This is something the new provider is exploring with him now he is in his new home - he is clear he wants to make new friends and this is written in his person centred plan.

2 people came up with suggestions for improved community connections:

"Staff need to produce a community map so the person can be linked to people within their local area."

"It's important that when people want to be, they are plugging into their communities from a cultural perspective."

Cross-cultural communication

Cross-cultural communication can play an important role in building trust and delivering equitable care, recognising both differences and similarities among cultural groups in order to effectively engage within a given context.

"It's good to hear people speaking one of my languages."

Most of the people that had conversations with us speak or understand at least some English, but conversed in additional languages such as Portuguese, Punjabi and Patois with their families and wider community. This often didn't apply to their communication with support staff:

"Staff need to understand what the person's first language is and maybe understand that people might speak words in more than one language. I speak English most of the time but also speak Punjabi and Urdu, especially with elders in my community."

One person, A talked a lot about travelling on the bus – which he finds stressful. A says that he needs someone with him who speaks Portuguese, especially when he is stressed and can't think clearly in English. He said that when he is out and about people can be mean to him and a lot of people are rude. On buses people sometimes stare at him or block him - crowding and pushing him – "they have no manners and don't say sorry." He mentioned that one day a lady on the bus supported him and held him so he didn't fall over. He said she helped him "because she was okay with it – not everybody is comfortable with it."

A also told us said that he doesn't like people to shorten his Portuguese surname to an initial: "I don't like it when people call me 'R' because it's not my real name."

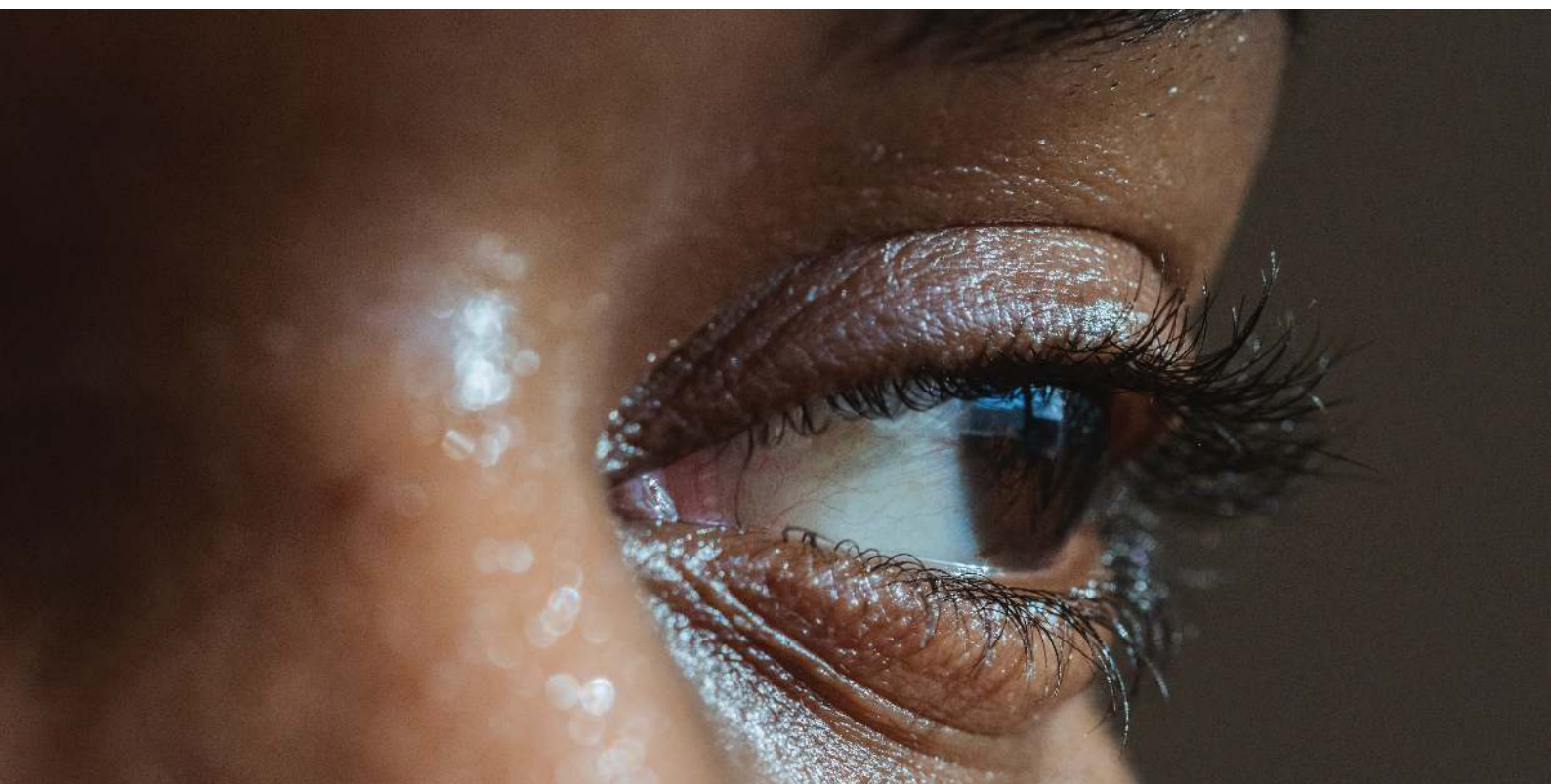
There were 2 examples from people about their support staff using other languages and taking a genuine interest in them as individuals:

"All the staff supporting H know that 'loon' means salt in Punjabi as we have to provide a diabetic friendly diet."

Another person, J says "my support worker gets me", she describes their working relationship as friendly and says she has got to know her really well. They both spoke about each other very warmly and J says that her support worker takes an interest in her and her family background.

Three of the people we worked with use no or few words and communicate using other formal or informal communication styles. One suggestion from a person related to social stories for people who don't use words:

"Social stories are not very ethnically diverse. Questions are too broad and generalised and they don't connect you back to your culture. They are not tailored to any specific Black, ethnic or cultural input."



Emotional support

Emotional support is important for our well-being, but the frequency by which we receive the social and emotional support we need and our experience of this can vary. People from minority ethnic communities can face specific issues and challenges because of their ethnicity. Many people when asked about emotional support spoke passionately about their identity and how they see themselves. They were proud of their ethnicity and heritage:

"I feel highly positive about my ethnicity in every way possible, I love my culture."

Q is very proud of her ethnicity and faith, "I'm only starting learning [about her religion and culture] now." She says she has recently been watching and enjoying Indian films and enjoying Indian food. She says, "I'm a dancer, so I'm learning to do Indian dance." This is all led by Q and she is learning through YouTube and through exploring these things herself. She is interested in the history of Pakistan and India and the conflict there and has learnt about this.

B was born in the UK but moved to St Lucia from 18 months where he lived until he was a teenager. He has many fond memories of the island. He enjoys talking about some of the things he did there when he was growing up and looking at pictures on the internet. He has been back to St Lucia a couple of times with family and says he would like to go back to the island for a holiday again, this was included in his person centred plan when he left hospital. B will often initiate conversations with other people about the island. Staff respond to this with varying degrees of interest and enthusiasm. If staff pick up on B's attempts to initiate conversation about the Caribbean and develop it, he shows lots of interest and enthusiasm and he appreciates people's interest in St Lucia.

J describes herself as mixed race. She has always lived in Britain but has visited Jamaica several times over the years to see her dad's family. She says in terms of her ethnicity, "I feel more like mom than dad" but says she has more of her dad's tan and personality. She says, "I've got the best of both worlds." She feels very positive about her identity and heritage and says she feels proud of it. She finds language around ethnicity difficult to navigate and doesn't like that language changes all the time. "I don't really know what you're supposed to say now. I'm mixed, I suppose."

After school, J went to residential college. She says she loved it there and that staff there were very accepting of her identity. She says "They taught me a lot about myself." She particularly remembers one of the staff there who was Jamaican. J says that she taught her a lot about the Jamaican culture and particularly about how to care for her hair. "Obviously my dad taught me a lot about the culture, but it's different coming from different people."

Other people described the ways people's lack of understanding or hostility around ethnicity has affected their emotional wellbeing and the way they have been perceived by others:

"In the family home since I was small, I have been encouraged to be proud and positive about my identity, race and culture. However in the past, my ethnicity has affected the way I'm seen and reacted to and been labelled as 'aggressive, unteachable, naughty and disruptive.'"

Q told us when she was born, her parents chose her a traditional Pakistani name. Q was in foster care from the age of 3 until 20. She was fostered by a white Christian family and so she says that many of her religious and family traditions just did not happen while she was a child. She was not allowed to practice Islam as a child. She says, "I was very confused. I didn't understand why I wasn't at home with my mum and dad." She says that it was her foster family who first decided to call her by an anglicised shortening of her name. She says she stopped going to the Mosque when she was fostered and she has never been back.



End of Life Support

Understanding people's wishes at the end of their life is always important. It can be particularly important if the individual and staff do not share the same culture. Cultural awareness is the ability to acknowledge differences.

Always doing the same things to mark the end of someone's life may not suit a particular person's religion or preferences and discussions around customs and preferences with the person and their family should take place. This should be part of end of life care planning.

Through our Future Planning work, research was conducted around a funeral plan for K. Developing this plan was a comprehensive job, ensuring a range of options were identified and considered and costs were carefully examined. This included thinking about providers, type of funeral, location, personalised elements like music, clothing and important guests, the wake and memorial. After much scrutiny and thought a funeral plan was developed to honour K's legacy; central to this were her ethnicity and heritage. Whilst being mindful of these important factors it was fundamental that the plan captured and reflected her personality and character to showcase and celebrate K's life.

Staff

For those people with a learning disability and autistic people who use support, the right support is key to enabling them to lead a good quality of life. This means supporting all aspects of a person's life including their identity which incorporates their ethnicity. Good support starts with the culture of an organisation or individual and the recruitment of support staff is embedded in this culture. Racial justice needs an accomplice. Allies lead out, amplify and bring action to issues that aren't about them. Talking about racism doesn't make you anti-racist, just as employing support staff from minority ethnic communities isn't enough.

In the words of a family member who we spoke to:

"Many people that come from Black, Asian and ethnic minoritised communities will have experienced racism, bias stereotyping or cultural misunderstandings and people with a learning disability and or autism face double discrimination accessing support and public services."

"We are an excluded social group and culturally informed independent advocacy is needed along with a diverse and skilled workforce."

For 2 people, B and K from our Future Planning programme, both of whom had lived in locked hospitals, an understanding of ethnicity was woven into their future support plans. B is a very sociable person who relates well to most people. Having just moved out of hospital, his new support provider has recruited a diverse team that reflects his cultural background. When searching for a property for B, his social worker was mindful of ensuring that the location was somewhere with a diverse population. However, whilst in hospital there was no mention of meeting his cultural needs in either the Care Programme Approach or the Care and Treatment Review process for B.

K recently moved into her own home and had a bespoke team recruited around her. Ethnicity, along with high expectations and ordinary life outcomes was central to this process as she has been stripped of her identity over decades of institutionalisation and the local authority, new support provider and independent advocate understood the importance of nurturing her rich heritage.

N told us that it can be hard for families from minority ethnic communities to qualify for care and they are less likely to have family members to advocate the complexity of the system because of a lack of information, and access to information. Then, when challenging that system private independent reports are often required to qualify their case, which presents an unfair disadvantage to people from minority ethnic communities because of the poverty gap.

Assumptions should not be made that everyone from a minority ethnic community wants a support worker who is the same ethnicity. J spoke about a support agency she used to have. They assigned her lots of Black staff members even though J doesn't necessarily have a preference. She clashed with one particular staff member who was Jamaican and made J feel awkward in her own flat. This member of staff would show their displeasure by sucking their teeth. "I don't like that. My dad does it too so I understand why she did it, but I hate it. I find it really rude." Although J is now very happy being supported by a worker who is white, she says that she doesn't have a preference for white or Black staff in terms of ethnicity, but for her it's more about their personality and what they're like as a person.

Regardless of whether people identified as being religiously affiliated, what was often highlighted is the distinct lack of education and interest of people in support roles around the people's ethnicity.

2 of the family members we worked with spoke about why they have chosen to keep their adult autistic sons living in the family home. Their shared experience is one of discrimination that their Black sons have faced from an early age:

"I have a strong civil rights background. We need more allies, peers that can speak up for them. That's why mainstream is important."

"There are limited services and support available to challenge, that truly understand the nuance of the situation that we face which is where advocacy started for us as a family as I had to learn how to do it for ourselves."

"My son still lives at home because I know he is safe. It's about trust and environment . The way that society views my son puts him at risk in the community, which is why he still lives in the family home. He would like to leave home and live independently and naturally I want this for him too. However, as a mother I have to put his safety above everything. He went out to enjoy a walk one day, like he does every day and ended up brutalised by police and sectioned in the mental health system. He's autistic, but they only saw his colour."

"I have found that at times people find it uncomfortable to talk directly about race. I've experienced two unrelated situations where staff fell short to say anything and I was left to defend myself."

"We live in a society that labels, so I gave up work to support my son and work to find the right PAs for a person centred approach. I have had to fight to get A support and this fight started when he was younger and I fought to get him into mainstream school. Inclusion in society is so important and A doesn't use words so I've always wanted him to have peers that can speak for him, one of the reasons why mainstream is important. The last 14 years have been a struggle. A has his own budget, but I have always struggled to find young Black British guys to support him as he has respect for other Black men. The best PAs come from universities, although often this means their support won't be long term. I look for people who are creative and resourceful, but most importantly have high expectations for my son and understand that he needs support to do the things that any young Black man wants from life. Experience isn't important as I train PAs and I find that most people with previous experience come with baggage."



A's mum told us about a 'circle of aunties' that she facilitated the development of for her son. She led the work to organise the circle, drew a map and started working through the possibilities for A with the aunties. The aunties include a childhood friend and their mum, a family friend and ex PA's that worked with A up to 10 years ago. "They understand the principle and have seen the difference that it makes. They are like family, more than family sometimes."

When asked, what makes it work we were told "there's a structure, they keep an eye on me, understand the battles, they all contribute and see a way forward when sometimes I am struggling."

"The circle suggested the DOE Bronze Award, one of the best things that A did in his 20's. The other young people were 15 and 16 but so see how they all worked together was incredible. He did the silver and gold with another group."

As a result of this approach A has other young Black men in his life which is of great significance to him. These relationships have further developed beyond the boundaries of their roles as supporter and employer, for example A was a guest of honour at the wedding of one of these men. Another saw A on a bus in the community and jumped on the bus to introduce his friend [another young Black man] to A.

Recommendations



Although this was a relatively small project drawing on 3 standards of our work (Quality of Life, Colour Between the Lines and Equal Treatment), and conversations with 18 research participants, we were able to draw out areas of learning that have the potential to bring about improvements to services and support if explored further.

Commissioning

- Commissioners to understand intersectionality and take ethnicity into account when scoping and planning new provision, as well as when monitoring quality.
- Quality checks to be commissioned that focus on ethnicity. This would give commissioners an in-depth look into the support that people receive from minority ethnic communities.
- Culturally appropriate short breaks should be commissioned.

Providers of social care and support

- Providers to embed an understanding of intersectionality and ethnicity into the way they view and support people with a learning disability.
- Providers to ensure their staff have an understanding of anti-racist approaches and proactively sign up to being anti-racist in their practice, policy and strategies.
- Support for individual's ethnicity flow through the recruitment and workforce development process from initial adverts, interviews, job descriptions and staff training.

Care Quality Commission

- The Care Quality Commission to consider a themed inspection focusing on ethnicity and quality of care and support.

Self-advocacy movement

- The self-advocacy movement needs to embed an intersectional approach in its work, recognising that fighting for disability rights can be done in harmony with an anti-racist perspective. This intersectional approach needs to be led by senior self-advocates and non-disabled managers in these organisations.

Healthcare

- Coproduce with individuals, communities and community leaders culturally tailored materials and resources to combat health inequalities.
- Reasonable adjustments need to be culturally specific.
- GPs need to ensure ethnicity is recorded in relation to access requirements, and they need direct people to any useful culturally adaptive services in the local area.
- Ethnicity to be a key feature of all health checks, including annual health checks.
- Care and Treatment reviews need to ensure they appreciate ethnicity and the impact this has on the person's life.

Advocacy

- Advocacy agencies need to ensure they employ advocates from minority ethnic communities so they can as much as possible be matched with people from the communities they are serving.

Social Stories

- Social stories need to be ethnically diverse and connect people to their culture.



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