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NHS RACE & HEALTH OBSERVATORY

We deserve better: Ethnic minorities with a learning disability and access to healthcare

Executive Summary

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Manchester Metropolitan University

LDE Learning Disability England

Race Equality Foundation

Executive Summary

Literature, which has spanned over two decades, has acknowledged that the intersection of ethnicity and disability, two marginalised identities in society, results in compounded discrimination. Such discrimination exacerbates inequalities in relation to health outcomes and healthcare among people from ethnic minority backgrounds with a learning disability. These existing disparities are due to the social determinants of health, which are further fuelled by discrimination, racism and marginalisation. In turn, people with a learning disability from ethnic minority backgrounds experience poorer access and experiences of healthcare services and poorer health outcomes.

To explore the barriers to healthcare faced by people with a learning disability from ethnic minority backgrounds, academics at the University of Central Lancashire worked in collaboration with Manchester Metropolitan University, Learning Disability England and the Race Equality Foundation in the production of this comprehensive mixed-methods report.

This report used an experience-based co-design approach, collaborating with a working group of experts by experience who either have or care for someone who has a learning disability, and are from ethnic minority backgrounds. The working group guided the research process.

Mixed-methods were used to explore the complex issues relating to barriers to healthcare. Quantitative methods included a policy review, an administrative dataset review, a scoping review, a case-study of ethnicity coding and an analysis of data from deaths of people with a learning disability from ethnic minorities. Qualitative methods were used to conduct workshops exploring the experiences of people with a learning disability from ethnic minority backgrounds and/or their carers.

Policy Review

Relevant national policy documents from 2001 onwards were reviewed for their relevance to people with a learning disability from ethnic minority backgrounds. It was found that references to people of ethnic minority backgrounds were rare in legislation pertaining to learning disability.

Administrative datasets review

Administrative datasets were reviewed in terms of their feasibility to provide analysis relating to learning disability in people from ethnic minority backgrounds. Of the 27 datasets reviewed, 5 compared some aspect of the experience of people with a learning disability from ethnic minority backgrounds. Other datasets did not have information relating to both ethnicity and learning disability or did not have this information in a format that allows them to be examined together.

Scoping review

An electronic database search of research published from 1990 onwards relating to both learning disability and ethnicity was conducted and 94 papers were assessed according to inclusion criteria to be included in the scoping review.

The following themes were constructed through an iterative process between the academic team and the working group: discrimination, community and family networks, the Learning from lives and deaths: people with a learning disability and autistic people (LeDeR) programme, COVID-19, digital access, transitional care and the learning disability register. We also report findings relating to health outcomes to update previous systematic review findings from Robertson et al. (2019).

Only two studies (Ali et al., 2013; Azmi, Hatton, Emerson & Caine, 1997), explicitly focused on discrimination. Experiences described in the studies included lack of culturally appropriate services, which was the focus of two further papers which described cultural needs not being met in inpatient services (Chinn et al., 2011; Bonell et al., 2011). References to racism were rare in the literature and where racism was mentioned it was not discussed in depth.

There are differences in community and family networks for people with a learning disability from ethnic minority backgrounds. Two studies found that

‘South Asian’ groups had more family members in their network who acted as support, and had more ethnically diverse networks (Bhardwaj, 2018; O’Hara, 2003) and people of ethnic minority backgrounds are more likely to live in their family home and receive their main support from family members (White et al., 2022). High levels of stress and psychological symptoms in carers of people with a learning disability from ethnic minority backgrounds were also found (e.g. Akbar et al., 2020; Masefield et al., 2022).

LeDeR reports suggest that people from ethnic minority groups die at a younger age: males from an ‘Asian/Asian British’ background with profound and multiple learning disability had a median age at death at around 30, the lowest median age at death of all groups. In comparison, for ‘White British’ males with profound and multiple learning disability the median age at death was 59 (Heslop et al., (2020).

Being from an ethnic minority and having a learning disability were both factors associated with an increased risk of adverse COVID-19 health outcomes, with greater likelihood of COVID-19 death (Heslop et al., 2021). However, interactions between ethnicity and learning disability were not analysed in larger cohort studies, when ethnicity and learning disability were identified as independent risk factors (e.g. Carey et al., 2021; Cummins et al., 2021).

No papers were identified which related to the theme of digital access. Only one paper focused on transitional care (Bhaumik et al., 2011) which reported greater levels of unmet needs in relation to culturally appropriate services in those from ‘South Asian’ backgrounds compared to those of ‘Caucasian’ ethnicity.

One study focused on the learning disability register (Chaplin et al., 1996) which found that ‘Asian’ adults were underrepresented on the register. Nine papers utilised learning disability registers for recruitment and/or analysis, suggesting the learning disability register is a valuable tool for researchers to identify people with a learning disability.

There were limited papers relating to health outcomes, and the focus of the papers was varied, ranging from prevalence of specific genetic or acquired syndromes, oral health to diabetes. Several papers reported findings relating to mental health outcomes, such as incidence of psychiatric disorders, problem behaviours and detainment. However, the findings of these studies were mixed in terms of identifying ethnicity as a factor influencing mental health outcomes, particularly as factors such as social deprivation were not always accounted for.

Case study of ethnicity coding within an Integrated Care Board (ICB)

A case study was conducted to explore the quality of ethnicity codes of patients recorded on the learning disability register held in GP clinical records as part of the Quality Outcome Framework within the Lancashire and South Cumbria Integrated Care Board (ICB). Supported by the Midland and Lancashire Data Quality Team, a search was created which included codes correlating to census categories 2001 and 2011 and was then run in GP clinical systems at a practice level. Once the search had been validated in a practice, the search was further tested in a Primary Care Network as part of a quality improvement initiative to improve completeness of ethnicity coding. The search was then approved to be run within each area of Lancashire and South and Cumbria ICB (previously recognised as Clinical Commissioning Groups). Some patients had multiple entries but only the latest entry was taken into account.

The completeness and validity of the ethnicity codes provided by the Lancashire and South Cumbria ICB were quantitatively analysed. Overall, the completeness of records was high, with 92.6% containing an ethnicity code. However, upon further inspection, only 73.4% of these ethnicity codes were valid according to the NHS Data Dictionary, and to a lesser extent, the 2011 census categories (72.7%). There was also variation between areas of the ICB; North Lancashire had the lowest proportion of ethnic codes that could be classified according to the NHS Data Dictionary, representing only 54.6% of patients. In comparison, the highest rates of validity were observed across Preston and West Lancashire, where approximately 83% of ethnicity codes were valid according to the NHS Data Dictionary.

LeDeR data analysis

The LeDeR programme reviews the deaths of people with a learning disability and autism as of June 2021 over the age of 4. LeDeR data of people who died between 2018 and 2021 were used to describe the number of notifications of people who were from an ethnic minority background, their demographics, circumstances of death and causes of death. Cox proportional hazard modelling was used to analyse the effect of ethnicity on age at death using data of people who died.

Of LeDeR notifications from 2018-2021, 90.2% were of people denoted as ‘white’, and 9.1% were of people of ethnic minority groups. The lowest proportion of notifications to LeDeR was of people whose ethnicity was denoted as ‘Other’, reflecting 1.3% of notifications.

People from ethnic minority groups had a significantly lower median age at death than people denoted as ‘white’. The median age at death for people from ethnic minority groups was 34 years (mix = 4, max = 96) compared to 62 years (min= 4, max = 104) for the ‘white’ ethnic group. These findings should be interpreted with caution due to the small number of people who were from ethnic minority groups compared to those denoted as ‘white’.

The highest proportion of hospital deaths was recorded for people denoted as ‘Other’ ethnic group (73%). People denoted as ‘white’ had the highest proportion of DNACPR recommendations in place at the time of death (73.0%). The lowest proportion of DNACPR recommendations in place at the time of death was observed for people denoted as ‘Black, Black British, Caribbean or African’ (51.5%).

There is under reporting of deaths for ethnic minority groups which constitute just 9.1% of the notification data compared to 2021 census data estimates of the ethnic minority population in England of 18.3%. Nevertheless, these findings suggest that the health outcomes of people from ethnic minority groups are significantly worse than people denoted as ‘white’.

Workshop findings

Experience-based co-design workshops were conducted with ‘experts by experience’ 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. Eight core themes were generated through findings from the scoping review and through discussion with the working group (as above). The themes were presented to participants to ascertain how lived experiences relate to academic findings and to consider ways in which care could be improved. Twenty participants (13 self-advocates, 5 family carers and 2 support workers) contributed to three workshops. People who could not attend the workshops provided their thoughts about the themes with the research team. The workshops were audio recorded, transcribed and thematically analysed.

Our findings suggest that people from ethnic minority backgrounds with a learning disability experience disparities in healthcare. Some participants experienced discrimination; however, due to the intersectional nature of discrimination, recognising and understanding the source was difficult. However, it was evident from people’s experiences that there was a lack of reasonable adjustments and a failure to recognise and accommodate an individual’s needs. 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 experiences led to some carers fearing for the future for their loved ones.

Some carers provided personal experiences of services where they acknowledged that they may have experienced racial discrimination. Examples of such discrimination included 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 which were expected to be free.

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, possibly due to learning disability being regarded as a “taboo”. This resulted in feelings of isolation among carers.

The intersection of disability and ethnicity results in compounded discrimination. Such discrimination exacerbates inequalities in access and experiences of healthcare for people with a learning disability from ethnic minority backgrounds. However, recognising and understanding the source of discrimination can be difficult for both carers and self-advocates. Future research should aim to qualitatively explore the concept of racism among people with a learning disability from ethnic minority backgrounds. People found it easier to identify the disparities that arise due to ableism. These barriers can be reduced by clinicians having effective communication and an enhanced understanding of learning disability. Understanding an individual’s needs from the first point of contact is important for the allocation of resources and ensuring that reasonable adjustments are adhered to.

Summary

This report aimed to explore the multifaceted factors which contribute to the inequalities in healthcare that are experienced by people with a learning disability from ethnic minority backgrounds. This marginalisation is enshrined in limited national legislation which explicitly pertains to inequalities in the lives of people with a learning disability in relation to ethnicity and reflected in a lack of research attention. There appears to be a systemic issue with recognition of ethnicity within health care systems, which may prevent the provision and allocation of appropriate healthcare resources. Within health and care settings, reasonable adjustments are not always adhered to, which further widens these disparities. Through a combination of such factors, people from ethnic minorities with a learning disability experience worse care and, ultimately, die at a younger age.

Recommendations

Actions for the Department of Health and Social Care and NHS England:

- Production of guidance on how to implement existing policies relating to people with a learning disability, emphasising coproduction approaches, in such a way that the health inequalities for people with a learning disability who are from ethnic minority communities can be addressed.
- The development of future policies should, as standard practice, include advice emphasising coproduction approaches to tackling health inequalities experienced by people with a learning disability from ethnic minority backgrounds.

Actions for NHS England:

- Add ethnicity data to the mandated data collected as part of The NHS Health and Social Care of People with Learning Disabilities dataset, to enable regular and ongoing analyses.
- Review the categorisation of learning disability in existing administrative datasets – moving towards categorisations that disaggregate learning disability and specific learning difficulties.
- Introduce focused questions on health inequalities among people with a learning disability across ethnic groups into the Learning Disability Improvement Standards for NHS Trusts.
- Develop co-produced guidance for primary care staff on obtaining self-disclosed ethnicity information from patients with a learning disability, and accurately recording this information in medical records.
- The NHS Data Dictionary to be implemented in all NHS commissioned services and be updated in line with the 2021 Census categories.
- NHS data systems should only use categorisations of ethnicity that are in-line with the latest NHS Data Directory definitions.
- Undertake a targeted awareness campaign amongst ethnic minority communities to help to tackle the under-reporting of deaths to the LeDeR programme.

- Medical Examiners in England should be provided with specific training and advice on identifying deaths of people with a learning disability and autistic people and notification to the LeDeR programme.

- 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:

- All NHS and care providers should routinely and accurately collect ethnicity data relating to people with a learning disability.

- Develop inclusive interventions for carers of people with a learning disability from ethnic minority backgrounds that address the range of challenges faced by carers, including those related to their well-being.

- The quality (completeness, validity, and accuracy) of ethnicity coding for people with a learning disability should be validated in health care records by integrated care boards.

- LeDeR reviewers should ensure that they accurately record in the LeDeR review the ethnicity of the person whose death they are reviewing. These data are best collected from the family as part of the review process, where the family can participate in the process.

- Ensure that the number of LeDeR reviews notified within their ICB reflect the demographics of their local population and take action to raise awareness of LeDeR within those communities, especially where notifications are below the anticipated number.

- 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:

- When commissioning research, NIHR should ensure that researchers are explicit about their approach to describing and grouping ethnicity. Where large, high-level groupings are used for analyses (e.g. South Asian), details should be provided about the specific communities represented (e.g. Pakistani).
- Future research on learning disability should aim to investigate differences in health outcomes by ethnicity.
- Specific research in under-represented groups such as asylum seekers, the Jewish community and Irish Travellers should be commissioned.
- Researchers should use co-production or participatory research designs to utilise the expertise of people with lived experience.
- Whilst recognising the difficulties in access to sufficient data, researchers should perform ethnicity specific (disaggregated) analyses on future research findings to better understand differences in health outcomes between populations.
- Future research should investigate how people with a learning disability from ethnic minority backgrounds understand and conceptualise racism.
- Future research should further explore what is driving lower age at death in ethnic minorities with a learning disability, including avoidable causes of death and modifiable contributory factors.
- More detailed analysis is recommended for avoidable causes of death in ethnic minority populations and uptake of health promoting initiatives such as vaccination and screening programmes.
- 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.

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