Collaboratives on addressing
racial inequity in covid recovery

Learning Disability

Briefing Paper

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Introduction

This paper examines the evidence on health inequalities experienced by Black, Asian and minority ethnic (BAME) people with a learning disability. While this issue has long been of concern, such as the higher risk of avoidable deaths in NHS care, the experience of the Covid-19 pandemic has shown in stark terms just how extreme these inequalities are. People with learning disabilities were six times more likely to die from Covid and 40 percent of these deaths were people from Black and Pakistani communities.

The premise of this paper, after considering the literature, is that the circumstances of our birth need to be considered as they profoundly affect our life chances. Social inequalities create a barrier and promote disadvantage that impact on both health and mental health. Our starting point as authors was to analyse the research and publications that outline the inequalities experienced by people with learning disabilities.* The lack of literature for people with learning disabilities from BAME communities provided information in itself and informs the conclusions at the end of this paper.

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* The difference between learning disability and learning difficulty- In general, a learning disability (sometimes called Intellectual Disability) is a condition that affects learning across all areas of life. A learning difficulty is a condition that makes specific areas of learning difficult (such as dyslexia)

1. Ethnicity and learning disability

There is little targeted information on learning disability and even less on learning disability from different communities. The latest targeted intervention that of Transforming Care, following the Winterbourne scandal that exposed the abuse of people with learning disabilities in residential settings,[1] contain no specific information in any of its guidance on how different communities were effected or how they would meet their intersectional needs. One might question whether this position suggests that the needs of BAME communities are not seen as 'Core Business.'[2] This can also be true on the lack of information on people with learning disabilities in mainstream policy and practice, excluded and kept invisible making it not relevant or core business. What we do know is that there is an estimated 1.2 million people in England with a learning disability.[3] They experience poorer health outcomes than the rest of the population including their mental health[4]. They are more than four times more likely to develop poor mental health.[5] One in seven of all children and young people with a mental health need in the UK will also have a learning disability. Just over a quarter (27.9%) of children and young people with a learning disability and mental health need had any contact with mental health services, similar to adults.[4]

Interviews with families indicated a six month wait for a referral to Child and Adolescent Mental Health Services (CAMHS), and even then, they would experience being left on a waiting list. Young people feel ignored and hopeless in getting any support from school or college, with a sense of fatalism for the future. This is the result of a lack of support by mainstream and specialist services, diagnostic overshadowing, a risk averse service system, lack of staff training, lack of early intervention, poor access to mental and physical health services, stigma and discrimination.[6] Practice in mainstream provision, such as Improving Access to Psychological Therapies (IAPT), were supported to think about their exclusion criteria, based on IQ, for people with learning disabilities. Their practitioners are the best providers of depression and anxiety and should be the providing reasonable adjustments to ensure they are accessible to ALL that need them.[7]

The available data does not give a definitive answer as to how many people with learning disabilities are from BAME communities. This may cause difficulty in ascertaining the exact numbers of People of Colour who are reported in the statistics. Race Equality Foundation research from 2007 refers to 60,000 people.[8] More recent research from the Equalities National Council and Scope suggests the number of disabled (but not specifically learning disabled) BAME people totals one million.[9]

According to Lancaster University's Centre for Disability Research, between 2011 and 2020, 25% of new entrants to adult social care with learning disabilities were from minority ethnic communities. However, higher rates of identification of more severe forms of intellectual disability are recorded among children of Pakistani and Bangladeshi heritage.[10,11]

Intersectional needs and Discrimination

The intersection of race and (dis)ability, two stigmatised identities in society, results in a double discrimination experienced for BAME people with learning disabilities and their families. O'Hara (2003)[12] has noted the double discrimination and has been calling for 'cultural competency' for almost two decades. Families and professionals have shared experiences of how a lack of time and cultural understanding can lead to inappropriate care decisions around the person with learning disability, particularly around supported living.[13]

The ways that people with learning disabilities and their families may experience double discrimination may create a distrust for services and professionals within BAME communities. Barriers such as racism, cultural ignorance and stigma from health professionals need to be challenged when engaging with

Black African Caribbean people and their families. For example, underlying psychological and social factors arising from racism and memories of slavery can lead to a general mistrust and suspicion of health care professionals.[14] Families who are seen as 'hard to reach', are not offered the same level of service and treatment that white British families are, and therefore results in worse outcomes in health.[15]

Stigma and discrimination by healthcare professionals towards those with learning disabilities has been identified for over a decade.[16] Structural racism has been found to be a determinant of health inequalities.[17] The treatment of BAME people with learning disabilities by healthcare professionals is even poorer. Black people with learning disabilities are less likely to be offered psychotherapy, more likely to be offered drugs, and more likely to be treated by coercion in inpatient settings, even after socioeconomic and diagnostic differences are taken into account.[18] Across community services, institutional discrimination is present and there is a long way to go before they meet the challenges of our multicultural society.[7]

Institutional racism and institutional disablism

Structural racism and discrimination are still endemic within our services and our communities and exert a significant impact on people with learning disabilities and their families.

The definition of 'institutional racism' used by Sir William McPherson (Home Office, 1999) in his judicial inquiry into the death of Stephen Lawrence was:

"The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people".

That definition was extended and defined to cover institutional disablism by Chris Hatton in 2017:[19]

"Systemic institutional disablism is the collective failure of organisations to provide an appropriate and professional service to people because of their learning disability. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and stereotyping which disadvantage people with learning disabilities" (Chris Hatton – Its institutional disablism – Deal with it, 2017).

It can be said, from the review of the literature, that what we are observing in the lives of people with learning disabilities in general and those from BAME communities in particular, is overt institutional racism and disablism in action.

It is evident that this intersection of institutional discrimination based on learning disability and race has resulted in gross inequalities in life.

"It's a double bubble, double discrimination because I am Black." Expert by experience.

"I was very sad and scared to go out because people would call me names that were not nice. They were racist so I asked to move to London." Expert by experience

2. Policy

The health and social care system, and people within it, regularly fail to listen or be aware of the real needs of people with learning disabilities from Black, Asian and Minority Ethnic communities.[20,21] For example, families describe having to fight constantly and having to threaten with judicial reviews to get the best outcome for their child.

"The so-called professionals need to listen without prejudice and work with me to support my son." Mum

"I don't want anything to do with this thing called social services, it does not fit with my family and the real support we can give our two sons to have an ordinary life. I found them rude and meddling rather than supporting and listening. They prejudged my family because of our culture, because we support, the family is there to love, care and support its members. We are not odd, this is how we do things." Mum

This is not the first time that the lack of progress in improving the outcomes and experiences of BAME people with a learning disability has been recognised. Valuing People in their Framework for Equality in 2001 highlighted the needs of Black, Asian and Minority Ethnic communities but the Framework for Action in 2012[11] by the Foundation for People with Learning Disabilities (FPLD) found no improvement in policy or practice. A subsequent report[6] found that their lives are unequal and ignored by policy and practice.

Valuing People Now (2009)[22] found that people from Black and other Minority Ethnic communities were found to experience double discrimination and insufficient and inappropriate services. The report said this was because policy was missing for this group, and that in its place were a set of wrong assumptions about their needs, language barriers and discrimination. Similar inequalities were found by FPLD in 2012 (Reaching Out to Families)[14] which identified similar themes, being ignored, lack of support, being able to measure the impact of policies and practice on different communities.

The Department of Health's 'Vision for Adult Social Care' (2010) report and priorities from Valuing People Now (2009)[22] was the national programme that set out a vision and steps for improving opportunities and services for people with learning disabilities and family carers. It found that despite the statutory duty to ensure there is equality in access to services for people with learning disabilities, very few services promoted diversity with any real success, and people from BAME communities were still facing discrimination and unsatisfactory quality of care. The report concluded that if we want to improve the access and inclusion of people with learning disabilities from BAME groups in health and social care services, it is crucial that we need to know the local population and the best ways of engaging and supporting all communities. It also concluded that it is important to understand the needs and anxieties of people from BAME communities as well as the gaps in current service provision.

The Race Equality Foundation also published information on Black, Asian and Minority Ethnic populations with learning disabilities in 2010[8] and found: poor engagement between service users and health care staff has a negative effect on access to services[23] and on the development of relationships between service users and professionals (Mir, 2007). It also pointed out the need for increased advocacy services to support BAME people with learning disabilities to access public services and experience the appropriate level of care that is required.

Learning disabilities and health

The literature into the health outcomes of people with a learning disability do not address specific outcomes by ethnicity. However, physical illness for people with a learning disability can often be ignored

or minimised as challenging behaviour, treated inconsistently by GPs,[24] leading to unnecessary hospital admissions for primary healthcare needs[25] and higher rates of common illnesses that could be risk factors for Covid-19.[26,27] Bullying and exposure to overt disablism also contribute to health inequalities.[26] These impacts are stronger for people with lower levels of material or social resources. Ethnicity, poor socio-economic and cultural factors all contribute to increase experiences of bullying.[16]

The pandemic has shone a light on inequalities experienced in general, people from Black and other ethnic communities whatever their social status and were disproportionately dying from COVID. This was also true for people with a learning disability who were six times more likely to die from COVID and 40% of which were from Black and Pakistani communities.

Unavoidable deaths are twice as likely in this population, being as high as 44% of all deaths for people with learning disability.[2] Prior to Covid-19, health inequalities and preventable deaths in the learning disability population were recognised to be extremely problematic. This situation appears to have worsened exponentially.

Ashmore (2020)[28] outlines the common barriers to health equality:

• Patients not identified as having a learning disability
• Staff having little understanding of learning disability and/or autism
• Failure to recognise that a person with learning disabilities is unwell
• Failure to make a correct diagnosis
• Anxiety or lack of confidence in people with a learning disability
• Lack of joint working between different care providers
• Not enough involvement allowed from carers
• Inadequate aftercare or follow up care

This was illustrated by the pandemic where DNR's (do not resuscitate or escalate) were placed as a rule in peoples files. They were also not prioritised for the vaccine despite having a higher risk of dying from COVID.[29]

"What we have found through our review is a worrying picture of poor involvement, poor record keeping, and a lack of oversight and scrutiny of the decisions being made. Without these, we cannot be assured that decisions were, and are, being made on an individual basis, and in line with the person's wishes and human rights." [29]

Public Health England (PHE, 2020)[30] reported in August 2020 that after accounting for the effect of sex, age, deprivation and region, people of Bangladeshi ethnicity had around twice the risk of death from Covid-19 when compared to people of White British ethnicity. People of Chinese, Indian, Pakistani, Other Asian, Black Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to White British. Inequality in COVID-19 mortality between ethnic groups is the opposite of that seen for all causes of death in previous years. This data however failed to identify those with a diagnosis of learning disability, hence not adding to our understanding of the impact from Covid-19 on them. Evidence and public commentary have not considered the intersection of race and learning disability within the data.[31,27]

In February 2020, the government acknowledged that the data about BAME people with learning disabilities deaths was unclear, and more work at local level was needed to gain a clearer picture of why these were occurring.[32] Since the pandemic, the death rates have worsened and it is yet unclear whether this recommendation by The Learning Disability Mortality Review (LeDeR) has been possible for services.

Housing

People living in overcrowding are three times more likely to have respiratory problems[33] and are at increased risk of catching Covid-19. The ONS found a shocking but unsurprising correlation between overcrowding and dying from Covid-19, which disproportionately impacts Black, Asian and Minority Ethnic communities (2020). 30% of Bangladeshi families and 15% of Black people experience overcrowding, compared to 2% of white people.[34]

It is more common for BAME families to care for people with additional needs within the family home. Therefore, BAME people with learning disabilities may be more likely to be living in overcrowded households and therefore exposed to this increased risk.

Do Not Resuscitate (DNR)

Prior to the Covid-19 pandemic, The Learning Disability Mortality Review reported the overuse of DNRs for people with learning disability, and 22% of these were reviewed as inappropriately completed and followed.[35]

In May 2019, Professor Stephen Powis, National Medical Director, wrote to senior clinicians to remind them that the terms 'learning disability' and 'Down syndrome' should never be a reason for issuing a DNR decision. The disabled community has the same rights as anyone else to adequate healthcare, and to be fully involved in decisions about their own lives. Despite Mental Capacity and Best Interest Assessments remaining in place, people from the learning disability population have been subject to blanket DNR decisions being placed on medical records despite organisations and medical professionals condemning this practice.[29]

The CQC DNR report 2021[29] confirmed that blanket DNR for people with a learning disability were proposed at a local level during the pandemic. Furthermore, the report indicated that families and carers of people with learning disabilities were discouraged from seeking healthcare support in hospitals, and for the person with learning disability to be cared for at home. This report highlighted a disproportionate number of 'BAME' patients with learning disabilities being given DNRs, and therefore leading to increase in deaths.[36]

Vaccine take-up

There were initial concerns about whether there would be a good uptake of the vaccine within BAME communities. Polls indicated 76% of people were willing to have the Covid vaccination, which fell to 57% for respondents from BAME backgrounds.[37] The priority list of those getting vaccinated also did not prioritise BAME populations despite the vulnerability and risk factors for this population being well evidenced.[38] Examining the intersection of risk factors for Black, Asian and Minority Ethnic people with learning disabilities would have further shown a need for priority. It was not until complaints and campaigning by Jo Whiley, in support of her sister with a learning disability, that people with a learning disability were prioritised for the vaccine, despite their greater risk of death.[39]

Following concerns about Black Asian and Minority Ethnic populations, there has been an update to the recording of ethnicity during the vaccination process to better understand the uptake across different communities. However, there is no evidence that learning disability diagnosis is recorded in the vaccination process.

3. Conclusions

Despite decades of evidence and campaigning for the health outcomes of both the Black, Asian and Minority Ethnic community, and people with learning disabilities, it remains evident that the inequalities in treatment and therefore outcomes are appalling. There is a disproportionate burden of poor health on people with learning disabilities and particularly those with a learning disability from BAME communities. The societal response to their needs has been found wanting from the moment of their birth be it because of their disability and also the colour of their skin.

The figures have shown that even when socio-economic deprivation is taken into account, Black and South Asian people living in the UK are more likely to die from Covid-19[30] These individuals are more likely to live with extended family in multi-generational households, increasing the risk of cross-infection, with some cultural practices making social distancing challenging.

Implicit bias presents a further disadvantage to people with a learning disability, more so to those from BAME communities. Equal opportunity is not apparent in the lives of people with a learning disability, rather segregation, stigma, separation and discrimination are apparent in much if not all of their lives from birth.

The overall picture shows that little progress has been made in the past twenty years and that institutional discrimination and racism is still endemic in the lives of people with learning disabilities from BAME communities. Building a system that is based on equality is crucial if we are to eradicate institutional disablism and racism. Strategic and financial investment is required in building a fair society that ensures equality.

Many questions remain unanswered in our attempt to understand the extent of institutional disablism and racism in the lives of People with learning disabilities. More important question being how can Government and Transforming Care not mention Black, Asian and Minority Ethnic communities, in terms of recording generally but more specific what are their intersectional needs. This may imply out of sight and out of mind policy leading to 'if it is not counted it is not important'.

What is needed is individual and collective actions to reduce inequalities. Tackling racism and disablism has to become a priority which requires true leadership.

The following questions give rise to an urgent need for us to ensure that social justice becomes part of the narrative in the lives of people with learning disabilities.

1. How can we better understand the needs of the local community, particularly those with learning disabilities from BAME communities? What can be done to make links to ensure that referral rates reflect the population and reasonable adjustment are made?
2. How can we commit, train, and plan to talk about inequalities, implicitly bias, systemic institutional disablism and racism? Should this training be mandatory, regular, and underpinned by human rights?
3. How do we talk to people with learning disabilities about racism and provide a therapeutic space to manage these experiences?
4. What can be done to better understand the impact of implicit institutional racism/disablism and its impact on all our practices from strategic development, policy and practice at all levels?
5. What should be put in place to develop a commissioning process that listens, knows its population, plans and measures impact and is guided by community, equality and inclusion? What is needed so that prevention and early intervention is at the heart of the commissioning process as well as antiracist, disablism and institutional discrimination?
6. How can research create understanding about this population and their experiences across health and social care settings, to further inform policy, training and practice?

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